



**AN EXPLORATION OF END-OF-LIFE CARE IN THE INTENSIVE  
CARE UNIT. A SYSTEMATIC REVIEW OF QUALITATIVE STUDIES  
INVESTIGATING THE EXPERIENCES AND PERCEPTIONS OF THE  
PATIENT'S FAMILY.**

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*The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.*

—GR Dunstan, University of London, 1984

## **Declaration of Originality**

This thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma.

No parts of this thesis have been submitted towards the award of any other degree or diploma in any other tertiary institution.

No other person's work has been used without due acknowledgment in the main text of the thesis.

All research procedures reported in the thesis received the approval of the Ethics Committees of the Australian Catholic University.

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Ms Alysia Ann Coventry

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## Abstract

**Background and aim:** In the absence of rigorous evidence-based clinical guidelines, end-of-life care (EOLC) practices in the ICU vary considerably. Ideally, EOLC should be appropriately planned, implemented and informed by robust evidence; however the ICU is a setting where a patient's health can deteriorate rapidly. Consequently, families (including family members, relatives and carers) are particularly vulnerable, and may experience shock, uncertainty and powerlessness in this technical and unfamiliar environment during EOLC. Families are optimally positioned to identify the key components of care at the end of life in the ICU, however their views and needs are under-represented in key policy and guidance documents. A potentially rich source of families' views is qualitative studies. By capturing the complex experiential aspects of healthcare phenomena, qualitative evidence can provide knowledge that may inform the delivery of healthcare.

A number of qualitative studies have examined the perspective of families on EOLC in the ICU, however, a systematic review of this evidence has not been undertaken. Therefore, a systematic review and meta-synthesis was conducted to identify the experiences and perceptions of patients' families, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn. The findings of this systematic review will provide policy-makers, clinicians and researchers with robust evidence to: (1) inform the development of future policy and evidence-based clinical guidelines; (2) promote quality and consistency of EOLC delivery, and; (3) assist with optimising the EOLC experiences of the patient's family in the ICU, when life-sustaining treatments are withheld or withdrawn.

**Methods:** Systematic review and meta-synthesis was conducted using meta-aggregation. A comprehensive search for eligible published and unpublished qualitative studies (January 2006 – May 2016) was conducted across seventeen electronic databases. Quality assessment, data extraction, data synthesis and ConQual (a method used to rate the confidence of the synthesised findings) were conducted using an adaption of the methods of meta-aggregation. Thematic analysis processes were added to achieve analytic depth.

**Results:** Thirteen studies of variable quality met the inclusion criteria. No Australasian studies were identified. Data collection methods across the studies included face-to-face interviews and focus groups. Meta-aggregation and thematic analysis resulted in 14

categories and five synthesised findings, as follows: (1) the dying person: valued attributes of patient care; (2) communication with the family and within the healthcare team; (3) preparing the family and promoting a peaceful family-centred death; (4) family-centred support and care, and; (5) bereavement care. A conceptual model of preparedness was developed based on these findings that reflects the elements of EOLC care that are most valued by families. Central to preparedness was communication.

**Conclusion:** The synthesised findings showed that families experienced both positive and negative aspects of EOLC, and have unmet needs for communication, family-centred support and care and bereavement care. The conceptual model of preparedness, which reflects families' views of high-quality EOLC in the ICU, can be utilised to target areas for practice improvement. As defined in this study, the concept of preparedness in the ICU, explains the circumstance in which families can best manage the death, their sadness, loss, and grief. The findings show that nurses in particular are optimally positioned to provide individualised support and care that aligns with the values, needs and wishes of each family. Achieving a state of preparedness in the ICU setting requires a unique combination of care and support, as reflected in the model.

Research, policy and education recommendations are suggested based on the findings of this systematic review. An Australasian qualitative, multi-centre study that captures this healthcare phenomenon would provide robust evidence to inform region-specific policy and guideline development. In addition, a qualitative synthesis that incorporates evidence on the views of survivors of critical illness, families of survivors, and clinicians about the quality of EOLC delivered in the ICU setting, will contribute to our understanding of the barriers and facilitators to effective EOLC. Development of a practice standard on the delivery of EOLC in the ICU is also recommended, that is aligned with key performance indicators and mandated by registration bodies and governing critical care nursing/medicine agencies. Finally, undergraduate and postgraduate courses should consider preparing nurses to provide individualised care across a range of clinical settings to the dying person and their family, including effective communication and bereavement care.

## **Abbreviations**

**ACSQHC** Australian Commission on Safety and Quality in Health Care

**ANZICS** Australian and New Zealand Intensive Care Society

**EOLC** End-of-life care

**ICU** Intensive care unit

**JB** Joanna Briggs Institute

**LACDP** Leadership alliance for the care of dying people

**PCA** Palliative Care Australia

**QARI** Qualitative Assessment and Review Instrument

## Definition of terms

**Comprehensive Review Management System (CReMS)** is software from JBI that researchers use to manage and document a systematic review (The Joanna Briggs Institute [JBI], 2014a). CReMS links to the four analytic modules of the System for the Unified Management, Assessment and Review of Information (SUMARI) and incorporates the ability to import data from citation management software and the capacity to generate publishable reports (Chambaere et al., 2010).

**End of life** is defined by Palliative Care Australia (PCA) (2008b) as “that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown” (p. 8).

**EOLC** is a broad term used to describe the services provided to care for a person at the end of their life (PCA, 2005). For the purpose of this study EOLC refers to care provided to the patient when life-sustaining treatments are withheld or withdrawn.

**Family** is defined as those closest to the patient, and may include the biological family, family by marriage, and friends (National Chronic Care Consortium, 1995).

**Family-centred care** is defined a model of care in which the patient and the patient’s family are recognised and formalised as the unit of care (M. L. Mitchell, Chaboyer, Burmeister, & Foster, 2009). In this model of care family can contribute to, and are involved in the planning and delivery of care in a mutually beneficial partnership between patients, families and clinicians, based on respect, collaboration and support (Institute for Patient- and Family-Centred Care, 2010; M. L. Mitchell et al., 2009). Similarly, the Standards for Providing Quality Palliative Care for all Australians (PCA, 2005) acknowledge the care recipient to be “the patient, their caregiver/s and family” (p. 23). A family-centred care model can be implemented in any setting (Institute for Patient- and Family-Centred Care, 2010) but is the exception rather than the norm in adult critical care (M. L. Mitchell et al., 2009).

**Life-sustaining treatment** is a term that is used to describe an active medical intervention, or a treatment that sustains life. These may include mechanical ventilation, cardiopulmonary resuscitation, or vasoactive medications. The term life-sustaining treatment is sometimes used interchangeably with the terms *life-support modalities*, *life-sustaining therapies* and *life-*

*support* (Curtis, Downey, & Engelberg, 2016; Kentish-Barnes et al., 2016). This is reflected in the Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) Study (Sprung et al., 2014) used the term life-sustaining treatment in their attempt to define and achieve international consensus on withdrawing and withholding of life-sustaining treatment. The relevance and currency of this publication to the aim of this systematic review and meta-synthesis provides justification for a change in terminology, from the term life-support modalities, published in the protocol for this systematic review (Coventry, McInnes, & Rosenberg, 2012) to life-sustaining treatments, which will thus be adapted for the remainder of this thesis.

***Meta-aggregation*** is a step in the meta-synthesis process, whereby findings with supporting textual data from each included study are extracted (Higginson et al., 2013).

***Meta-synthesis*** is a type of systematic review, which involves the systematic review of qualitative research. The aim of a meta-synthesis of qualitative studies is to analyse and synthesise the findings of the included studies, and in doing so, to develop new understandings about the phenomenon under investigation (Campbell et al., 2003; Sandelowski, Docherty, & Emden, 1997).

***Palliative care*** is defined by the World Health Organisation (World Health Organisation, 2010) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (“WHO Definition of Palliative Care”, para. 1).

Furthermore, palliative care:

1. “Provides relief from pain and other distressing symptoms;
2. Affirms life and regards dying as a normal process;
3. Intends neither to hasten or postpone death;
4. Integrates the psychological and spiritual aspects of patient care;
5. Offers a support system to help patients live as actively as possible until death;
6. Offers a support system to help the family cope during the patient’s illness and in their own bereavement;



7. Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
8. Will enhance quality of life, and may also positively influence the course of illness; and
9. Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications” (World Health Organisation, 2010, “WHO Definition of Palliative Care”, para. 2).

***QARI:*** JBI computer software developed specifically for the meta-aggregation of qualitative research studies, currently version 5.0 (v5.0).

***Quality EOLC*** is evident when strong relationships can be demonstrated between the community and all care providers (PCA, 2008b).

***SUMARI:*** The Joanna Briggs Institute (JBI) analytical modules for the systematic review of literature. SUMARI includes the CReMS software, which then links to four analytical modules:

1. Qualitative Assessment and Review Instrument (QARI);
2. Narrative, Opinion and Text Assessment and Review Instrument;
3. Meta-Analysis of Statistics Assessment and Review Instrument; and
4. Analysis of Cost, Technology and Utilisation Assessment and Review Instrument.

***Terminal care*** is the healthcare provided to patients with an incurable progressive condition (days or hours prior to death) (PCA, 2008b).

***Withdrawing treatment*** is the term used to describe cessation of life-sustaining treatments (Sprung et al., 2003). This action is based on the premise that life should only be prolonged to the point where further life will exist at the expense of a quality life (Sandman, 2005).

***Withholding treatment*** occurs when a decision is made *not to* escalate or commence life-sustaining treatments, for example: not undergoing cardiopulmonary (Sprung et al., 2003).

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## **CHAPTER 1**

### **INTRODUCTION AND OVERVIEW**

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## **Chapter 1: Introduction and overview**

### **1.1 Introduction**

This chapter presents the context in which the thesis is located, the ideas that have contributed to both the formulation of the aim and choice of methodology. First, the overview introduces the concepts and ideas that lead to the development of the aim and choice of systematic review method. Second, the aim and thesis structure are presented. Third, a brief description of the rationale for the methodology is provided.

### **1.2 Overview of the research problem**

In Australia and globally, EOLC practices instigated in the ICU when life-sustaining treatments are withheld or withdrawn vary considerably (Decato et al., 2013; Mark, Rayner, Lee, & Curtis, 2015; Sprung et al., 2014). To date, rigorous evidence-based clinical guidelines have not been developed to assist clinicians to deliver quality EOLC in this context (Chan & Webster, 2016; Efstathiou & Clifford, 2011). As a result an accepted gold standard of healthcare relating to EOLC practices in the ICU does not exist. In the ICU, family members are optimally positioned to identify the key components of care at the end of life, however their views and needs are under-represented in key policy and guidance documents. A potentially rich source of families' views is qualitative studies, and the consolidation of this evidence would add to the existing evidence base.

In the ICU there is increasing emphasis on improving EOLC, because this is a setting where death occurs often after life-sustaining treatments have been withheld or withdrawn (Bloomer, Tiruvoipati, Tsiripillis, & Botha, 2010; Kentish-Barnes et al., 2016). Globally, EOLC has been reported to fall below the expectations of patients and their families, with examples of potentially preventable physical, emotional and spiritual distress for the dying person and their family (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2015; Healthcare Commission, 2007; NHS National End of Life Care Programme, 2010; Office for National Statistics, 2015) and a lack of clear and consistent guidelines is suggested to be a major influencing factor (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2013). Since patient deaths are expected in the ICU, particularly when life-sustaining treatments are withheld or withdrawn (Mark et al., 2015),

there is a need for EOLC to be appropriately planned and implemented (Bloomer, Tiruvoipati, et al., 2010), and informed by a robust evidence base.

Family-centred care is considered essential to high-quality EOLC in the ICU and should be part of a caring culture that provides for the needs of the whole family, in a mutually beneficial partnership between patients, families and clinicians (Institute for Patient- and Family-Centred Care, 2010; M. L. Mitchell et al., 2009). In this specialised environment it is not always feasible to study patients' experiences of dying and the quality of care they receive at the end of life (Glavan, Engelberg, Downey, & Curtis, 2008; Hardy, 2005). The inherent challenges associated with ICU and palliative care research in ICU include difficulties in collecting data from patients who are unable to communicate due to severe life-threatening illness, ethical issues, and methodological issues (Grande & Todd, 2000; Wiegand, Norton, & Baggs, 2008). As a result, current policy, consensus initiatives, guidelines, position statements, frameworks and standards of care have been developed without support from evidence relating to ICU patients' needs during EOLC.

Although the patient is the most important individual in determining satisfaction with care delivery, the patient's family has valuable information to offer (Keenan, Mawdsley, Plotkin, Webster, & Priestap, 2000). During EOLC in the ICU, the family is not only required to provide support to patients, but also to become "the voice" of the patient (M. L. Mitchell et al., 2009, p. 544). Authors agree that a family-centred approach to care is entirely appropriate during treatment withdrawal and EOLC in the ICU (ACSQHC, 2015; Bloomer, Endacott, Ranse, & Coombs, 2016; Coombs, Parker, Ranse, Endacott, & Bloomer, 2016; Hinkle, Bosslet, & Torke, 2015). Thus, the experiences and perceptions of a patient's family are as important as those of the patient and should be harnessed to contribute to the current evidence base. This is reflected in the Standards for Providing Quality Palliative Care for all Australians from PCA, which articulates that the recipient of care is not just the patient, but patients and their families (PCA, 2005). In this context, qualitative research has an important role in informing evidence-based healthcare because it can represent the human dimensions and experiences of healthcare consumers (Denzin & Lincoln, 2011; Edwards & Titchen, 2003; Thomas et al., 2004). Furthermore, the consolidation of qualitative evidence in the form of a systematic review provides a stronger and more robust form of evidence, which has more rigour than an individual qualitative study.

A strong evidence base has already been synthesised that reports on qualitative and quantitative studies of the nurse's role in preparing and supporting families around the withdrawal of life-sustaining treatments in the ICU (Coombs et al., 2016; Noome, Beneken genaamd Kolmer, van Leeuwen, Dijkstra, & Vloet, 2016). Also, quantitative evidence exploring factors associated with family satisfaction with EOLC in the ICU has been synthesised (Hinkle et al., 2015). However, there exists a gap in the literature. as there is no published systematic review of the experiences and perceptions of the patient's family in relation to the EOLC provided in the ICU setting, when life-sustaining treatments are withheld or withdrawn.

A number of qualitative studies have examined the perspective of families on EOLC in the ICU as a means to foster improvements in care (Coombs, 2015; Fridh, Forsberg, & Bergbom, 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams, Morton, & Peters, 2009; Nelson et al., 2010; Noome, Dijkstra, van Leeuwen, & Vloet, 2016; Pattison, 2011; Pattison, Carr, Turnock, & Dolan, 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010). A systematic review of this evidence has not been undertaken previously. The consolidation and synthesis of knowledge on this topic will identify research gaps and provide robust evidence upon which to inform clinical decision-making, training, theory building, policy development, and to build a research agenda in the future. The findings from such a synthesis have the potential to address the lack of consistency evident in current practice, and the under-representation of families' views in related policy.

### **1.3 Thesis aim and design**

The aim of this thesis is to identify and synthesise qualitative studies on the experiences and perceptions of the patient's family in relation to EOLC provided in the ICU setting, when life-sustaining treatments are withheld or withdrawn. This aim is addressed by conducting a systematic review and meta-synthesis of qualitative studies in order to identify the key components of EOLC that are considered important by families and to identify where care might be improved. This will consolidate and synthesise knowledge and identify research gaps, which in turn will provide robust evidence upon which to inform clinical decision-making, theory building, policy development, and training and to build a research agenda.

Meta-aggregation was chosen as the method for this systematic review and meta-synthesis (JBI, 2014a). It provides an established, pragmatic and validated framework, with clear and transparent supportive guides in a suite of online tools (Hopp & Rittenmeyer, 2015; JBI, 2014a; Lockwood, 2011; McInnes & Wimpenny, 2008). As explained in Chapter 4, thematic analysis (Boyatzis, 1998; Thomas & Harden, 2008) was used alongside meta-aggregation method to add depth, transparency and rigour to the analysis techniques. An in-depth description and justification for the selection of this methodology is provided in Chapter 3 (see section 3.5).

## **1.4 Thesis structure**

This thesis is organised into six chapters. The current chapter provides the introduction and overview of the research problem and presents the aim. In Chapter 2, a broad range of literature is critiqued to give the reader a clear indication of the research gap, how this research came about and why it is important. The chapter begins by providing evidence for the need of high-quality EOLC in the ICU. This is followed by a review of relevant national, international, government and non-government policy and quality initiatives, position statements, standards of care, guidelines, care pathways, recommendations and related peer-reviewed studies that provide context to the development of the aim of this systematic review and meta-synthesis. An introduction to the systematic review, focusing on experiences and perceptions is then provided and subsequently the additional value in conducting meta-synthesis. The chapter concludes with a statement of the significance of the proposed aim.

Chapter 3 provides a comprehensive critique of the methodology adopted in this systematic review; first, systematic review as a recognised research methodology; and second, the strengths and limitations of the main methods used for systematic review and meta-synthesis. The epistemological frameworks and assumptions underpinning each method will also be presented. A continuum was developed to organise the common qualitative meta-synthesis methods, from numeric to interpretive, in order to articulate the relationships between, and differences among these methods. The qualitative synthesis methods grounded formal theory, meta-ethnography, thematic synthesis, and meta-aggregation are then critiqued against current literature. Chapter 3 closes with the rationale and justification for selecting meta-aggregation methodology.

Chapter 4 provides an in-depth exploration of meta-aggregation and thematic analysis methods and techniques used in this systematic review. Detailed in this chapter are the inclusion and exclusion criteria, including the types of studies, types of participants and the phenomena of interest. Justification is provided for the specified search strategy, followed by a detailed description of the search strategy itself. Study selection, quality appraisal, data analysis and synthesis methods are also presented in a contemporary critique of these techniques. Finally, a discussion of the methodological safeguards employed that contribute to the rigour of the systematic review and meta-synthesis is provided, classified under the headings of credibility, dependability, confirmability and transferability.

Chapter 5 presents the results of this systematic review and meta-synthesis. First, a brief description of the search and sifting results is provided followed by an exploration of the characteristics of the included studies. A discussion of the results of the quality appraisal and of ConQual (a method used to rate the confidence of the synthesised findings which was evaluated here in terms of its methodological contribution) follows. Second, a narrative description of the synthesised findings is presented as aggregated and synthesised thematically. The chapter ends with a description of a conceptual model of care for the delivery of high-quality family-centred EOLC in the ICU (see Figure 6) and a summary of the main findings of the systematic review and meta-synthesis.

Finally, Chapter 6 presents the discussion and conclusion. This chapter demonstrates how the aim of this thesis was met, and presents an overview of the key findings derived from the systematic review and meta-synthesis. In the main body of the discussion, the key findings are compared to relevant research literature, current policy and guidelines. The methodological strengths and limitations related to the conduct of this systematic review and meta-synthesis are then provided. In the final section the recommendations for future research, policy, training and practice development are presented. The conclusion draws the findings together and provides the reader with the wider implications of this systematic review and meta-synthesis.

## **1.5 Summary**

This chapter has presented an introduction and overview to the research problem and presents the aim and thesis structure. In the next chapter, a critical review of the relevant national and international literature is provided to give a clear indication of the research gap and to provide context to the ideas that informed the development of the aim of this systematic review and meta-synthesis.



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## **CHAPTER 2**

### **REVIEW OF THE LITERATURE**

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## **Chapter 2: Review of the Literature**

### **2.1 Introduction**

In this chapter, a detailed and critical review of relevant research and policy is presented. The importance of addressing the identified research gap is outlined, as well as how the research aim of this systematic review and meta-synthesis emerged. A broad range of literature has been critically reviewed. This includes a review of key national, international, government and non-government policy and quality initiatives, position statements, standards of care, guidelines, care pathways, recommendations and related peer-reviewed studies that have informed the rationale for undertaking the research reported in this thesis.

This chapter is organised into six sections, as follows: (1) satisfaction with EOLC: perceptions of families and key stakeholders; (2) policy and quality initiatives that aim to improve EOLC, with a focus on Australia, North America, and the UK; (3) the value of the systematic review: research on experiences and perceptions; (4) meta-synthesis: what it adds to the systematic review; (5) significance of the proposed research and thesis aim; and (6) chapter summary.

For the remainder of this thesis, *qualitative synthesis* will be used as a substitute for *systematic review and meta-synthesis*. The next section presents evidence for the need of high-quality EOLC in the ICU.

### **2.2 Satisfaction with EOLC in the ICU: Perceptions of families and key stakeholders**

Admission to the ICU can be unexpected following a life-threatening illness or event. This can create a state of crisis for the family (Stayt, 2009). Despite advances in healthcare technology and medical care, many people fail to survive (Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). Dying in the ICU is also frequently associated with a decision to withdraw treatment.

End-of-life care in the ICU is complicated by an unpredictable dying phase, following the withdrawal or withholding of life-sustaining treatments, which does not always make possible the thorough preparation for death that is encouraged in palliative care settings (Bloomer, Lee, & O'Connor, 2010; Trankle, 2014; Wunsch, Harrison, Harvey, & Rowan,

2005), where care recipients are known to be dying (Henriksson et al., 2015). Not all deaths in these circumstances are rapid however, with some patients experiencing a dying phase of days to weeks (Bloomer, Tiruvoipati, et al., 2010). In both scenarios, there is a clear need for EOLC to be appropriately planned and implemented based on the best available evidence. The reality of a sudden death can evoke overwhelming shock, emotional distress and helplessness in a family member, a scenario quite often observed in the ICU (Worden, 2009).

In the UK, a report that analysed consumer complaints ( $n = 16,000$ ) between 2004 and 2006 found a general dissatisfaction by patients and their families with the quality of EOLC in acute hospital settings, including the ICU (Healthcare Commission, 2007). According to this report, complaints about in-hospital care of the dying and their family were very common (Healthcare Commission, 2007). For example, families complained that they received contradictory information from staff, that they felt emotionally unprepared for the death, and that they were not always provided the opportunity to be present for the death (Mayor, 2007). Similarly, in 2010, a study by the NHS National End of Life Care Programme analysed complaints from four hospital Trusts ( $n = 1254$ ) found that complaints largely related to communication issues (NHS National End of Life Care Programme, 2010). The most recent National Bereavement Survey (VOICES), conducted in 2015, reported that the quality of EOLC was lowest when provided by urgent care services (including ICU). According to this survey, significantly more families of patients who died in an acute hospital (as opposed to palliative care settings) reported EOLC lacked: (1) effective communication; (2) a supportive relationship with staff; (3) compassion, respect and dignity (Office for National Statistics, 2015).

Likewise, in Australia it has been identified that EOLC is one of “inequity and inconsistency”, where some patients experience quality needs-based care, while others may receive care that is fragmented, and “fails to acknowledge care preferences” and “delivers insufficient support to meet social, emotional and physical needs at the end of life” (PCA, 2008a, p. 6). A recent national consultation process (involving healthcare consumers, clinicians and policy makers) confirms these findings, and highlights persistent gaps in the quality and safety of EOLC in Australia (ACSQHC, 2015). It was reported: (1) end-of-life experiences are highly variable; (2) care often falls below the expectations of patients and their families, and (3) care resulted in potentially preventable physical, emotional and spiritual distress for the dying person and their family (ACSQHC, 2013; ACSQHC, 2015).

In a background document to the current National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care, the Australian Commission on Safety and Quality in Health Care (2013) highlighted that although there is general agreement and some evidence about what the problems are “there is currently a lack of either clear evidence or consistent agreement about what the standard of care should be, or how to achieve it” (ACSQHC, 2013, p. 3). Importantly, the National Consensus Statement acknowledges that EOLC should recognise the needs of both the patient and their family, but “in order to work toward improving the quality and safety of end-of-life care in acute hospitals, it is first necessary to achieve consensus about the standard of care that should be expected” (ACSQHC, 2013, p. 3).

In response to the observed global variability of EOLC practices in ICUs, the Consensus for Worldwide End-of-Life Practice for Patients in Intensive Care Units (WELPICUS) Study was conceived. The study invited critical care societies worldwide to review 81 statements related to end-of-life decision-making, withdrawing treatment, withholding treatment and EOLC practices in the ICU. Consensus was obtained (defined as >80% agreement) for 77 of 81 statements (Sprung et al., 2014). Although patient and family satisfaction with the quality of EOLC is one of the consensus domains, the authors did not seek the experiences and perceptions of family members.

The under-representation of families’ experiences and perceptions is a gap in key policy and guidance documents and the value of including their views of the EOLC delivered in the ICU setting has been overlooked. Whilst much research is focused on decision-making processes and communication with critically-ill families, important areas of EOLC such as support given to families in preparation for and during the process of withdrawing life-sustaining treatment have been inadequately researched in the ICU (Coombs et al., 2016).

Where support has been given, a number of quantitative studies have reported factors associated with family satisfaction with EOLC in the ICU, with synthesised data from 14 unique studies, including randomised controlled trials ( $n = 3$ ), non-randomised interventions ( $n = 4$ ) and descriptive studies ( $n = 7$ ) (Hinkle et al., 2015). Satisfaction is defined to encompass several domains, including patient care, communication and long-term wellbeing of family members (Hinkle et al., 2015). This important piece of work also remains invisible in current policy and guidance documents relating to EOLC in the ICU. However, authors

reported a wide variation in study quality and design, little similarity in study variables associated with satisfaction, and little consistency with family satisfaction (Hinkle et al., 2015). Thus, although there is value in synthesising quantitative studies for answering questions of effectiveness, a lack of robust, interventional studies on this topic supports qualitative evidence synthesis as an essential complementary methodology to capture the complex experiential aspects of this healthcare phenomenon.

There are several qualitative studies that have captured the experiences and perceptions of the patients' family, of EOLC in the ICU, which have not been used to inform the aforementioned documents (Coombs, 2015; Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010). A qualitative synthesis of the evidence in this area has also not been undertaken. Such a synthesis would provide robust evidence upon which to inform clinical decision-making, build theory, develop policy, training and to build a research agenda.

In the next section relevant national and international, government and non-government policy and other approaches to improve EOLC will be discussed in relation to the aim of this thesis. This discussion will build on previous arguments, and contribute to the rationale for undertaking the research reported in this thesis.

### **2.3 Policy and quality initiatives to improve EOLC**

In recent years, EOLC has become a topic widely debated across all healthcare settings. Evidence of a national policy focus or the implementation of quality initiatives is most prominent in Australia (Australian and New Zealand Intensive Care Society [ANZICS], 2014; ACSQHC, 2015), the UK (Leadership Alliance for the Care of Dying People [LACDP], 2015; Neuberger et al., 2013) and North America (Downar, Delaney, Hawryluck, & Kenny, 2016; Institute of Medicine, 2014b), thus these nations will be the focus of this discussion. This section begins with a policy and guidance document focus in Australia.

### **2.3.1 The Australian context**

In Australia, despite a lack of high-quality evidence, numerous frameworks, position statements, recommendations, quality measures and strategies have been developed over the past 15 years to guide the overall delivery of EOLC. In 2005, PCA (2005) provided the fourth edition of Standards for Providing Quality Palliative Care for all Australians, to support the delivery of high-quality, needs-based care for families facing life-limiting illness. These standards were developed based on a mixture of expert opinion and research evidence. Health services and clinicians are encouraged to adopt the standards and accreditation bodies are advised to incorporate the standards as part of their assessment of related healthcare service delivery. Specifically, PCA suggest mandating EOLC standards as key performance indicators in acute care settings (including ICU), based on the Standards for Providing Quality Palliative Care for all Australians, as a means to foster improvement in EOLC delivery (PCA, 2008a). This however, has not occurred. These standards are the most current of their kind in Australia to support the delivery of high-quality family-centred palliative and EOLC services, and these values have been used to guide the development of subsequent EOLC guidance documents (ACSQHC, 2015; PCA, 2010).

In 2010, PCA (2010) published the guidance document Health System Reform and Care at the End of Life. The need for this comprehensive end-of-life guidance document was seen as critical, given the increasing number of reform processes underway in Australia at the time (PCA, 2010). The document articulated the need for practice to be driven by evidence, and that evidence-based policy and practice is an essential first step in achieving high-quality EOLC. However, it was highlighted that there is little systematic research about the quality and outcomes of EOLC and the consumer experience of EOLC (PCA, 2010). This identified gap in the literature supports the need for further systematic research to ensure that the needs of the dying person and their family are met at the end of life. However, whilst parallels can be drawn between palliative care and EOLC, the sudden and unexpected nature of an admission to ICU and thus the specialised needs of families during EOLC mean that the standards and guidance documents developed by PCA may not entirely meet the needs of the dying person and their families in this setting.

Subsequently, the Australian and New Zealand Intensive Care Society (ANZICS) (2014) produced the first edition of the ANZICS Statement on Care and Decision-Making at the End

of Life for the Critically Ill, the first document of its kind in Australia. This document is intended to provide a framework for best practice for ICU staff involved in the care of critically ill persons and their families at the end of life, again clinicians are encouraged, not required to adopt the standards. The ANZICS Statement provides guidance for care of the dying person and their family, including specific reference to the dying process, withdrawal of treatment, communicating with families about what to expect and care of the family during grief and bereavement (ANZICS, 2014). This document was developed through a consultation process, with reference to many relevant resources, and some peer-reviewed research studies, however support from evidence is limited, with many relevant research studies missing. Of importance, no reference was made to studies of families' experiences of the EOLC delivered in the ICU, falling short of the aforementioned guidance recommended by PCA of the fundamental need for evidence-based policy and practice to facilitate high-quality EOLC.

The most recent addition to the Australian guidance documents on EOLC was published in 2015, namely, the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care (ACSQHC, 2015). Once again, this statement makes recommendations rather than mandatory requirements for practice in acute care settings where EOLC is provided (including ICU), and was written following consultation with health consumers, carers and experts in the field. Authors acknowledge that some content is aspirational, indicating that for many acute care organisations, significant cultural change may be necessary; for example, the systematic implementation of evidence into a formal policy framework aimed to effect improvements in families' experiences (ACSQHC, 2015). Sufficient detail is provided in regard to evaluation, audit and feedback, including specific reference to data collection methods and other measures of quality for EOLC, which is important because evaluation of EOLC interventions will contribute to the current limited evidence base. The generic nature of the recommendations falls short of describing the specific nuances of support and care important to meet the needs of families in the ICU during EOLC. What is lacking is guidance on preparing the family, how the psychosocial, cultural and spiritual needs of patients, families and carers in the setting of withdrawal can be met, and support of special needs groups or individuals, such as families of organ donors. Although the ACSQHC document acknowledges the importance of meeting the needs of both

the patient and their family, there is no reference to evidence gained from research into families' perspectives of this care.

In the next section, key EOLC policy and guidance documents from North America will be discussed in relation to the thesis aim, building on the literature presented from the Australian context.

### **2.3.2 The North American context**

North America has moved toward a more family-centred model of EOLC emerging from a growing need to improve the quality of EOLC. However, despite a national policy focus in Canada and the USA, the under-representation of qualitative evidence on the experiences and perceptions of families on EOLC in the ICU is quite evident.

In 2008, Recommendations for End-of-Life Care in the Intensive Care Unit: A Consensus Statement was published in the USA to support a family-centred model of EOLC care (see Definition of terms) (Truog et al., 2008). The recommendations are comprehensive, and are the most current of their kind, however an evidence grading system was not used because “most of the recommendations are based on ethical and legal principles that are not derived from empirically-based evidence” (Truog et al., p. 953). It is unclear why empirically based evidence was not incorporated, how consensus was reached and what methods were used in the conduct of the literature review. The recommendations do provide information on how to support the needs of the patient's family, where treatment is withheld or withdrawn in the ICU in an effort to further improve the care of the dying and their families in the ICU (Truog et al., 2008). Although a broad range of literature was consulted, only one quantitative study was incorporated that assessed family member satisfaction with communication in family conferences about EOLC (McDonagh et al., 2004). Qualitative evidence that reports on the experiences and perceptions of patients' families, when life-sustaining treatments are withheld or withdrawn has been overlooked.

In 2014, the Institute of Medicine (2014a) conducted a consensus study Dying in America: Improving Quality and Honouring *[sic]* Individual Preferences Near the End of Life. This study provides comprehensive recommendations based on evidence (peer-reviewed literature and direct consumer experiences), expert judgement, policy, clinical practice, professional development, and public education and engagement related to end of life in all settings of



care (including ICU) (Meghani & Hinds, 2015). Key findings and recommendations recognise that high-quality, comprehensive, patient-centred, family-oriented EOLC involves consideration of the needs of the patient and their family, including: (1) physical, emotional, social, and spiritual needs; (2) meaningful communication between patients, families, clinicians and clergy about values, goals and preferences; and (3) provision of information and materials about care near the end of life (Institute of Medicine, 2014b).

In 2016, Guidelines for the Withdrawal of Life-Sustaining Measures were developed for use in Canadian ICUs in response to ongoing concerns about variation in how life-sustaining treatments were withdrawn and the lack of comprehensive evidence-based clinical guidelines (Downar et al., 2016). In this study, an interdisciplinary group of ICU clinicians was convened and a modified Delphi process was used to achieve consensus. The literature review revealed very little evidence (mostly observational or qualitative studies, reviews, guidelines, and opinion pieces) on the process of withdrawing life-sustaining measures (Downar et al., 2016). No studies were included on the experiences and perceptions of the patient's family. The ongoing under-representation of families' views in current policy and guidance documents on the EOLC delivered in the ICU setting and the key components of care considered important in a family-centred model of care constitutes a gap in the existing evidence base. It is therefore timely to undertake a synthesis of available qualitative studies on this topic.

The next section presents an overview of current policy and guidance on EOLC originating from the UK, places this in the context of the thesis aim and builds on the literature presented from Australia and North America.

### **2.3.3 The United Kingdom context**

Policy development and research has been a focus in the UK over the last decade, to address shortcomings in the delivery of EOLC across all sectors of healthcare. The work includes a national policy focus, EOLC frameworks and research into the effectiveness and usefulness of evidence-based clinical guidelines/pathways for the care of the dying and their families at the end of life (Gold Standards Framework, 2016; Guy's and St Thomas' NHS Foundation Trust, 2015; LACDP, 2015; NICE, 2015; Neuberger et al., 2013; Welsh Government, 2013).

In the UK, consensus was recently established on the value of evidence-based clinical pathways to deliver EOLC across all healthcare settings (including ICU), however it was recommended that generic protocols are not the right approach to care (Neuberger et al., 2013). There is recognition that evidence-based clinical guidelines/pathways, generated from the systematic identification and synthesis of the best available evidence should be more widely utilised across all healthcare sectors (NICE, 2015; Neuberger et al., 2013). In 2013, The Neuberger Report critiqued a broad array of evidence, from key stakeholders, professional bodies, peer-reviewed literature, and hospital complaints, and recommends individualised care plans and setting-specific guidelines to ensure the needs and preferences of the dying person and their family are met to achieve optimal EOLC (Neuberger et al., 2013, p. 6). This recommendation from The Neuberger Report seems to reflect the general consensus among clinicians that each family is unique and that there should not be a “one size fits all” approach during EOLC (Heland, 2006, p. 26). In ICU, family members are optimally positioned to identify key components of care at the end of life. Thus, a qualitative synthesis that reports on the experiences and perceptions of patients’ families, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn could provide a valuable addition to the evidence base for future pathway development, as recommended.

In 2015, Leadership Alliance for the Care of Dying People (2015) published *One Chance to get it Right: Improving People’s Experience of Care in the Last few Days and Hours of Life*. This report defined priorities, setting out an approach to care of the dying person and those important to them, which organisations and clinicians in the UK should adopt in future. The report reiterated that generic EOLC protocols are not appropriate, rather individualised care plans and setting-specific guidelines were recommended, to “reflect the needs and preferences of the dying person and those who are important to them” (LACDP, 2015, p. 6). A robust and setting-specific evidence base is needed to support the development of such guidelines and clinical pathways in the intensive care.

In the UK, the nature and delivery of EOLC has become the focus of health service improvement. The identified gaps in the literature and call for setting specific evidence-based clinical pathways suggest that the systematic identification and synthesis of the best available evidence into families’ experiences and perceptions of EOLC in the ICU is needed to optimise care.

The next section introduces the systematic review and its important role in facilitating the consolidation of primary qualitative evidence on experiences and perceptions.

## **2.4 The value of the systematic review: research on experiences and perceptions**

Systematic review is considered to be the most reliable method used to search, appraise and synthesise findings of primary studies and rigorous qualitative synthesis have become important for the advancement of evidence-based practice, guideline and policy development in healthcare (Dixon-Woods, Bonas, et al., 2006; Mohammed, Moles, & Chen, 2016; Porritt & Pearson, 2013). As well as summarising and consolidating a body of evidence, systematic reviews can identify gaps in research (Atkins et al., 2008; Foster, 2011).

The systematic review of randomised controlled trials was once the main method of systematic review (Hannes & Lockwood, 2011). However, over almost three decades, there has been a rapid increase in the development of systematic review methods, which have been used to synthesise findings from a broad range of both qualitative and quantitative study designs (Booth et al., 2016; Campbell et al., 2011). In particular, reviews and syntheses of qualitative studies investigating the views of healthcare consumers have become more common (Dixon-Woods, Bonas, et al., 2006; Hannes & Lockwood, 2011). This shift came in response to an increasing realisation among researchers and policy-makers that quantitative systematic reviews provide only part of the evidence and may not be suited for research questions investigating the needs, preferences, experiences and perceptions of healthcare consumers (Dixon-Woods, Bonas, et al., 2006; Mohammed et al., 2016). A large increase in the volume of primary qualitative research and the development of qualitative synthesis methods, as well as a need to make better use of these findings has also contributed to this shift (Mohammed et al., 2016).

Syntheses of qualitative research can provide a complementary source of evidence to systematic reviews of quantitative studies. Used in combination, or as a standalone research methodology, the synthesis of qualitative evidence can broaden knowledge about the delivery and receipt of care, by capturing the experiential complexities of healthcare phenomena (Pearson, Robertson-Malt, & Rittenmeyer, 2011; Pope, Mays, & Popay, 2007). For example, a systematic review that captures families' experiences and perceptions of the EOLC delivered in the ICU setting, would provide a robust form of evidence about care experiences

that could inform the development of interventions to assist families to cope in these circumstances. When combined with evidence from quantitative studies, a rich and complementary knowledge source can be achieved, representing for example, effectiveness of an intervention and patient views of their experience with that intervention (Banner & Albarran, 2009; Booth et al., 2016).

Qualitative research is distinguished from quantitative research in its emphasis on providing rich, in-depth data, most commonly on experiences and perceptions. The findings from qualitative health research can provide information on: (1) personal and cultural interpretations of disease and treatments; (2) personal perspectives on living with and managing the clinical manifestations of chronic illness; and (3) decision-making on intervention selection across the lifespan (Barroso et al., 2003). The systematic review of qualitative research has an especially valuable role to play in answering questions relevant to EOLC in the ICU such as evaluating the perceived quality of care. Consolidating the available qualitative literature on this topic provides a robust form of evidence to inform the development of interventions and to assist in understanding families' experiences of care (Boeije, van Wesel, & Alisic, 2011; Wiegand et al., 2008).

The main established methods of qualitative synthesis will be presented in an in-depth critique in Chapter 3. In the next section the value of meta-synthesis is established in line with the thesis aim.

## **2.5 Meta-synthesis: what does it add to the systematic review?**

As discussed in previous sections, to help to address variation in the quality and type of EOLC practice in the ICU, when life-sustaining treatments are withheld or withdrawn, a consistent evidence-based approach to care needs to be established (Chan & Webster, 2016; Mark et al., 2015). One part of addressing this is to understand the views of family members. In the ICU, because of the inherent challenges associated with assessing the needs of patients at the end of life, families are optimally positioned to identify the key components of EOLC. However, at present this source of information is under-represented in current policy and guidance documents.

A number of qualitative studies have investigated the experiences and perceptions of patients' families, of the EOLC delivered in the ICU setting, when life-sustaining treatments have been

withheld or withdrawn (Coombs, 2015; Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010). In order to comprehensively and systematically utilise the findings from these qualitative studies and enhance their usefulness for decision making and policy development, a systematic review and meta-synthesis is arguably the most appropriate method of review (Booth, 2006; Hannes & Lockwood, 2011). This will provide a stronger and more robust evidence base that has more trustworthiness than an individual qualitative paper. Failing to optimise the outcomes of qualitative research can undermine the value of qualitative inquiry in informing evidence-based healthcare as well as result in wasted effort and repetition of studies (Finfgeld-Connett, 2014).

Meta-synthesis is a research method used to systematically review qualitative research and analyse textual data. The aim of a meta-synthesis of qualitative studies is to analyse and synthesise the findings of eligible studies to develop new understandings about the phenomenon under investigation that were not apparent in individual studies (Campbell et al., 2011). This synthesis method may provide another reading of the primary research data or an opportunity to reflect on the data in new ways by considering the findings of each eligible paper in relation to the other and building a consolidated and synthesised set of findings (Mohammed et al., 2016). For the findings of individual studies to have impact, they must be positioned in a larger interpretive context, and presented in an accessible and usable form in order to be useful in “the real world of practice and policy making” (Sandelowski & Barroso, 2007, p. 365).

For these reasons, a systematic review and meta-synthesis is appropriate for addressing the aim of this thesis, for generating findings useful for practice, and for advancing research in this field by addressing gaps in the evidence. This will be achieved using meta-aggregation (JBI, 2014a) and thematic analysis (Boyatzis, 1998; Thomas & Harden, 2008), as explained in Chapter 4. An in-depth description and justification for the selection of this methodology is provided in Chapter 3 (see section 3.5).

Next, the significance of the proposed thesis aim is presented in the context of the critiqued policy, guidance documents and literature.

## **2.6 Significance of the proposed research and thesis aim**

In this Chapter, it has been demonstrated that patients' families' experiences and perceptions, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn in the ICU are under-represented in current policy and guidance documents. The practical and methodological challenges inherent in conducting end-of-life research in ICU (Wiegand et al., 2008) have resulted in the development of policy, guidelines, position statements and standards without the support of a robust evidence base representing patients and families' views on EOLC in the ICU. Qualitative research that captures the experiences and perceptions of the dying person's family has an invaluable role to play in informing evidence-based healthcare in this context (Banner & Albarran, 2009).

There are a number of qualitative studies that have reported patients' families' experiences and perceptions, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn (Coombs, 2015; Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010). A qualitative synthesis has the potential to build theory, identify gaps in the literature, target areas for improvement in policy and practice, address the lack of consistency evident in current practice and add depth to the evidence base upon which recommendations specifically for EOLC in the ICU could be developed. A qualitative synthesis of the evidence in this area has not previously been undertaken. Accordingly, the aim of this thesis is to synthesise the existing qualitative research findings on the experiences and perceptions of patients' families, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn.

This qualitative synthesis will be achieved using meta-aggregation (2014a) and thematic analysis (Boyatzis, 1998; Thomas & Harden, 2008), as explained in Chapter 4. An in-depth description and justification for the selection of this methodology is provided in Chapter 3 (see section 3.5). The findings of this synthesis will provide a valuable addition to existing knowledge on the key components of EOLC considered important to meet the needs of families. This can be used to inform the development of policy and guidance documents for EOLC in the ICU and thus clinical decision-making in the future.

## **2.7 Summary**

This chapter has presented a critical review of both policy and research studies to provide background and context to the development of the aim of this qualitative synthesis. Included was an introduction to the systematic review, and the value inherent in meta-synthesis of qualitative studies of patients' families' experiences and perceptions of EOLC, when life-sustaining treatments are withheld or withdrawn. Following this relevant national and international, government and non-government policy and quality initiatives, position statements, standards of care, guidelines, care pathways, recommendations and related peer-reviewed studies that have informed the rationale for undertaking the research reported in this thesis were presented. This chapter concluded with a statement of the significance of the proposed thesis aim and the relationship of the literature to the proposed qualitative synthesis.

The next chapter provides a contemporary critique of the literature in an overview of the main established qualitative methods of qualitative synthesis. These methods are presented on a continuum to help clarify the relationships between, and differences among the more common methods, including the chosen method, meta-aggregation. The rationale and justification for selecting meta-aggregation it for this qualitative synthesis will then be provided.

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**CHAPTER 3**  
**METHODOLOGY**

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## **Chapter 3: Methodology**

### **3.1 Introduction**

This chapter expands on the introduction to qualitative synthesis provided in Chapter 2, with an overview of the main established methods of qualitative synthesis and an examination of the strengths and weaknesses of each method. A continuum was developed to organise the most common qualitative synthesis methods, from numeric to interpretive, to help clarify the relationships between, and differences among, these methods. Also included is a discussion of the epistemological frameworks and assumptions underpinning the most commonly used synthesis methods. The qualitative synthesis methods of grounded formal theory, meta-ethnography and thematic synthesis are presented and critiqued as part of the justification for the selection of the synthesis method used in this thesis. The chapter closes with an in-depth review of meta-aggregation, the chosen method for this qualitative synthesis and gives the rationale and justification supporting its selection. The addition of thematic analysis will be explained in Chapter 4.

### **3.2 Qualitative synthesis of empirical research**

Methods for synthesising quantitative studies in healthcare are well established (Campbell et al., 2011). A systematic review of randomised controlled trials is considered the highest level of evidence (Higgins & Green, 2011). Meta-analysis is the statistical method used to analyse pooled data from homogenous quantitative studies to calculate the effect of an intervention (Shorten & Shorten, 2013). However, systematic review and meta-analysis of data does not capture the experiential aspects and complexities of healthcare phenomena.

The richness of qualitative evidence provides a credible, complementary medium to fill the gaps apparent in practice and policy-related questions by capturing the experiences and perceptions of individuals relating to interventions and care delivery (Korhonen, Hakulinen-Viitanen, Jylhä, & Holopainen, 2013). The growing interest in qualitative synthesis has been labelled as “the urge to synthesize [*sic*]” (Sandelowski & Barroso, 2007, p. 1). This growth in interest is associated with a large increase in the publication of primary qualitative research and the need therefore to facilitate better dissemination of findings (Major, 2010). The synthesis of qualitative evidence both in combination with quantitative data, and as a standalone research methodology, broadens the meaning and applicability of knowledge

about the delivery and receipt of healthcare to support evidence-based practice (Conn & Coon Sells, 2014; Kent & Fineout-Overhold, 2008; Korhonen et al., 2013).

Qualitative studies are usually characterised by an investigation of the meanings of participants' experiences in situations that are uniquely contextual (Finfgeld-Connett, 2014). A range of qualitative methodologies and epistemological standpoints are adopted to achieve such investigations (Booth et al., 2016). Just as the aims, methods and epistemology of qualitative research projects are highly variable, so too are the aims, methods and epistemology of a qualitative synthesis. The aims of qualitative synthesis can include generation of new knowledge, reinterpretation of primary research findings, development of theory or theoretical models, to inform the development of evidence-based policy and clinical guidelines or identification of gaps in existing literature (Campbell et al., 2011; Ludvigsen et al., 2016; Saini & Shlonsky, 2012).

In an early study, three theory-related aims for qualitative synthesis have been described: (1) theory building; (2) theory explication; and (3) theoretical development (Schreiber, Crooks, & Stern, 1997). In theory building, findings from diverse sources are used to extend theory beyond the level possible using data from only one study. Theory explication is described as a lateral and deductive analytic process, where an abstract concept in one study is understood through synthesis of findings from other studies (Schreiber et al., 1997). Finally, theoretical development refers to the synthesis of findings so that the theoretical outcome is richly descriptive, comprehensive and unique, such as the development of a conceptual model (Finfgeld-Connett, 2014; Toye et al., 2014). Such processes can often be blurred, as any of these three theoretical aims can be "complementary or over-lapping" (Schreiber et al., 1997, p. 315).

Other aims of a qualitative synthesis may be to provide an in-depth interpretive description of a phenomenon through the use of hermeneutic phenomenology, (Lindseth & Norberg, 2004; van Manen, 1990) or to increase the transferability (generalisability) of research findings in order to make them more accessible for application to practice (Thorne, Jensen, Kearney, Noblit, & Sandelowski, 2004). It has been suggested that in a qualitative synthesis, the development of theory at a level of abstraction that: (1) reports concepts using thick descriptions (Lincoln & Guba, 1985); (2) makes action and interactional elements of the theory clear (Strauss, 1987); and (3) draws conclusions that have meaning outside the

immediate context of the study can enhance its transferability (Hellstrom, 2008; Ruddin, 2006; Schofield, 2000). However it has been emphasised that all theoretical frameworks are tentative until successful transference into a new context takes place (Finfgeld-Connett, 2010).

Researchers have developed a range of methods to synthesise qualitative research in order to inform health related policy and practice and thus the delivery and receipt of care (Dixon-Woods, Fitzpatrick, & Roberts, 2001; Noblit & Hare, 1988; Pawson, Greenhalgh, Harvey, & Walshe, 2004; Pearson, 2004; Popay & Roen, 2003; Sandelowski et al., 1997; Thomas et al., 2004). These methods include, but are not limited to narrative synthesis, content analysis, meta-ethnography, thematic synthesis, grounded formal theory and meta-aggregation. Due to the rapid expansion of this field of research, standardisation of terminology has not yet occurred. Some researchers use these terms interchangeably, whereas others recognise both major and minor differences between them (Campbell et al., 2011; Dixon-Woods, Bonas, et al., 2006; Korhonen et al., 2013; Saini & Shlonsky, 2012). There is disagreement in the literature about the optimal methods to synthesise qualitative studies (Downe, 2008; France et al., 2014; Hannes & Macaitis, 2012; Paterson, 2012; Pope et al., 2007; Sandelowski & Barroso, 2007). A common focus of this debate is the argued degree of interpretiveness of the data analysis approach (Foster, 2011; Thorne et al., 2004).

It is agreed by many working in this field that interpretive methods bring together findings from different studies, usually using an inductive approach to construct new interpretations, to allow a deeper understanding of phenomena, to decipher meaning, or to develop new theories or explanatory frameworks (Campbell et al., 2011; Dixon-Woods, Bonas, et al., 2006; Holly, Salmond, & Saimbert, 2012; Miles & Huberman, 1994; Noblit & Hare, 1988; Saini & Shlonsky, 2012). Induction is defined as pursuing intuition, or reasoning from observation and the development of explanations (Bazeley, 2009; Schofield, 2000). Deduction is based on priori reasoning in which theories are developed prior using common sense, experience or from the literature, a hypothesis is established and then the observations commence, which either confirm or negate the hypothesis (Schofield, 2000). Meta-ethnography and grounded formal theory are examples of methodologies that employ highly interpretive analytical methods. Given the variation in the level of interpretation involved, the following table provides detail on a selection of commonly used qualitative synthesis methods (see Table 1).

**Table 1: Conducting a Qualitative Evidence Synthesis: Which Review Processes Are Required?**

Component of Review Process	Best Fit Framework Synthesis	Concept Analysis	Ecological Triangulation	Framework Synthesis	Grounded Formal Theory	Meta-Aggregation	Meta-Ethnography	Meta-Interpretation	Meta-Study	Meta-Summary	Narrative Synthesis	Qualitative Interpretive Meta-Synthesis	Textual narrative synthesis	Thematic synthesis
Generating Theory	⊕	⊕	⊗	●	⊕	⊗	⊕	⊕	⊗	⊗	●	●	⊗	⊗
Exploring Theory	●	⊕	⊕	●	⊕	⊗	⊕	⊕	⊗	⊗	⊕	●	⊗	⊕
Testing Theory	⊕	⊕	⊕	⊕	⊕	⊗	⊕	⊕	⊗	⊗	●	●	⊗	⊗
Use of Logic Models	●	⊗	●	●	⊗	●	⊗	⊗	⊗	⊗	●	●	⊗	⊗
Comprehensive Search	⊕	⊗	⊕	⊕	●	⊕	●	⊗	⊕	⊕	⊕	⊗	⊕	⊕
Purposive Search	●	⊕	●	●	⊕	⊗	●	⊕	⊗	⊗	⊗	⊕	⊗	⊗
Rich Conceptual Data	⊗	⊕	⊕	⊗	⊕	⊗	⊕	⊕	⊗	⊗	⊗	●	⊗	⊗
Thick Contextual Data	⊗	⊗	⊕	⊗	●	⊗	●	⊕	⊗	⊗	⊗	●	⊗	⊗
Quality Assessment	⊕	⊗	⊕	⊕	●	⊕	●	⊕	●	●	⊕	⊕	⊕	⊕
Interpretive level of Themes	●	⊕	⊗	●	⊕	⊕	⊕	⊕	⊗	⊗	⊗	●	⊗	●
Model as Output	⊕	●	⊗	●	⊗	⊗	●	⊗	●	●	●	●	⊗	⊗
Graphical Presentation	⊕	●	⊕	●	⊗	⊗	●	⊗	●	●	●	●	⊗	⊗
⊗ = Not Required ● = Uncertain ⊕ = Essential														

Note. Reproduced from Booth et al. (2016, p. 28)

Placing various methods of qualitative synthesis within a continuum from low to high level of interpretation allows better understanding of qualitative synthesis classification and terminology (Booth et al., 2016; Campbell et al., 2011). It has been suggested that we need to “look beyond labels when searching and reviewing this area of work and for developing an agreed terminology” (Campbell et al., 2011, p. 6). The assumption that not each qualitative synthesis method is unique and that many of their processes overlap justifies a review of classification and terminology via a new continuum.

### **3.3 The ‘interpretive continuum’: differences and similarities of qualitative synthesis methods**

In this section, a continuum of qualitative synthesis methods will be presented based on a critique of relevant literature and the differences and similarities of qualitative synthesis methods. This continuum will be organised by numeric methods, integrative methods and interpretive methods.

It is outside the scope of this thesis to provide an exhaustive explanation of all methods, but rather, examples will be grouped on the continuum according to their interpretiveness to help clarify the relationships between, and differences among, some of the more commonly used qualitative synthesis methods. This will provide a basis for the selection of the chosen synthesis method.

#### **3.3.1 Numeric methods of qualitative synthesis**

The term *numeric synthesis* is used to describe qualitative synthesis methods at the minimally interpretive end of the continuum. These methods have a variety of aims, including to pool and tally data, show frequencies, rank the relative importance of findings and calculate probabilities. Methodologies considered numeric have been proposed for the purpose of converting qualitative data into quantitative form for combined numerical analysis and synthesis (Campbell et al., 2011). Such methods may include the case-survey method (Yin, 1989) and Bayesian synthesis (Crandell, Vooils, Chang, & Sandelowski, 2011). Some have described these methods as aggregative, because their purpose was the accumulation and generalisation of evidence (Crandell et al., 2011; Hammersley, 1990). Numeric methods are amongst the most under-used because: (1) they lack sensitivity to interpretive aspects of

evidence; (2) techniques have not advanced significantly since early attempts to test them, and; (3) methodological issues including those relating to determination of prior beliefs and the impact of different methods of qualitative synthesis remain unresolved (Crandell et al., 2011).

### **3.3.2 Integrative methods of qualitative synthesis**

The term *integrative synthesis* is used to describe the next group of qualitative synthesis methods on the interpretive continuum. The use and meaning of the term *integrative* in relation to qualitative synthesis varies in the literature (Campbell et al., 2011; Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Holly et al., 2012; Noblit & Hare, 1988; Pearson et al., 2011; Saini & Shlonsky, 2012). This term has been used to describe qualitative syntheses that were concerned with combining or amalgamating data from primary studies and where a basic comparability in the phenomena of interest could be demonstrated (Dixon-Woods, Agarwal, Young, Jones, & Sutton, 2004). One view is that integrative synthesis methods can be distinguished from interpretive methods because they are primarily suitable for synthesising quantitative data (Noblit & Hare, 1988). These authors argue that interpretive synthesis methods involve induction and interpretation, and aim to anticipate what might be involved in analogous situations and to understand how things connect and interact (Noblit & Hare, 1988). Similarly, contemporary authors discuss integrative methods to involve the inductive development of thematic interpretations of a phenomenon, event or experience, to provide a foundation for the development of conceptual descriptions of phenomena across studies (Saini & Shlonsky, 2012). In this continuum, the proposed conceptualisation of integrative synthesis aligns more aptly with a definition of aggregative synthesis, the aim of which is to “achieve an aggregation of findings or check the comparability and replication of findings, based on narrative rather than numeric methods” (Campbell et al., 2011, p. 7). According to the literature, the primary focus of an integrative synthesis is not to reinterpret primary findings, to develop new levels of abstraction, or theoretical frameworks (Booth et al., 2016; Hannes & Lockwood, 2011; Holly et al., 2012; JBI, 2014a; Pearson et al., 2011).

The qualitative synthesis method of meta-aggregation contributes an additional aspect to this discussion. Meta-aggregation shares similarities with some processes of aggregative synthesis described above, such as the pooling of data based on similarity of meaning to create categories and synthesised findings (Campbell et al., 2011; Dixon-Woods, Bonas, et al., 2006). This analysis technique also shares similarities with the constant comparative method,

used in more interpretive methods of qualitative synthesis such as grounded formal theory, meta-ethnography and thematic synthesis (see section 3.4).

Integrative methods have been described as somewhere between numeric and interpretive, with a focus on summarising findings and the development of “integrated thematic interpretations of an event, phenomenon or experience” (Saini & Shlonsky, 2012). Others agree that the output of integrative methods is a taxonomy of the interpretations made by the primary researchers, which provide the foundation for the future development of theoretical interpretations (Sandelowski & Barroso, 2007). It has been argued that integrative syntheses are suited to produce theories of causality, and may also include claims about generalisability (Dixon-Woods, Agarwal, et al., 2005). For example, a meta-aggregation may show factors influencing nursing home staff decisions to transfer residents to hospital (Laging, Ford, Bauer, & Nay, 2015). Integrative synthesis methods may include narrative synthesis (Centre for Reviews and Dissemination, 2009; McNaughton, 2000; Miles & Huberman, 1994), meta-aggregation (JBI, 2014a; Laging et al., 2015; Pearson et al., 2011) and meta-synthesis (Sandelowski & Barroso, 2003, 2007; Thorne et al., 2004; Walsh & Downe, 2005).

It is important to acknowledge that some integrative synthesis methods share processes or aspects of procedures with those observed in other qualitative synthesis methods, including numeric methods, and interpretive methods. This notion provides justification for the development of this new continuum. There is growing recognition that most approaches to qualitative synthesis employ processes that use a combination of interpretation and aggregation (Dixon-Woods, Agarwal, et al., 2005; Pearson et al., 2011; Saini & Shlonsky, 2012).

### **3.3.3 Interpretive methods of qualitative synthesis**

The term *interpretive synthesis* will be used to describe the group of qualitative synthesis methods on the highly interpretive end of the continuum. Commonly used highly interpretive methods include meta-ethnography (Britten et al., 2002; Campbell et al., 2011; McInnes, Seers, & Tutton, 2011; Noblit & Hare, 1988), thematic synthesis (Boyatzis, 1998; Miles, Huberman, & Saldana, 2014; Thomas & Harden, 2008) and grounded formal theory (Eaves, 2001; Finfgeld, 2003; Glaser & Strauss, 1967, 1971; Kearney, 1998; Pope et al., 2007). Interpretive approaches aim to construct theory and interpretive explanations of phenomena

under investigation, by translating key concepts or interpretive metaphors from one study to another (Booth et al., 2016; Campbell et al., 2011).

The ability of any one qualitative synthesis method to adequately capture the contextual nature of qualitative research has been questioned (Saini & Shlonsky, 2012). Therefore, in the next section four common qualitative synthesis methods will be critiqued in terms of their advantages and disadvantages, similarities and differences to provide context to the selection of meta-aggregation as an appropriate method to meet the thesis aims.

### **3.4 Overview of methods for qualitative synthesis**

In this section, the qualitative synthesis methods grounded formal theory, meta-ethnography, thematic synthesis, and meta-aggregation are critiqued against relevant literature leading to the rationale for choice of meta-aggregation in the subsequent section (see section 3.5). These methods were selected, as they are the main established methods of qualitative synthesis, and are most likely to be able to address the aim of this qualitative synthesis. This critique will demonstrate that there may be more than one method appropriate to address the aim of this qualitative synthesis.

#### **3.4.1 Grounded formal theory**

In the late 1960s and early 1970s sociologists Glaser and Strauss, creators of the qualitative methodology grounded theory (Glaser & Strauss, 1967), undertook the first synthesis of qualitative studies (Eaves, 2001). Glaser and Strauss' seminal book *Status Passage*, involved the synthesis of four studies, with a focus on the process of dying and other major life transformations (Glaser & Strauss, 1971). Referred to as grounded formal theory, this qualitative synthesis method is described as an extension of grounded theory, therefore interpretive in nature (Kearney, 1998; Thorne et al., 2004) and has evolved over time from the original work of five grounded theorists, namely, Glaser and Strauss (1967), Charmaz (1983), Chesler (1987), and Strauss and Corbin (1990).

Grounded formal theory shares some commonalities with meta-ethnography, including juxtaposition and comparison of themes or codes, attention to divergent data in the process of synthesis, and theory development as an intended outcome (Campbell et al., 2011; Glaser & Strauss, 1967; Noblit & Hare, 1988; Zimmer, 2006). However, this method is said to give a



stronger emphasis on the analysis and reporting of verbatim data (Zimmer, 2006). Grounded formal theory involves a number of key processes, including simultaneous data collection and analysis; an inductive analysis approach; the use of the comparative analysis procedures between or among groups; and the use of purposive sampling. Purposive sampling (as opposed to exhaustive sampling) is defined as the selective inclusion of studies (Booth et al., 2016). The described key processes of grounded formal theory are utilised to achieve theoretical saturation and the generation of new theory (Barnett-Page & Thomas, 2009; Eaves, 2001).

Comparative analysis is a central feature of grounded theory and is often referred to as the constant comparative method (Glaser & Strauss, 1967; Strauss & Corbin, 1990). The constant comparative method is a widely reproduced element of grounded theory, probably because it provides a set of clear procedures by which data may be analysed and because it allows a researcher to identify patterns and relationships between these patterns.

Similar to other methods of qualitative synthesis, criticisms of grounded formal theory relate to its lack of transparent processes and poor guidance on appraisal of studies for inclusion (Barnett-Page & Thomas, 2009; Dixon-Woods, Agarwal, et al., 2005; Saini & Shlonsky, 2012). A strength of this method lies in its adaptability to multiple epistemologies, including pragmatism, poststructuralism, critical reflexivity, symbolic interactionism, postcolonial theory, feminism, interpretivism and constructivism (Kearney, 1998; Thorne et al., 2004). Depending on the philosophical framework guiding a qualitative synthesis, each of these epistemologies may influence the knowledge derived from data analysis (Saini & Shlonsky, 2012). In other words, it is always possible that the epistemology chosen for a qualitative synthesis may lead to the generation of quite different knowledge and theory development as that attained in the original studies (Jensen & Allen, 1996). This is viewed by some as an added complexity to formulating theory through meta-synthesis (Estabrooks, Field, & Morse, 1994). Thus, to be included in grounded formal theory, it is recommended by some that studies be both epistemologically consistent and use a grounded theory orientation (Finfgeld, 2003; Kearney, 1998; Pope et al., 2007; Saini & Shlonsky, 2012).

Based on this critique, grounded formal theory would not be a suitable method to meet the intended thesis aim, because the qualitative studies that are to be synthesised are not epistemologically consistent, nor do they use a grounded theory orientation. Also, a comprehensive search strategy is preferred (as opposed to purposive sampling), to enable a

comprehensive and complete exploration of the research topic. However, an analysis technique similar to the constant comparison method may be useful in this qualitative synthesis as it provides a set of clear and widely published procedures by which data may be analysed.

### **3.4.2 Meta-ethnography**

In 1988, Noblit and Hare (1988) proposed the first iteration of meta-ethnography as an alternative to the quantitatively grounded meta-analysis. In their seminal works, they argued that a meta-ethnography should be interpretive rather than aggregative and “driven by the desire to construct adequate interpretive explanations” (Noblit & Hare, 1988, p. 3).

A meta-ethnography involves: (1) determining how studies are related; (2) ordering lists of concepts; (3) comparing and contrasting them to identify the relationship between the studies; (4) translating the studies into each other; (5) synthesising the translations, and; (6) expressing the synthesis in a way that can be communicated effectively to the intended audience, taking into account culture, concepts and language (Campbell et al., 2011; Saini & Shlonsky, 2012). As with other methods of qualitative synthesis, the comparison of studies to identify relationships between phenomena can be likened to the constant comparative method described in grounded theory (see 3.4.1). In contrast Noblit and Hare (1988) suggest that meta-ethnography comprises seven distinct phases. In reality, each phase may overlap or occur in parallel (Doyle, 2003), which has been described as an advantage of this method but is also common to other methods of qualitative synthesis, including meta-aggregation. Findings are extracted and translated from one study to another using an idiomatic (inductive, abstract) rather than a verbatim (word-for-word) translation, as seen in meta-aggregation to create a broader and deeper understanding of the phenomenon (Holly et al., 2012; Reis, Hermoni, Van-Raalte, Dahan, & Borkan, 2007).

Noblit and Hare also described three possible types of relationship that guide a translation and subsequent synthesis. A ‘reciprocal translational analysis’ is recommended when concepts are directly comparable and involves a process of comparing themes and concepts (Barnett-Page & Thomas, 2009; France et al., 2014; Noblit & Hare, 1988). In a ‘reciprocal translation’, it may be revealed that the metaphors of one study are better than those of others in representing both studies, or that other descriptive metaphors conceptualised by the reviewer may be reasonable (Campbell et al., 2011). A ‘refutational synthesis’ is used to

describe and explain contradictions between synthesised studies. This is an uncommon technique and has the potential to identify paradoxes that arise over time (Atkins et al., 2008; France et al., 2014). Lastly, a 'lines-of-argument synthesis' involves the development of new interpretations by drawing together different aspects of a topic under study (France et al., 2014; Noblit & Hare, 1988). This is achieved through the detailed study of the similarities and differences among studies to be synthesised to develop a new model, theory or understanding of a phenomena. In practice a single meta-ethnography may contain elements of all three forms of synthesis, namely, reciprocal translational analysis, refutational synthesis and lines-of-argument synthesis (Campbell et al., 2011; Dixon-Woods, Agarwal, et al., 2005).

Since Noblit and Hare's first iteration of meta-ethnography there have been a number of developments, some controversial, in the processes for search strategy, study selection, quality appraisal, analysis and synthesis and the inclusion of non-ethnographic studies (Atkins et al., 2008; Britten et al., 2002; Campbell et al., 2011; Malpass et al., 2009). For example, Britten et al. (2002) published an earlier worked example of meta-ethnography, building on Noblit and Hares' method to develop what they called 'third-order interpretations', which extended beyond the original findings. Others have used meta-ethnography to synthesise a large amount of quantitative and/or qualitative data (Atkins et al., 2008; Campbell et al., 2011; Dixon-Woods, Kirk, et al., 2005).

Meta-ethnography is still advocated by some authors to be best suited to address conceptual questions through synthesis of a limited number of conceptually rich studies, as it employs purposive rather than exhaustive sampling (Britten et al., 2002; Campbell et al., 2011). Meta-ethnography has shown its ability to produce theories with greater explanatory power than could be achieved in an integrative literature review. The use of this method has evolved somewhat since its first iteration, including its application in the synthesis of a broad range of methodologies rather than ethnographies alone (Atkins et al., 2008; Britten et al., 2002; Campbell et al., 2011; Doyle, 2003; Pound et al., 2005). Even though meta-ethnography is applied in diverse ways, current reporting standards are criticised for their inconsistency, lack of transparency and poor overall quality (France et al., 2014; Hannes & Macaitis, 2012). Meta-ethnography has also been described as a technical and laborious method that requires a high degree of qualitative research skill (Dixon-Woods, Agarwal, et al., 2005; France et al., 2014).

As a result of the diversity described in how a meta-ethnography is operationalised, it should be acknowledged that there is no one set of procedures to follow. For example, in a review of 25 meta-ethnographies, variation was reported between the meta-ethnography methods described, applied and reported (Hannes & Macaitis, 2012). This may be due to the limited detail provided by Noblit and Hare in the continuous comparative analysis of text undertaken during translation and synthesis, making it in part, open to interpretation. These can be considered barriers to the use of meta-ethnography, as they relate to the assessment of methodological rigour, credibility and trustworthiness of the findings. As with most qualitative synthesis methods, meta-ethnography is still evolving, and cannot be considered an approach appropriate for application in every circumstance.

Based on this critique, meta-ethnography was not considered appropriate for the aim of the review. This decision is based on the following rationales: (1) verbatim as opposed to idiomatic translation (and thus reciprocal translation) is appropriate in order to remain close to the participant voice, which is necessary to strengthen the value and relevance of the findings to clinicians and policy-makers, and; (2) a comprehensive search strategy was appropriate (as opposed to purposive sampling) to enable a comprehensive and complete identification of relevant studies.

### **3.4.3 Thematic synthesis**

A number of researchers have used thematic synthesis to synthesise qualitative views studies (Atwal, Spiliotopoulou, Plastow, McIntyre, & McKay, 2012; Mavhu, Mupambireyi, Hart, & Cowan, 2014; Thomas & Harden, 2008; Tong et al., 2014). This integrative synthesis method can be used to synthesise qualitative and/or quantitative evidence (Booth et al., 2016; Gough, Oliver, & Thomas, 2012). Thematic synthesis builds upon techniques from both grounded theory and meta-ethnography (Barnett-Page & Thomas, 2009; Hannes & Lockwood, 2012) and can be facilitated through the use of web-based software (Thomas, Brunton, & Graziosi, 2010). Thematic synthesis, grounded theory and meta-ethnography share some degree of overlap, demonstrating similarities in their inductive analytical approach, such as line-by-line coding and the development of descriptive and analytical themes. Similar processes are also observed in the analytical processes of other methods, such as meta-aggregation (Booth et al., 2016). The adaptability of a thematic synthesis is also reflected in its ability to be converted to a meta-ethnography, for example where the source data proves sufficiently rich (Booth et al., 2016).

Thematic synthesis builds upon methods for thematic analysis (Hannes & Lockwood, 2012). Thematic analysis is the analytical technique used to “formalise the identification and development of themes” during a thematic synthesis (Thomas & Harden, 2008, p. 3). This analytical process can be used with most qualitative synthesis methods (Booth et al., 2016; Boyatzis, 1998). In a thematic analysis, line-by-line coding is used to conceptualise the data and inductively identify concepts (see section 3.2) (Tong et al., 2014). Codes are then used to develop descriptive themes, which are then further interpreted to produce analytical themes (Thomas & Harden, 2008). The first two stages of the analysis are mainly inductively driven, but the development of analytical themes is driven by the synthesis aims. The synthesised findings are then used to develop implications and recommendations for the phenomena under study (Hannes & Lockwood, 2012).

The adaptability of thematic synthesis has been highlighted. Thematic analysis has many forms and its broad and utilitarian nature has also been acknowledged previously (Dixon-Woods, Agarwal, et al., 2005; Hannes & Macaitis, 2012; Thomas & Harden, 2008). As with meta-ethnography, the diversity of thematic synthesis methods holds the inherent risk of inconsistency in its application, as there is no single set of procedures to follow. This has implications for the assessment of methodological rigour, credibility and trustworthiness of the results, thus synthesisers need to demonstrate transparency in reporting.

The availability of software and the published literature on thematic analysis and synthesis make this an appealing method for research on experiences and perceptions (Boyatzis, 1998; Thomas & Harden, 2008; Tong et al., 2014). However meta-aggregation was thought better suited to address the thesis aim. An in-depth description and justification for the selection of this methodology is provided in the next two sections (see section 3.4.4 and 3.5).

#### **3.4.4 Meta-aggregation: qualitative synthesis method**

Another approach to qualitative synthesis is meta-aggregation, as described by the JBI (2014a). Meta-aggregation method is said to draw from Husserlian phenomenology in its endeavour to find common meaning (Lockwood, 2011). The epistemological nature of Edmund Husserl’s work is exemplified by his description of experience being the fundamental source of knowledge. Husserl (1970) also argues that phenomena must be presented without the researcher’s interpretation of participants’ experiences. Later research confirms these claims, where Valle, King and Halling (1989) describe the aim of

phenomenological enquiry as the rigorous and unbiased study of things as they are, in order to arrive at an essential understanding of human experience. Moran (2000) also supports this in his statement “explanations are not to be imposed before the phenomena have been understood from within” (p. 4).

Husserl devised the process of phenomenological reduction in order to *bracket* subjective perspectives and theoretical constructs, and to allow the exact nature of the phenomena to emerge without bias (Racher & Robinson, 2003). Using this approach, researchers bring no judgement, preconceptions or presuppositions to an investigation. More specifically they bracket their pre-judgements (Dowling, 2007). Bracketing one’s preconceptions to interpret and combine data in an attempt to find common meaning illustrates a similarity between Husserlian phenomenology and the philosophies underpinning meta-aggregation (Pearson et al., 2011; Racher & Robinson, 2003; Valle et al., 1989). Arguably, it is not possible for a researcher to completely bracket their pre-judgements and approach data analysis in an unbiased, value-free manner (Denzin & Lincoln, 2011). However, this philosophical standpoint is suited to capture the experiential complexities of healthcare phenomena.

The contrasting philosophical imperative in Heidegger’s Hermeneutic Phenomenology (a constructivist interpretive position) encourages researchers to engage with data and involve their own understandings to explore the lived experience, with the focus on understanding rather than describing (Dowling, 2007; Heidegger, 1962; Reiners, 2012). Constructive interpretivism aligns more strongly with meta-ethnography, with its focus on re-conceptualising research findings (Cohen, David, & Steeves, 2000; Lindseth & Norberg, 2004; Noblit & Hare, 1988).

Thus, meta-aggregation, which draws Husserlian phenomenology, is considered an appropriate method to meet the aim of this qualitative synthesis. This method will allow qualitative research about the experiences and perceptions of patients’ families on EOLC in the ICU to be synthesised in a way that maintains the integrity of the primary authors’ findings. A synthesis that remains close to the participant voice will strengthen the value and relevance of the findings to clinicians and policy-makers.

The meta-aggregative approach provides a set of supportive tools and software to guide the review and synthesis process, which have been validated and refined over a number of years (Flemming & Briggs, 2007; Hannes & Lockwood, 2011; JBI, 2014a; McInnes & Wimpenny,

2008). In a paper exploring the theoretical and methodological nuances of qualitative evidence synthesis, it was asserted that:

Any approach can be valid, as long as the teams using them understand and pay attention to the underlying theoretical perspective adopted, and are explicit about the strengths and weaknesses involved, and the limits these impose on what they claim their findings say about the particular area of study they have approached (Downe, 2008, p. 6).

Similar to other methods, meta-aggregation, provides clear and transparent processes, and supportive computer software, and has the potential to produce a rigorous qualitative synthesis, that is less likely to be subject to criticism of conduct and reporting standards (consistency, transparency and demanding processes) directed at other qualitative synthesis methods. The requirement of a published protocol adds to the rigour of the synthesis, by contributing to authenticity (see section 4.10.1). Ensuring quality in conduct and reporting standards are essential elements of a methodologically sound systematic review (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

Meta-aggregation is said to perform best where themes under which findings are summarised are largely secure and well specified (Pearson et al., 2011). A secure and well-specified analysis is achieved when a clear relationship between a generated theme and the participants' expressed experiences is established. For example, in an integrative synthesis of the impact of educational interventions on uptake of pertussis immunisation in new mothers, the key variables of uptake, new mothers and educational intervention would be defined at an early stage in the synthesis and would likely form the categories under which the data extracted from primary studies would be summarised (Hannes & Lockwood, 2011).

Producing secure and well-specified data assists with transparency of the synthesisers decisions in aggregating particular groups of findings, leading to a reliable set of categories from the synthesis exercise, another appealing aspect of meta-aggregation. This concept has been referred to as *inter-reviewer agreement*, defined as the consistency of the extraction and synthesis of qualitative data and thus the interpretive authenticity (an element of credibility in qualitative research) of the synthesis (see section 4.10.1) (Florence, Schulz, & Pearson, 2005). In meta-aggregation, this can be, in part, attributed to the use of verbatim extraction,

which is appropriate in order to remain close to the participant voice, particularly in research investigating families' experiences and perceptions of the EOLC given in the ICU setting.

Recent methodological developments in the assessment of confidence in the synthesised findings of qualitative synthesis have led to the publication of two approaches; the Confidence in the Evidence from Reviews of Qualitative Research (CERQual) Approach (Lewin et al., 2015) and the Establishing Confidence in the Output of Qualitative Research Synthesis: The ConQual Approach (Munn, Porritt, Lockwood, Aromataris, & Pearson, 2014). These approaches were developed to contribute to the establishment of rigour and trustworthiness in qualitative synthesis; both are still at an early stage of development and are not yet established techniques.

The CERQual approach focuses on four components: methodological limitations; relevance; coherence; and adequacy of data (Lewin et al., 2015) whereas the ConQual approach focuses on the evaluation of dependability (the congruency between methodology, objectives, data collection methods and data analysis techniques and a clear author statement regarding theoretical standpoint, values and beliefs) and credibility (application of a level of credibility to each finding assessing the congruency between the author's interpretation and the supporting data) (Munn et al., 2014). The ConQual approach was developed as an extension to meta-aggregative methods (Munn et al., 2014), whereas the CERQual approach is proposed for use with a range of qualitative synthesis methods (Lewin et al., 2015). These techniques stem from work undertaken by the GRADE group (Grading of Recommendations Assessment, Development and Evaluation) who developed a systematic process to establish and present confidence in qualitative synthesis (Goldet & Howick, 2013).

The objective of all such approaches, irrespective of the nature of the evidence is to transparently assess how much confidence decision makers and other end-users can place in synthesised review findings. Such processes have the potential to support policy development by providing analysis of the strength and quality of the evidence. For example, a World Health Organisation panel utilised the CERQual Approach to qualitative synthesis in investigation of health worker interventions for maternal and child health (World Health Organisation, 2012). Their qualitative synthesis *summary of findings tables*, were shown to improve understanding and accessibility of their results (Langendam et al., 2013; Rosenbaum, Glenton, & Oxman, 2010; Treweek et al., 2013). Thus, a process to assess how



much confidence to place in specific review findings has value in supporting such decision-making.

Examples of qualitative syntheses using meta-aggregation are commonplace (Gibson et al., 2015; Laging et al., 2015; Lawrence, Pringle, Kerr, & Booth, 2015). This approach allows qualitative studies to be combined regardless of epistemological or methodological framework, which has been a criticism of some other methods (see 3.4.1 and 3.4.2) (Barnett-Page & Thomas, 2009; Dixon-Woods, Agarwal, et al., 2005; Saini & Shlonsky, 2012). In an early publication, authors conveyed “an urgent need for rigorous methods for synthesising evidence of diverse types generated by diverse methodologies... in order to meet the needs of policy-makers and practitioners...” (Dixon-Woods, Agarwal, et al., 2005, p. 52).

Despite theoretical argument, in the current research climate, combining findings from different qualitative methodologies is recognised as an acceptable and pragmatic synthesis technique (Booth et al., 2016; Campbell et al., 2011; Foster, 2011). Combining findings from a range of methodological approaches will enable a richer, more flexible and dynamic approach to generating new insights as it can help to collate multiple perspectives and develop a wider picture of the phenomenon under study (Downe, 2008). In keeping with current practice in qualitative evidence synthesis, findings will be combined from studies that have used diverse qualitative methodologies.

In this discussion and critique of commonly published qualitative synthesis methods, it has been demonstrated that many share similar techniques and procedures (see section 3.4). Given that there are a range of qualitative synthesis methods to consider and that there is considerable overlap between the different methodologies, it is important to make an informed choice regarding selection of an appropriate method and to provide a transparent justification in the selection of a qualitative evidence synthesis methodology. With this in mind, the next section will provide a justification as to why meta-aggregation is suitable to meet the aims of this qualitative synthesis.

### **3.5 Rationale for choice of meta-aggregation**

Meta-aggregation was chosen from the potentially suitable qualitative synthesis methods presented and critiqued above (see section 3.4). A meta-aggregative approach will allow qualitative research about the experiences and perceptions of patients' families' on EOLC in the ICU to be synthesised in a way that maintains the integrity of the primary authors' findings. It is particularly important in this topic to ensure accurate representation of participant voice. A unique aspect of meta-aggregation, which lends itself well to this aim, is that findings are aggregated and translated from one study to another using verbatim translation (as opposed to idiomatic translation seen in more interpretive methods) (Holly et al., 2012; Reis et al., 2007). Categories derived from the analysis are not subjected to further interpretation, they are aggregated in a descriptive manner, in order to construct a synthesis that resonates with the primary study findings, provides descriptions of the similarities and differences apparent in the data, identify barriers and facilitators to the phenomena of interest and potential biases in the data. Thus, meta-aggregation supports the development of practice recommendations grounded in data that have the potential to inform policy development and service delivery across Australia under the National Palliative Care Strategy (Department of Health and Ageing, 2010).

The final product of this meta-aggregation will also identify gaps in the existing literature and provide direction for future investigations (McNaughton, 2000; Meleis, 1997; Walker & Avant, 1995). Some agree that for findings to have impact they must be "presented in an accessible and useable form in the real world of practice and policy making" (Sandelowski et al., 1997, p. 365). The use of thematic analysis (see 3.4.3) (Boyatzis, 1998; Thomas & Harden, 2008) may also enhance the chosen approach. Thematic analysis is presented and explained in Chapter 4.

The integrative nature of meta-aggregation is viewed as a limitation by some authors, who advocate the benefits of a more interpretive approach, to provide a deeper understanding of phenomena and develop new explanatory frameworks or abstract theories (Britten et al., 2002; Campbell et al., 2011; Dixon-Woods, Bonas, et al., 2006; Holly et al., 2012; Hopp & Rittenmeyer, 2015; Miles & Huberman, 1994; Noblit & Hare, 1988). However, the choice of methodology should depend on the aim and purpose of the review, timeframe to completion, resources available, proposed audience and availability of primary research, not just the theoretical nuances of the method itself.

Similar to other methods, meta-aggregation provides a well-established, pragmatic and validated framework, with clear and transparent supportive guides (Hopp & Rittenmeyer, 2015; JBI, 2014a; Lockwood, 2011; McInnes & Wimpenny, 2008). This method has also been used before to synthesise experiential aspects of healthcare phenomena (Laging et al., 2015). The QARI v5.0 computer software provides a unique suite of online tools and checklists, used to: (1) manage and organise literature; (2) document each step of the decision making process; (3) link synthesised statements to findings retrieved from original studies, and: (4) facilitating a clear and transparent process for data analysis (Banner & Albarran, 2009; Hannes & Lockwood, 2011; McInnes & Wimpenny, 2008). Meta-aggregation also provides recommendations that take into account the strength and quality of the evidence, and this method is linked to an online best-practice database, which supports the dissemination of research and knowledge directly to clinicians. Finally, the ConQual approach is adopted as a methodological addition in the current study, firstly, to assess how much confidence to place in specific review findings; secondly, to provide an opportunity to critique and propose recommendations for future methodological improvements relating to ConQual; and thirdly, to test the inclusion of this technique in a meta-aggregation (see section 4.9).

In summary, meta-aggregation is highly appropriate for the analysis and synthesis of qualitative literature that reports patients' families' experiences and perceptions of the EOLC delivered in the ICU setting. This approach will enable the thesis aim to be met.

### **3.6 Summary**

This chapter has discussed the nature of knowledge derived from qualitative synthesis, emphasising some of the key methodological debates currently in play. An historical overview of qualitative synthesis was presented, including an overview of commonly used methods. These methods were critically analysed and located within a continuum from minimally to highly interpretive. In addition similarities, differences and how and when processes overlap were identified. Finally justification was provided for the choice of meta-aggregation as the qualitative synthesis method. The next chapter presents the methods used in this qualitative synthesis.

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## **CHAPTER 4**

### **METHODS**

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## **Chapter 4: Methods**

### **4.1 Introduction**

The previous chapter set the scene by providing rationale and justification for selecting the meta-aggregation method to meet the aim of this qualitative synthesis. The aim is to identify and synthesise qualitative studies on the experiences and perceptions of the patient's family in relation to EOLC provided in the ICU setting, when life-sustaining treatments are withheld or withdrawn.

This chapter provides a comprehensive overview of the meta-aggregative methods and processes used in this qualitative synthesis. The inclusion and exclusion criteria guiding the synthesis are detailed, including the types of studies, types of participants and phenomena of interest. Justification for the chosen search strategy is provided, followed by a detailed description of the search strategy itself. Study selection, quality appraisal and data analysis methods will also be discussed, supported by contemporary literature. Finally, safeguards employed to ensure the rigour of the synthesis are discussed in relation to credibility, dependability, confirmability and transferability.

In the discussion of methods, the primary reviewer is Alysia Coventry (AC) and the secondary reviewers are Elizabeth McInnes (EM), Rosemary Ford (RF) and John Rosenberg (JR). Where reference to the *supervisory panel* is made, this involves EM, RF and JR.

The next section presents the inclusion and exclusion criteria.

### **4.2 Inclusion and exclusion criteria**

In this section, the key inclusion and exclusion criteria are identified, discussed and justified. These include the types of studies considered, types of participants, the setting and the phenomena of interest. The exclusion criteria are made explicit by the clear identification of the inclusion criteria (see Table 2).

**Table 2: Inclusion Criteria**

Criteria	Inclusions
<b>Types of Studies</b>	All primary qualitative research (published and unpublished)
<b>Publication Year</b>	January 2005 – June 2016
<b>Topic</b>	Experiences and perceptions of patients’ families, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn.
<b>Types of Participants</b>	Family members of adult ICU patients
<b>Phenomena of Interest</b>	Experiences and perceptions of the quality of EOLC
<b>Setting</b>	Adult ICU
<b>Language</b>	English
<b>Availability</b>	All formats published, unpublished, print, digital

*Note.* Where studies did not meet the inclusion criteria, they were excluded.

#### **4.2.1 Types of studies**

This review considered all primary qualitative research (published and unpublished), regardless of methodology. Included studies were published in the English language between January 2005 and June 2016. This year limitation was applied because a focus on experiences and perceptions relevant to current ICU practices is important. In addition, much of the seminal work in EOLC (including national and international government funded initiatives) has occurred within this timeframe (ANZICS, 2014; Department of Health and Ageing, 2010; LACDP, 2015; PCA, 2010; Truog et al., 2008).

#### **4.2.2 Types of participants and setting**

Studies that reported on the views, experiences and perceptions of *adult* ICU patients’ families were considered (see Definition of terms).

#### **4.2.3 Phenomena of interest**

Studies were considered if the focus was on the experiences or perceptions of patients’ families, of the EOLC delivered in the ICU setting, when life-sustaining treatments were withheld or withdrawn. To be included, reported data needed to be collected after the decision to withdraw or withhold life-sustaining treatments was made, and this needed to be

explicit. As the scope of this qualitative synthesis is to examine EOLC, perceptions of organ donor families were considered for inclusion, as this can be considered care delivered at the end of life in the ICU.

The next section provides justification for the techniques used in the search strategy.

### **4.3 Search strategy justification**

A comprehensive and systematic search technique was employed for this qualitative synthesis (Booth et al., 2016). The practical challenges and barriers inherent in searching for qualitative evidence are highlighted in the literature (Finfgeld-Connett & Johnson, 2013; Flemming, 2007; Gorecki, Brown, Briggs, & Nixon, 2010; Walters, Wilczynski, & Haynes, 2006; Wilczynski, Marks, & Haynes, 2007). Database indexing and search filters for quantitative literature is well established, but the emergence of similar systems for the identification of qualitative research has been much slower (Gorecki et al., 2010). Variation exists with regard to terminology used to describe and index qualitative methods by authors and within electronic databases (Barroso et al., 2003; Flemming, 2007).

Research evaluating qualitative search techniques has found that subject-specific search strategies are more effective than methodology-based strategies (Gorecki et al., 2010). It is suggested that methodologically based search strategies are less effective because of the unique nature of qualitative research, and hence language variation occurs in titles, abstract content and also the indexing practices of electronic databases (Gorecki et al., 2010). As there is no gold standard search method, and to ensure a high recall and sensitivity of search results, both subject and broad-based terms, which is a tested strategy recommended for identifying qualitative research studies (Flemming & Briggs, 2007). Bates' Model of Berrypicking (Barroso et al., 2003; Bates, 1989) was adopted to enhance the meta-aggregation search method. The berrypicking approach involves continually following up on leads (such as searching reference lists) and including new keywords identified in databases and journal articles to expand the synonym base (Barroso et al., 2003). A similar model was referred to by Cooper (1982) as "the ancestry approach" (p. 295), which involved retrieving studies by following citations from one study to another.

In summary, this tested comprehensive search strategy is pragmatic in nature, and aims to maximise recall and sensitivity, enabling a comprehensive exploration of the research topic. The next section provides a detailed description of the techniques used in the search strategy.

#### 4.4 Search strategy

A three-step approach to searching guided the search strategy for this systematic review (JBI, 2014a; Pearson et al., 2011).

The first phase involved a preliminary search of CINAHL and MEDLINE using a set of search terms and their associated synonyms determined by concept mapping. The search terms *intensive care units* and *family* were used as subject headings combined with *end-of-life care* as a free-text search term. An analysis of words contained in the titles, abstracts and indexing terms of each article was conducted to identify new keywords and subject headings for these databases.

**Table 3: CINAHL and MEDLINE Search Terms**

Concept 1 (subject)	Concept 2 (subject)	Concept 3 (free-text)
<b>intensive care units</b>	<b>Family</b>	<b>end-of-life-care</b>
SYNONYMS		
<b>CINAHL</b> (Subject Heading)	<b>CINAHL</b> (Subject Heading)	end-of-life
critical care	significant other	withh*
critical care nursing	family attitudes	withdr*
	visitors to patients	life sustain*
	extended family	life support
	spouses	euthanasia
	caregivers	terminal*
	patient-family relations	palliat*
		end of life
<b>MEDLINE</b> (MeSH)	<b>MEDLINE</b> (MeSH)	EOLC
intensive care	visitors to patients	EOL
critical care	family relations	death
	spouses	dying
	caregivers	
	patient-family relations	



This set of search terms was used as a baseline to search all subsequent databases. Using an identical comprehensive and methodical process in accordance with Bates' Model of Berry picking (Barroso et al., 2003; Bates, 1989), a unique set of search terms and synonyms was derived for each database prior to the implementation of the search. This process can be compared to the method of *abstracting*, whereby the reviewer selects a set of keywords or phrases and then compares them with terms used to index studies (Cooper, 1982).

The second phase involved a search using a unique set of search terms for each database, across a broad range of electronic databases (see Appendix A). There is no clear evidence that a particular number or type of databases should be searched in a qualitative systematic review (Pearson et al., 2011; Wilczynski et al., 2007), therefore to increase dependability and transferability (see sections 4.10.2 and 4.10.4) in this qualitative synthesis, a broad search was undertaken. The following databases were searched: CINAHL complete, MEDLINE, Health Source – Nursing/academic edition, Academic Search Complete, Health Collection, CareSearch, British Nursing Index, ProQuest Central, PsycINFO, Journals@Ovid, AMED, and the search for unpublished literature included Mednar, ProQuest Dissertations & Thesis Database, Australian Digital Thesis program and EThOS. The Joanna Briggs Institute and Cochrane Library were searched for qualitative systematic reviews as a means to identify relevant primary studies.

The final phase of the search involved manual scrutiny of the reference lists of all included studies to locate additional studies and second, a search using Web of Science Core Collection to identify citations of included studies (Jacso, 2004; JBI, 2014a; Webb & Roe, 2007). Downe (2008) refers to the careful examination of reference lists of included studies as *backchaining*. In addition, authors considered experts in the field (authors who have published multiple relevant journal articles, books or book chapters on the topic or who had spoken at relevant conferences) were identified and searched in CINAHL to identify additional studies that may fall within the scope of this review. Hand searching was not undertaken because the topic literature covers a wide range of online journals and publications (see Appendix B).

The next section describes the sifting process.

## 4.5 Sifting process

During the first sift the primary reviewer (AC) assessed titles and abstracts for eligibility and relevance against the inclusion/exclusion criteria. All clearly irrelevant articles were excluded by reading the title and abstract; if eligibility could not be determined, the paper was allocated to the next sift phase. Duplicates were deleted, year limitations applied and all remaining titles were retrieved in full.

During the second sift the primary reviewer (AC) assessed full text studies for eligibility and relevance against the inclusion/exclusion criteria. A study was considered for inclusion if it was clear that life-sustaining treatment was withheld or withdrawn, and where the perceptions of family members on EOLC delivered in the ICU were reported. All potential inclusions were then reported to the supervisory panel (EM, RF, JR). Decisions on final inclusions were made after full text assessment was agreed upon via a discussion with the supervisory panel (EM, RF, JR).

In the next section, a critique of contemporary literature on the use of quality appraisal to evaluate the methodological quality of primary qualitative studies is presented. This critique leads to a discussion of how and why quality appraisal was used as a supportive technique in this qualitative synthesis.

## 4.6 Quality appraisal

Quality appraisal processes evaluating the methodological quality of quantitative studies are generally regarded as an essential element in determining internal validity (Higgins & Green, 2011). According to Carroll and Booth (2015) “these processes are driven by the need to determine how far the primary research evidence, singly and collectively, should inform findings and, potentially, practice recommendations” (p. 149). Qualitative researchers continue to debate what constitutes *validity* and *reliability* in their work, thus there is uncertainty in the literature regarding the need for and methods of quality appraisal in relation to qualitative evidence synthesis (Carroll & Booth, 2015; Dixon-Woods, Sutton, et al., 2007; Garside, 2014; Hannes, Lockwood, & Pearson, 2010). There are not only different views on the need for quality appraisal, but no standardised criteria exist for assessing the quality of all qualitative research (Tong et al., 2012). It is argued by some that standardising criteria for appraising the quality in qualitative research that embraces a range of philosophical and

epistemological designs is neither possible nor appropriate (Barbour, 2001; Spencer, Ritchie, Lewis, & Dillon, 2003).

A number of authors have developed quality appraisal methods and checklists (Boeije et al., 2011; Costantini, Di Leo, & Beccaro, 2011; Downe, 2008; Garside, 2014; Harden & Gough, 2012; JBI, 2014a). Some approaches to qualitative evidence synthesis clearly require a quality appraisal, while others oppose it or judge quality as the extent to which it informs policy or on relevance (Boeije et al., 2011; Dixon-Woods, Bonas, et al., 2006; Downe, 2008; JBI, 2014a; Noblit & Hare, 1988; Thomas & Harden, 2008).

There is also disagreement in the literature on the rationales underpinning quality appraisal, and whether studies should be weighted or excluded on the basis of quality scores (Boeije et al., 2011; Dixon-Woods, Sutton, et al., 2007; Harden & Gough, 2012; Tong et al., 2012). For example, Sandelowski and Barroso (2002b) take a rather equivocal stance; on the one hand proposing a detailed quality appraisal tool, whilst urging that it should be applied carefully, citing that all studies may contribute to the emerging understanding of a field of study, regardless of a quality assessment score. In contrast, Walsh and Downe (2005) assert that the synthesis of methodologically flawed studies may result in a qualitative evidence synthesis that lacks validity, and according to Lincoln and Guba (1985) this will contribute to a significant level of uncertainty in the area already under scrutiny. Downe (2008) suggests that if the point of undertaking a qualitative evidence synthesis is to inform policy and practice, a pragmatic approach is necessary, entailing an inclusive, transparent and justified approach to quality appraisal. Barbour (2001) argues similarly for checklists to be viewed as “reflective rather than constructive of good research” (p. 1115). It is this practical approach that will be adopted in this systematic review, and this will be justified in the subsequent paragraphs.

Furthermore, no clear evidence exists to inform judgement on the use of any one tool for qualitative evidence appraisal (Noyes, Popay, Pearson, Hannes, & Booth, 2008; Tong et al., 2012). The quality appraisal tool used in this systematic review was that recommended for use with the QARI v5.0 computer software and meta-aggregative reviews (see Appendix C) (JBI, 2014a). This tool has been favourably reviewed for its coherence in a comparison of three online appraisal instruments; however the authors comment that further assessment of all three instruments is needed (Hannes et al., 2010).

The JBI (2014a) critical appraisal tool for qualitative research consists of 10 questions that address:

1. The congruity between the stated philosophical perspective, research methodology, study methods, representation of the data, the interpretation of the results and conclusions drawn;
2. The degree to which the biases of the researcher are made explicit, that is does the primary author identify how or if their beliefs, values, relationships and/or role may influence the study or his/her interpretations;
3. The relationship between what the participants are reported to have said and the conclusions drawn in analysis; and
4. That ethical approval was obtained from an appropriate body or that standards were followed.

In a comparison of three online appraisal instruments, authors reported that the JBI quality appraisal tool evaluates descriptive, interpretive, theoretical and evaluative validity, but not external validity (transferability) (Hannes et al., 2010).

Ongoing debate around quality appraisal denotes a lack of definitive evidence supporting its use in qualitative systematic reviews (Dixon-Woods, Sutton, et al., 2007; Garside, 2014; Hannes et al., 2010; Noyes et al., 2008). Despite such debate, the emerging trend in recent years has demonstrated more reviewers perform quality appraisal rather than elect not to do so (Hannes & Macaitis, 2012). It is also JBI policy that “all study types must be critically appraised using the standard critical appraisal instruments for specific study designs” (JBI, 2014a, p. 31). Quality appraisal is not used in this qualitative synthesis as basis to exclude literature or to weight studies in the analysis, rather it is used in a descriptive way to inform the reader of which criteria a study may or may not fulfil. A pragmatic approach, such as that taken in this qualitative synthesis, is the most useful way to provide empirical evidence to inform public health policy-making (Centre for Public Health Excellence, 2009; Downe, 2008; Garside, 2014).

Two reviewers (AC and RF) independently assessed the included studies for methodological quality by selecting a response of *yes*, *no*, *unsure* or *not applicable* to each criterion, which were remotely entered in the QARI v5.0 computer software. The responses were discussed and agreed upon *a priori*, where:

1. *yes* indicated that the primary author addressed the criterion;
2. *no* meant that the primary author did not address the criterion;
3. *unsure* meant that the primary author did not fully address that criterion, or the available information was ambiguous; and
4. *not applicable* was indicated when the criterion did not apply.

Variation in the assessment of methodological quality between AC and RF were resolved through face-to-face discussion, without the need for a third reviewer. Once agreement was reached the primary reviewer (AC) entered the final quality appraisal results into the QARI v5.0 computer software. The next four sections provide a detailed discussion of the analysis and synthesis techniques adopted in this qualitative synthesis.

#### **4.7 Data extraction**

Data extraction in meta-aggregation involves two steps, which align with how data is entered into the QARI v5.0 computer software: (1) the preliminary data extraction; and (2) the extraction of the findings during the analysis and synthesis phase. The preliminary data extraction is focused on the identification of relevant study characteristics such as the phenomena of interest, population, study methods, settings and outcomes of significance to the review question (JBI, 2014a). Preliminary data were extracted by the primary reviewer (AC).

Data from both phases were to be entered into the QARI v5.0 computer software. However, during the data extraction it became apparent that the computer software had shortcomings that impacted upon ease of data management. The online module did not allow the reviewer to copy and paste text directly due to its limited compatibility with syntax and punctuation marks, requiring the manual input of all data. Thus the decision to abandon further use of the QARI v5.0 computer software was made during data extraction. This decision represents a justified deviation from the published protocol (Coventry et al., 2012). As an alternative, relevant preliminary data were extracted then transcribed into an electronic spreadsheet for more effective data management.

The second step of data extraction, the extraction of findings and accompanying illustrations forms part of data analysis and synthesis. More specifically, in a meta-aggregation this occurs

as part of the first-level data synthesis, which is why it will be discussed in detail in the next section.

## **4.8 Data analysis and synthesis**

In this meta-aggregation, a three-step process for the synthesis of data was adopted, as described by JBI (2014a). The three-step process of meta-synthesis involves processes of data extraction and analysis, which lead to the development of synthesised findings. Thematic analysis (see section 3.4.3) (Boyatzis, 1998; Thomas & Harden, 2008) was also used as a model for data analysis, adopted in an attempt to add depth, transparency and rigour to the analysis techniques. In the following section the processes of analysis and synthesis are discussed and described.

### **4.8.1 The process of analysis**

In broad terms, data analysis involves making sense of disparate or ambiguous meanings in the data, while preserving the uniqueness of the experiences and perceptions of study participants and demonstrating an understanding of the phenomena (Pattison, 2011). Data analysis is considered by some to be the most difficult part of the research process, due to both the volume of data resulting from qualitative research and the complexity involved in its analysis (Jirwe, 2011). There are a number of accounts and critiques of data analysis techniques for qualitative synthesis (Atkins et al., 2008; Barnett-Page & Thomas, 2009; Campbell et al., 2011; Dixon-Woods, Kirk, et al., 2005; Miles et al., 2014; Noblit & Hare, 1988; Noyes et al., 2013; Thomas & Harden, 2008). However, it is evident in some studies documenting the use of specific methodologies, for example meta-ethnography, that comprehensive steps in the analytical process are rarely described, and analysis processes are applied in divergent ways (Britten et al., 2002; Campbell et al., 2011; Jensen & Allen, 1996; Noyes & Popay, 2007; Pound et al., 2005). It is agreed that yielding meaningful and useful results requires qualitative data to be analysed in a methodical and transparent manner (Tong et al., 2012).

As with other qualitative synthesis methods, some details of the meta-aggregation synthesis process remain unclear, and thus require guidance from other data analysis techniques. To meet the aim of this qualitative synthesis, an interpretation of the three-step data synthesis process was adopted with the addition of thematic analysis as a model for data analysis. This

position was adopted following an exhaustive review and evaluation of key critiques (Booth et al., 2016; Campbell et al., 2011; Dixon-Woods, Agarwal, et al., 2005; Hannes & Lockwood, 2011; Sandelowski, 2006) and qualitative syntheses (Byrth & Aromataris, 2014; Hughes, 2011; Laugesen & Gronkjaer, 2015; Lockwood, 2011; Macdonald et al., 2015; Munday, Kynoch, & Hines, 2015; Thomas & Harden, 2008).

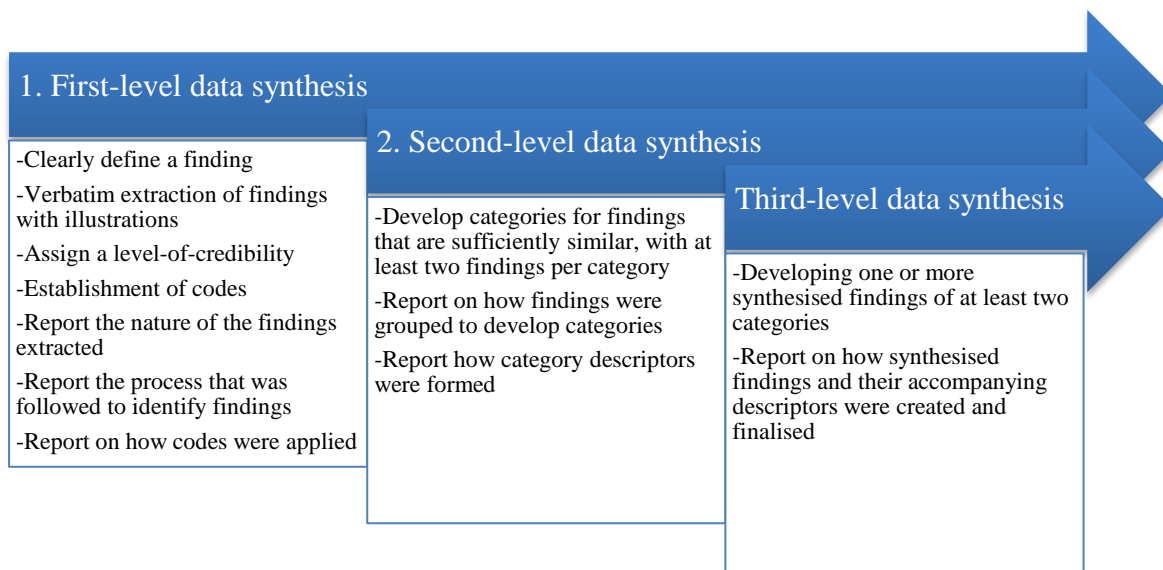
Thematic analysis was identified as one of a range of potential methods for qualitative synthesis, and is selected here because: (1) it has been previously used effectively to translate and synthesise otherwise heterogeneous studies (Boyatzis, 1998; Dixon-Woods, Kirk, et al., 2005; Harden, Brunton, Fletcher, & Oakley, 2006; Thomas & Harden, 2008; Thomas et al., 2003); (2) it can be used to code inductively allowing themes to emerge that are grounded in the data, thus avoiding the rigidity and premature closure of developing a priori themes using a deductive approach (Fereday & Muir-Cochrane, 2006; Lapadat, 2010); and (3) processes have been described comprehensively in the literature, making it a transparent and reproducible technique, aspects which are important in the conduct of this qualitative synthesis (Boyatzis, 1998; Britten et al., 2002; Eaves, 2001; Glaser & Strauss, 1967; Thomas & Harden, 2008). Hannes and Lockwood (2011) describe thematic analysis as a process that involves line-by-line coding, development of descriptive and analytical themes (placed in an external theoretical framework) and the summary of findings of primary studies under thematic headings.

In the next section, the meta-aggregative three-step process of data synthesis is introduced.

#### **4.8.2 The three-step process of data synthesis**

As already identified, meta-aggregation involves a three-step process to data synthesis. The overall synthesis process is presented visually in Figure 1 below, and an in-depth narrative description, with justifications, is provided thereafter.

**Figure 1. Meta-aggregative synthesis with thematic analysis flow diagram**



#### **4.8.3 First-level data synthesis**

In a meta-aggregation, the extraction of findings is both the second stage of the data extraction and the first phase of the data synthesis. This phase of the synthesis can be likened to the analysis technique termed “data reduction”, the first of three concurrent “flows of activity”, described as a process of selecting, simplifying, abstracting, focusing and transforming data (Miles & Huberman, 1994, p. 10). This stage of data synthesis is descriptive in nature; identifying findings that are extracted from sources verbatim, with associated illustrations also extracted verbatim (Hughes, Closs, & Clark, 2009).

Various definitions exist for what a finding is in qualitative research (JBI, 2014a; Lewin et al., 2015; Sandelowski & Barroso, 2002a; Sandelowski & Leeman, 2012). Findings are described as catalogued and integrated discoveries, judgements or statements “reviewers have offered about the events of experiences under investigation” (Sandelowski & Barroso, 2002a, p. 214). In a qualitative synthesis, findings may be presented in many forms, such as: (1) declarative statements of recurring topics or themes; (2) a conceptual theory or model; (3) a cultural explanation of an event or experience; (4) an ethnographic description; (5) a phenomenological description; or (6) some other structured reframing of the aims of a research project (Sandelowski & Barroso, 2002a). These detailed descriptions are useful, as



they highlight the diverse nature of study data and the broad nature of findings that may be extracted in a qualitative synthesis. In a meta-aggregation, findings are defined as a verbatim extract of the author's analytic interpretation (conclusion reached) accompanied by an illustration of participant voice, fieldwork observations or other data (JBI, 2014a; Munn et al., 2014).

During the extraction process, line-by-line coding was used (Boyatzis, 1998; Thomas & Harden, 2008). Coding is described as a basic analytic strategy, and in thematic analysis, the synthesiser looks for recurrent themes, relationships or topics, and marks similar passages with a word or label to categorise them for later retrieval and theory-building (Lapadat, 2010). A theme is described as a pattern found in data that acts on a continuum, at one end describing and organising the possible observations and at the other used as a medium to interpret aspects of phenomena (Boyatzis, 1998). Line-by-line coding involves the inductive identification of words or phrases that capture the essence or meaning of each sentence (Thomas & Harden, 2008). The rationale for selecting codes is to create a comprehensive set of categories for organising the data and to facilitate analysis (McNaughton, 2000).

Coding is one aspect of a flexible and overlapping synthesis process that enables the translation of concepts from one study to another (Britten et al., 2002; Fisher, Qureshi, Hardyman, & Homewood, 2006), an aspect of which has been similarly described in the use of meta-ethnography and grounded formal theory (Eaves, 2001; Glaser & Strauss, 1971; Noblit & Hare, 1988). Translation can be defined as the process of "taking concepts from one study and recognizing [*sic*] the same concepts in another study, though they may not be expressed using identical words" (Thomas & Harden, 2008, p. 3). However, line-by-line coding is not a simple process of translation; as well as translating concepts between studies, the synthesis process should be occurring in parallel. The analytic journal of Doyle (2003) describes this phenomenon:

Determining key descriptors and writing translations are not as distinct as I had thought. I planned to code one study independently from the others, when in fact the coding of one study is influencing my thinking about the next and back to the first and so on...I keep trying to isolate and determine, when am I interpreting and when am I translating? (p. 331).

This quote illustrates the complexity of qualitative data analysis, that it is not a structured or ordered process, but rather one that requires intuition, flexibility, and allows the steps in the process to overlap, intertwine and weave back and forth until the synthesis is complete.

Prior to the commencement of data extraction, each paper was read and re-read to ensure familiarity with the content, with particular focus on the results and discussion sections. A pilot extraction was conducted during a face-to-face meeting, whereby the primary (AC) and secondary (EM) reviewers independently coded and extracted the findings from one paper. This was carried out to add to the credibility and transferability of the research methods and thus synthesised findings (see section 4.10.1 and 4.10.4). The pilot extraction, that is the extracted findings, supporting data, codes and assessed levels of credibility were then discussed until agreement was reached. Next, the primary reviewer (AC) extracted findings and illustrations relevant to the review aim from the remaining studies. Each extracted finding was concurrently evaluated by applying a level of credibility to articulate the congruency between the primary authors' interpretation and the supporting data. The levels of credibility used are shown in Table 4 (JBI, 2014a, p. 41).

**Table 4: Levels of Credibility**

Level of Credibility	Description of Level of Credibility
Unequivocal (U)	Relates to evidence beyond reasonable doubt, which may include findings that are matter of fact, directly reported/observed and not open to challenge.
Credible (C)	Those that are, albeit interpretations, plausible in light of data and theoretical framework. They can be logically inferred from the data. Because the findings are interpretive they can be challenged.
Unsupported (US)	When neither 1 nor 2 apply and when most notably findings are not supported by the data.

*Note.* Reproduced from The JBI Reviewers' Manual (2014a, p. 40).

Each study was first coded individually and then these codes were added to a bank of codes. New codes were developed when necessary, every sentence had at least one code applied and most were categorised using more than one code (Thomas & Harden, 2008). During the coding process, the primary reviewer (AC) ensured that each code had the following elements, documented by means of an analytical journal: (1) a label; (2) a narrative of what the theme concerns; (3) a description of how to know when the theme occurs; (4) a

description of any exclusions to the identification of the theme; (5) and examples of both positive and negative, to eliminate possible confusion when looking for the theme (Boyatzis, 1998).

In line with the protocol deviation discussed in section 4.7, findings, supporting textual data, levels of credibility and codes were entered into a word processing file for each analysed paper using tables with the following sub-headings: (1) finding; (2) illustration; (3) coding terms; (4) categorisation; and (5) comments. A bank of codes was also established in electronic spreadsheet format. Once complete, the extracted data were discussed with a secondary reviewer (RF) until agreement was reached. Where ambiguous data were identified this was referred to a secondary reviewer (EM) for guidance. Before completing this stage of the synthesis, all coded text was re-examined by the primary reviewer (AC), to check the consistency of interpretation and to determine if additional levels of coding were required (Thomas & Harden, 2008).

The next section provides a description of the second-level data synthesis processes of meta-aggregation, guided by the procedures of thematic analysis.

#### **4.8.4 Second-level data synthesis**

During this stage, the primary reviewer looks for similarities and differences between the codes in order to start grouping them into a hierarchical tree structure of categories, a step referred to as “developing descriptive themes” in thematic analysis (Thomas & Harden, 2008, p. 4). Similarities can be seen between this stage of thematic analysis and the technique of constant comparison used in grounded theory, an analytical method of comparing codes and categories for similarities and relationships (Eaves, 2001; Glaser & Strauss, 1967; Paterson, 2012). This stage also shares similarities with phases four and five in a meta-ethnography, in which key metaphors are selected and analysed for similarity and difference (Campbell et al., 2011; Glaser & Strauss, 1967). The goal of this level of data synthesis in a meta-aggregation is to “develop categories for findings that are sufficiently similar, with at least two findings per category” (JBI, 2014a, p. 41). The comparison of coded data, concepts or themes across studies, or translation, strives to establish concepts that encompass more than one study, which can constitute a synthesis (Popay, 2006). The product of this stage is a synthesis that is very close to the original findings of the included studies, where the findings of each study

are combined into a whole via a hierarchical listing of descriptive themes (JBI, 2014a; Thomas & Harden, 2008).

In order to achieve this, the primary reviewer (AC) created new codes (where necessary) to capture the meaning of groups of initial codes; these were then synthesised on the basis of similarity in meaning, resulting in a tree structure with several layers that was used to organise the resultant categories (Thomas & Harden, 2008). Codes were created that were: (1) close to the data; (2) conceptually meaningful to the phenomena of interest; and (3) succinct, summarising the essence of the theme in the fewest words possible (Boyatzis, 1998). This comparative process involved a review of the narratives and descriptions developed during the initial coding process in first-level data analyses, in order to identify similarities and patterns between the coded data, and thus the development of categories.

In line with the aforementioned protocol deviation (see section 4.7), that is the abandonment of the QARI v5.0 computer software, this process was undertaken using an electronic spreadsheet. Within the spreadsheet, colour coding, multiple sheets and the sort function were used to analyse and synthesise the data effectively, while maintaining a good workflow and an audit trail. Hand-written concept maps were also used to visualise the grouping of codes at all levels of data synthesis.

The next section provides a description of third-level meta-aggregation data synthesis processes alongside thematic analysis.

#### **4.8.5 Third-Level Data Synthesis**

In a meta-aggregation, third-level data analysis involves “developing one or more synthesized [*sic*] findings of at least two categories” (JBI, 2014a, p. 41) to produce a comprehensive set of synthesised findings. The equivalent thematic analysis step is referred to as “generating analytical themes” (Thomas & Harden, 2008, p. 7). The overarching goal of this stage is to produce a synthesis that directly addresses the experiences and perceptions of patients’ families, of the EOLC delivered in the ICU setting. This stage is potentially the most subjective, “since it is dependent on the judgment and insights of the reviewers” (Thomas & Harden, 2008, p. 7) and it is the most poorly described stage of analysis in the literature.

The idea of going beyond the content of the original studies has been described by some as a defining characteristic of qualitative synthesis (Britten et al., 2002; Thomas & Harden, 2008; Thorne et al., 2004). Interpretive analysis seen in methods such as meta-ethnography, critical interpretive synthesis and grounded formal theory, aims to produce *higher-order findings*, *third-order interpretations* or *theoretical models* that may or may not generate additional understandings about a phenomenon (see section 3.3) (Barnett-Page & Thomas, 2009; Britten et al., 2002; Campbell et al., 2011).

In a meta-aggregation, categories derived by the reviewer are not subjected to further interpretive analysis, rather they are combined, in order to construct a synthesis that: (1) echoes the primary study findings; (2) provides descriptions of the similarities and differences in data; (3) identifies gaps, barriers and facilitators, and; (4) explores potential biases in data (JBI, 2014a). For example, bias may be found in sampling and methodological perspectives. The final synthesis also has the potential to generate direct recommendations for practice (JBI, 2014a; Pearson, 2004; Thomas & Harden, 2008). For example, a meta-aggregation and thematic analysis reported that findings were synthesised into 19 categories, which were then aggregated into five synthesised findings (Laging et al., 2015, p. 2230). From this, authors identified that changes to decision-making processes would optimise the management of nursing home residents at the time of deterioration. Similarly, in a thematic synthesis, “inferred barriers and facilitators from the views children were expressing about healthy eating or food in general” were captured by descriptive themes, and recommendations were made for intervention development (Thomas & Harden, 2008, p. 7). In the above qualitative syntheses, analytical themes that emerged were used to answer the review questions, and the end result was the development of a number of themes that led to recommendations for interventions.

In this final stage of the meta-aggregation, through a number of meetings, the primary reviewer (AC) discussed the emerging themes with the supervisory panel (EM, RF, JR) to develop more refined meanings and new concepts. This cyclical process was repeated until the final analytical themes sufficiently described and/or explained all of the initial descriptive themes (Thomas & Harden, 2008; Walsh & Downe, 2005). The hand-written concept maps (see section 4.8.4) established in second-level data synthesis over time evolved into a multi-level tree-structure, a visual overview of each synthesis and included categories. To ensure consistency in this process, multiple hand-written drafts of the multi-level tree-structure of

the synthesised finding were submitted to the supervisory panel (EM, RF, JR) until agreement was reached on the final structure of the syntheses. These diagrams were transcribed and updated into a working version of the electronic spreadsheet as the analysis progressed, and an audit trail of their development was entered into the analytical diary.

The following section provides a critique of the literature that reports on the ConQual method, a process recommended for use with meta-aggregation to assess the confidence in the synthesised findings (JBI, 2014b). Justification for its use will then be provided, followed by a detailed discussion of its application.

#### **4.9 Assessing the Confidence in the Synthesised Findings: ConQual**

It has been established that findings derived from qualitative research have an important role to play in informing evidence-based healthcare because it can represent the human dimensions and experiences of healthcare consumers on health and social interventions (Denzin & Lincoln, 2011; Edwards & Titchen, 2003; Thomas et al., 2004). However, policy makers among governments, international organisations, and other health institutions more often use quantitative systematic reviews of effectiveness to inform decisions about health or social care interventions (Lewin et al., 2015). Although this remains a highly debated topic, it is agreed by many that transparency in conduct and reporting standards are important factors in judging the rigour, trustworthiness and credibility of any qualitative study (Dixon-Woods, Agarwal, et al., 2005; France et al., 2014; Hannes & Lockwood, 2011; Tong et al., 2012). Therefore, testing an approach to assist clinicians and policy makers in establishing confidence in the synthesised findings of qualitative systematic reviews is important and may encourage the use of qualitative data in future healthcare policy decisions (Florence et al., 2005; Goldet & Howick, 2013; Lewin et al., 2015; Munn et al., 2014). This approach is referred to as ConQual (Munn et al., 2014).

Developers of the ConQual approach advocate that it is grounded in the establishment of *dependability* and *credibility*; some consider these terms the qualitative equivalents for *reliability* and *internal validity* in quantitative research (Munn et al., 2014). Dependability is referred to as the establishment of consistency in relation to qualitative research findings (Krefting, 1991). This definition is based the philosophy of Guba's Model (Guba, 1981), in which the concept of dependability is aligned with reliability in the rationalist paradigm, and implied trackable variability. This was achieved by providing an exact description of data

gathering, analysis and interpretive methods, which provided information on reproducibility of the study (Kielhofner, 1982; Krefting, 1991). Guba (1981) used the term *audible* to describe the situation in which another researcher can clearly follow a decision trail. Credibility refers to the *fit* between the representation of participants' voices and the researcher's representation of them (Janesick, 2000; Schwandt, 2001; Tobin & Begley, 2004); in other words, does the explanation align with the description?




In order to provide an overall ranking for each synthesised finding, all studies are initially assigned a ranking of *high* on a scale of *high*, *moderate*, *low* and *very low* regardless of methodology, allowing the findings of individual studies to be downgraded based on their assessed dependability and credibility (Munn et al., 2014). At the conclusion of this process an overall score of *high*, *moderate*, *low* or *very low* is applied to each synthesised finding, this ranking is considered a rating of confidence in the qualitative synthesised finding, labelled ConQual by Munn and colleagues (see section 3.4.4) (Munn et al., 2014, p. 5). The format of the ConQual Summary of Findings Table (see Table 8) is aligned with the structure of the table formulated by GRADE for effectiveness reviews, while presenting information that a reader or policy maker would find useful (Goldet & Howick, 2013; Munn et al., 2014).

First, five questions from the standardised 10-item JBI critical appraisal tool for qualitative research (see Appendix C) were used to establish the dependability of each individual study (hence all of the findings in that paper), these were:

1. Is there congruity between the research methodology and the research question or objectives? (Q2);
  2. Is there congruity between the research methodology and the methods used to collect data? (Q3);
  3. Is there congruity between the research methodology and the representation and analysis of data? (Q4);
  4. Is there a statement locating the researcher culturally or theoretically? (Q6);
  5. Is the influence of the researcher on the research, and vice-versa, addressed? (Q7) .
- (JBI, 2014b, p. 7)

Second, studies were downgraded for dependability when the five quality appraisal criteria were not met, according to the process in Figure 2 below (Munn et al., 2014, p. 4).

**Figure 2: Ranking for Dependability of a Synthesised Finding**






Measurement	Ranking system:
Measured by asking the following questions:	
1. Is there congruity between the research methodology and the research question or objectives?	 4-5 'yes' responses, the finding remains unchanged
2. Is there congruity between the research methodology and the methods used to collect data?	 2-3 'yes' responses: move down 1 level
3. Is there congruity between the research methodology and the representation and analysis of data?	 0-1 'yes' responses: move down 2 levels
4. Is there a statement locating the researcher culturally or theoretically?	
5. Is the influence of the researcher on the research, and vice-versa, addressed?	

Note. Reproduced from Munn et al. (2014, p. 5).

Third, each synthesised finding was assessed for dependability. In this process, an average level of dependability of the studies (or findings) that contributed to each synthesised finding was calculated. For example, if the majority of extracted findings combined to create a synthesised finding with a *moderate* level of dependability, this designation was applied to that synthesised finding (Munn et al., 2014).

Fourth, a synthesised finding was downgraded for credibility when not all findings included were considered *unequivocal*, according to the process in Figure 3 below (Munn et al., 2014, p. 4).

**Figure 3: Ranking for Credibility of a Synthesised Finding**

Measurement	Ranking
Assign a level of credibility to the findings:	
<b>Unequivocal</b> (findings accompanied by an illustration that is beyond reasonable doubt and; therefore not open to challenge)	 The synthesised findings contains only unequivocal findings No change
<b>Equivocal</b> (findings accompanied by an illustration lacking clear association with it and therefore open to challenge)	 Mix of unequivocal/equivocal findings Downgrade one level (-1)
<b>Unsupported</b> (findings are not supported by the data, or with no illustration)	 All equivocal findings Downgrade two levels (-2)
	 Mix of plausible/unsupported findings Downgrade three levels (-3)
	 No supported findings Downgrade four levels (-4)

Note. Reproduced from Munn et al. (2014, p. 5).

At the conclusion of this process an overall score of *high*, *moderate*, *low* or *very low*, was applied to each synthesised finding by the primary reviewer (AC). A ConQual Summary of



Findings Table was then created (see Table 8), including the major elements of the review and details on how the ConQual score was established (JBI, 2014b).

The following section presents a detailed discussion of the methodological safeguards implemented during the conduct of this qualitative synthesis to demonstrate trustworthiness in the synthesised findings. Trustworthiness is established through a discussion of measures in credibility, dependability, confirmability and transferability.

#### **4.10 Ensuring the Rigour of the Synthesis**

An important aspect of qualitative synthesis is the ability of the synthesiser to demonstrate quality and robustness in their methods, and trustworthiness in their results. This section will present the measures that were implemented to demonstrate rigour in methodological processes and presented findings.

In the literature, the establishment of rigour in quantitative research is often referred to in relation to the trilogy of reliability, validity and transferability (Tobin & Begley, 2004). In qualitative research, the terms credibility, authenticity, dependability, transferability, trustworthiness and confirmability are more often used (Denzin & Lincoln, 2011; Lincoln & Guba, 1985). Trustworthiness in qualitative research generally encompasses the domains of credibility, dependability, transferability and conformability (Lincoln & Guba, 1985). In this qualitative synthesis, trustworthiness was established in a number of ways, and some of these methodological safeguards can be considered additions to meta-aggregation. The following sections explain these processes, beginning with credibility.

##### **4.10.1 Credibility**

Credibility refers to the establishment of truth, accuracy and believability in the research processes (Denzin & Lincoln, 2011; Hertz, 1997; Pearson et al., 2011; Sandelowski & Barroso, 2007). In a qualitative synthesis, the adequacy of this partly relies on the degree of methodological detail provided in the primary research (Pearson et al., 2011). The nature of quantitative research requires the researcher to be detached or withdrawn from the data to avoid some elements of bias (Byrman, 1988). Qualitative research however, is characteristically idiographic, whereby the researcher is expected to be somewhat immersed in the data from the development of aims through to the analysis and synthesis of data

(Pearson et al., 2011). However, all analysis methods involve some level of interpretation and subjectivity, thus additional safeguards were applied to demonstrate credibility.

Authenticity can also be associated with credibility; when evident, it is said to represent a balance so that all views, voices and perspectives are represented, and can be considered an element of credibility (Denzin & Lincoln, 2011). In this qualitative synthesis, authenticity translates to providing a comprehensive representation of all participant voices, without weighting studies (and thus findings) in the analysis. Verbatim illustrations from participants and the primary author's conclusions were represented accurately and without interpretation, and a level of credibility (see Table 4) was applied to findings at the point of extraction as an additional measure of authenticity (JBI, 2014a; Munn et al., 2014). Authenticity was also assessed by comparison of the completed review with its paired protocol, the use of which is considered a gold standard for identifying reporting biases (D. Moher et al., 2015).

Furthermore, peer checking was adopted; this strategy involves using a panel of experts or an experienced colleague to check or concurrently analyse some of the data (Rolfe, 2006). This is a debated technique, as it thought by some to encourage conformity in the analysis of the data at the expense of the meaningfulness of the findings (Sandelowski & Barroso, 2007).

However, this analysis will result in a more descriptive interpretation of the findings, as opposed to a more interpretive or abstract theoretical model, thus this technique lends itself well to this meta-aggregation. In some phases of the analysis a secondary reviewer was employed; for example, prior to data extraction a pilot extraction was undertaken to ensure accuracy and consistency in the process (see section 4.8.3) (Pearson et al., 2011). In addition, the supervisory panel (EM, RF, JR) was consulted at regular intervals (every one to two weeks) throughout the analysis phase, and additionally if difficulties were encountered, in order to maintain accuracy in the data analysis processes, another element of peer checking (Rolfe, 2006).

Critical and reflexive accounts of processes also contribute to authenticity, particularly with evolving synthesis techniques (D. Moher, Stewart, & Shekelle, 2015). This is particularly important because meta-aggregation is a new and evolving synthesis technique. An audit trail was maintained in the form of an analytic journal, kept to record memos on thought processes behind decisions; to track when thoughts, concepts or relationships were identified in the analysis; and to record rationales and consequences of decisions in this process, from the analysis through to the presentation of results (Boyatzis, 1998; McNaughton, 2000; Miles &

Huberman, 1994; Strauss & Corbin, 1990; Thomas & Harden, 2008; Walsh & Downe, 2005). Documentation and reflections on this process will provide important data from which strategies to minimise methodological limitations in future iterations of this synthesis technique may enable the methods to be further developed (Dixon-Woods, Cavers, et al., 2006).

#### **4.10.2 Dependability**

In a qualitative synthesis, dependability is described as the extent to which the findings and processes are reproducible in different circumstances (Pearson et al., 2011). Dependability has also been referred to as the consistency of observation, labelling, and interpretation (Boyatzis, 1998).

In this qualitative synthesis, dependability was managed in five ways:

1. A comprehensive search strategy was employed using both subject and broad-based terms across a range of electronic databases (see section 4.4), to maximise recall and sensitivity.
2. The maintenance of an audit trail was used (as discussed above in section 4.10.1) (Dixon-Woods, Booth, & Sutton, 2007; France et al., 2014; Hannes & Macaitis, 2012). It is recognised that a lack of trust in the conduct and findings of any evidence synthesis reduces the likelihood that it will be used to influence future healthcare research, policy and practice (France et al., 2014; D. Moher, Liberati, Tetzlaff, & Altman, 2009). The ENTREQ framework, which directs reporting on 21 domains, was used to demonstrate comprehensive and transparent reporting quality during this qualitative synthesis (France et al., 2014; Tong et al., 2012). This was considered an essential safeguard to demonstrate dependability because inconsistency and poor transparency in reporting standards are often identified as limits to the quality of qualitative synthesis methods;
3. ConQual (Munn et al., 2014) was adapted in order to demonstrate transparency in conduct and reporting standards, as these elements are important factors in judging the rigour and trustworthiness of a qualitative synthesis (Dixon-Woods, Agarwal, et al., 2005; France et al., 2014; Hannes & Lockwood, 2011). ConQual was developed to promote comprehensive and unambiguous reporting with relation to establishing confidence in the output of qualitative research synthesis (Munn et al., 2014). The

implementation of ConQual will assist to demonstrate dependability and credibility in the synthesised findings (see section 4.9).

4. An attempt to demonstrate interrater dependability with relation to coding data in the analysis will be presented. Interrater dependability is defined as “consistency of judgment among multiple observers” (Boyatzis, 1998, p. 147), or when different people analysing data see the same themes in the same information. However, Dey (1993) suggests that there are many ways of seeing the data and that there are no single set of categories or themes are “waiting to be discovered” (p. 110). Boyatzis (1998) suggests that the closeness of a code to the raw data increases the likelihood that if the process was repeated, future reviewers would code similarly, and that this ensures a higher interrater dependability. Further, dependability in this sense is more easily demonstrated during the extraction process using meta-aggregation, due to its propensity to extract and translate findings from one study to another using verbatim excerpts (Holly et al., 2012; JBI, 2014a; Reis et al., 2007). To demonstrate this, a summary of extracted findings, categories and syntheses has been provided, which can be compared to the included studies (see Appendix F).

#### **4.10.3 Confirmability**

Confirmability is the qualitative equivalent to the concept of objectivity in quantitative research, and refers to the presentation of data, interpretations and findings free from the influence of the authors’ values, beliefs and biases (Denzin & Lincoln, 2011; Patton, 2002).

Commonalities can be seen between the phenomenological notion of reduction and the Husserlian philosophy of bracketing (Racher & Robinson, 2003; Valle et al., 1989).

However, as previously discussed in Chapter 3 (see section 3.5) it is not possible for a researcher to become immersed in phenomena in such a pure and value-free manner (Denzin & Lincoln, 2011).

Feldman (1995) asserts that the challenge in interpreting qualitative data is not “in learning how to create interpretations but in learning how to get away from pre-established interpretations” (p. 64). The author identifies two pre-established interpretations that are difficult to circumvent: (1) those made by other researchers about similar phenomenon to the ones under study; and (2) those made by people in the setting being studied (Feldman, 1995). Thus, it is essential that an author is able to move away from their assumptions and knowledge on these pre-established interpretations in order to interpret the phenomena

reflected in data under study. In this study, the audit trail documents decisions that lead to the formulation of synthesised findings, and also any personal beliefs or preconceptions related to contentious statements, which will help to demonstrate that the synthesis findings are grounded in the data. Confirmability in qualitative research also requires researchers to examine their own assumptions. Thus, a statement of the reviewer's values and beliefs is necessary to establish reflexivity, defined as the examination, consideration and reflection of the objective relationship with the subjective (Ratner, 2002) in order to identify these assumptions. This is provided below:

### **Research Statement**

As Noblit and Hare (1988) state "... each study is translatable into our own experience as well as into the synthesis we create" (p. 80). In the process of analysis it must be acknowledged that the translator is always translating studies into her or his own *worldview* (Jones, 2004).

I have been employed as an academic lecturer for almost a decade and have taught across both undergraduate and postgraduate courses during this time. Prior to this, I dedicated a large portion of my career to working in the ICU of a major metropolitan hospital in Melbourne. While there, I completed my Post Graduate Diploma in Advanced Clinical Nursing (ICU) and went on to become a Clinical Nurse Specialist in the field. Over the years I have worked clinically in many roles, at many facilities and in many specialty areas, including some time abroad. Through this work it became clear to me that I have a strong interest in EOLC practices within the ICU environment. I gain a sense of satisfaction in providing care to the dying person, and equally satisfying is the challenge of developing trust and rapport with family and friends at the bedside.

My exposure to qualitative research throughout the conduct of this qualitative synthesis and related coursework combined with my clinical experience had led me to believe that evidence in this area of practice is limited, and in this context multiple sources of evidence are needed to develop comprehensive recommendations for practice, and most importantly that the family has a very important role to play in this process. This could be considered a bias on my part; in that decisions for treatments and interventions should be implemented with input from all of the key stakeholders.

In relation to EOLC, I believe a family-orientated approach is important, that is involving the family in all aspects of care. However, the patient is the most important person in this process, and their wishes should also be upheld. Although decision making is not the focus of this systematic review, decisions made prior to the withdrawal of life-sustaining treatments may impact the clinician-family relationships developed thereafter. My values and beliefs align with the decision making process that currently exists within the Australian healthcare system; this involves the family, but removes the burden that final decisions to withdraw may bring, and places the responsibility firmly with the healthcare team. I believe this is a good example of a family-centred model. I do, however, acknowledge that there are many other models of care.

In summary, the results of this qualitative synthesis represent decisions I have made based on my understanding and interpretations of the primary findings. I have endeavoured to maintain a perspective grounded in the data from the studies, and to avoid subjectivity I have reflected regularly on how my own assumptions may influence my decisions during the analysis.

#### **4.10.4 Transferability**

Transferability of qualitative findings refers to the degree to which they can be generalised between contexts (Fingeld-Connett, 2010), an aspect of qualitative research that is the subject of ongoing debate (Hellstrom, 2008; Ruddin, 2006; Saini & Shlonsky, 2012; Schofield, 2000). The term transferability was first introduced by Lincoln and Guba (1985) specifically to refer to case-to-case transfer of knowledge. Rather pragmatically, Morgan (2007) asserts that it is not possible for research results to be either so generalised that they apply to every possible historical and cultural setting or so unique that they have no implications for any other setting. Some suggest that there can be value in a qualitative project, even in isolation (Bazeley, 2013). In a qualitative synthesis, each paper effectively acts as a replication of the study in a different person or setting; this gives some assurance that results obtained are not completely “idiosyncratic” or more broadly applicable (Bazeley, 2013, p. 411). In other words, when findings are combined, if predictions are supported in other settings, analytic outcomes are strengthened. Even outlier findings can strengthen transferability, as they will add depth to established knowledge on a phenomenon of interest. Similarly, Jensen and Allen (1996) maintain that transferability can be made possible when the findings are grounded in the studies themselves, reflecting both their typical and atypical elements.

In this qualitative synthesis, three strategies were adopted in an attempt to increase the transferability of the synthesised findings. First, a detailed description of the studies is provided, which includes demographic and contextual data about the participants and study environments (see Appendix D). This detail enables others to judge the applicability of the synthesis findings to a particular situation or setting.

Second, diverse sampling methods can be demonstrated, which contribute to transferability by ensuring saturation and thus a broad interpretation of the research topic (Bondas & Hall, 2007; Kent & Fineout-Overhold, 2008). Qualitative synthesis researchers are urged to secure a diverse sample by developing an exhaustive and broad search strategy, to locate all topically relevant studies from journals, books, and grey literature (Finfgeld-Connett, 2010; Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014). In this synthesis, a comprehensive, exhaustive and systematic search technique was employed for this purpose (see sections 4.3 and 4.4).

Finally, transferability of synthesised findings can be enhanced using a second tier of triangulation strategies (Finfgeld-Connett, 2010). In relation to primary research, triangulation refers to the use of multiple investigators, methods, participants and theoretical frameworks, and, used alone or in combination, these techniques can reduce chance associations and the influence of biases, which can lead to increased confidence in the findings (Lincoln & Guba, 1985). In a qualitative synthesis, this concept is referred to as “second-tier triangulation” (Finfgeld-Connett, 2010, p. 249), because it is acknowledged that although triangulation strategies may contribute to both the credibility and transferability of findings, the final results are several steps removed from the first-tier safeguards that were implemented during the primary research studies (that is the research studies were triangulated a priori) (Finfgeld-Connett, 2010; Paterson, Thorne, Jillings, & Canam, 2001; Sandelowski & Barroso, 2007). In this qualitative synthesis, this drawback, or point of contention to some, was addressed using a number of strategies as described by Finfgeld-Connett (2010), including:

1. Involving multiple investigators in the analysis of data, for example, as previously discussed (see section 4.8.3), a pilot extraction was undertaken and the supervisory panel (EM, RF, JR) were consulted regarding difficult data decisions;
2. Use of a range of sampling strategies (discussed above);
3. Combining findings generated from a range of epistemological approaches;

4. Extracting verbatim findings and illustrations;
5. Use of thematic analysis, including line-by-line coding to develop descriptive themes, and fully explicating emergent findings using rich descriptions so as to maintain the integrity of the primary data (see section 4.8.3).

#### **4.11 Summary**

This chapter has provided an in-depth overview of the meta-aggregative methods and thematic analysis used in this qualitative synthesis. Specifically, the following processes were discussed:

1. The identification and selection of studies including detail on the inclusion and exclusion criteria, search strategy, sifting processes and quality appraisal techniques applied;
2. The process of analysis including data extraction, analysis and synthesis, with a focus on the three-step process of data synthesis recommended for use with the meta-aggregative methods;
3. The addition of thematic analysis in an attempt to provide further guidance throughout the analysis process and therefore add depth, transparency and rigour to the analysis techniques;
4. Testing ConQual, a technique recommended for use with meta-aggregative methods, to assess the confidence of synthesised findings; and
5. The methodological safeguards that contribute to the rigour of the synthesis, including processes that addressed credibility, dependability, confirmability and transferability..

The next chapter will provide a brief description of the search and sifting results and the characteristics of the included studies, followed by a discussion of the results of the quality appraisal and ConQual technique. Thereafter, the synthesised findings are presented in narrative form, with rich descriptions and participant illustrations.



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## **CHAPTER 5**

### **RESULTS**

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## **Chapter 5: Results**

### **5.1 Introduction**

This chapter provides the results of the search, the characteristics of the included studies, a discussion of the appraisal of methodological quality, a summary of the credibility of the evidence and a narrative description of the results as aggregated thematically in this qualitative synthesis. The syntheses are: (1) the dying person: valued attributes of patient care; (2) communication with the family and within the healthcare team; (3) preparing the family and promoting a peaceful family-centred death; (4) family-centred support and care; and (5) bereavement care.

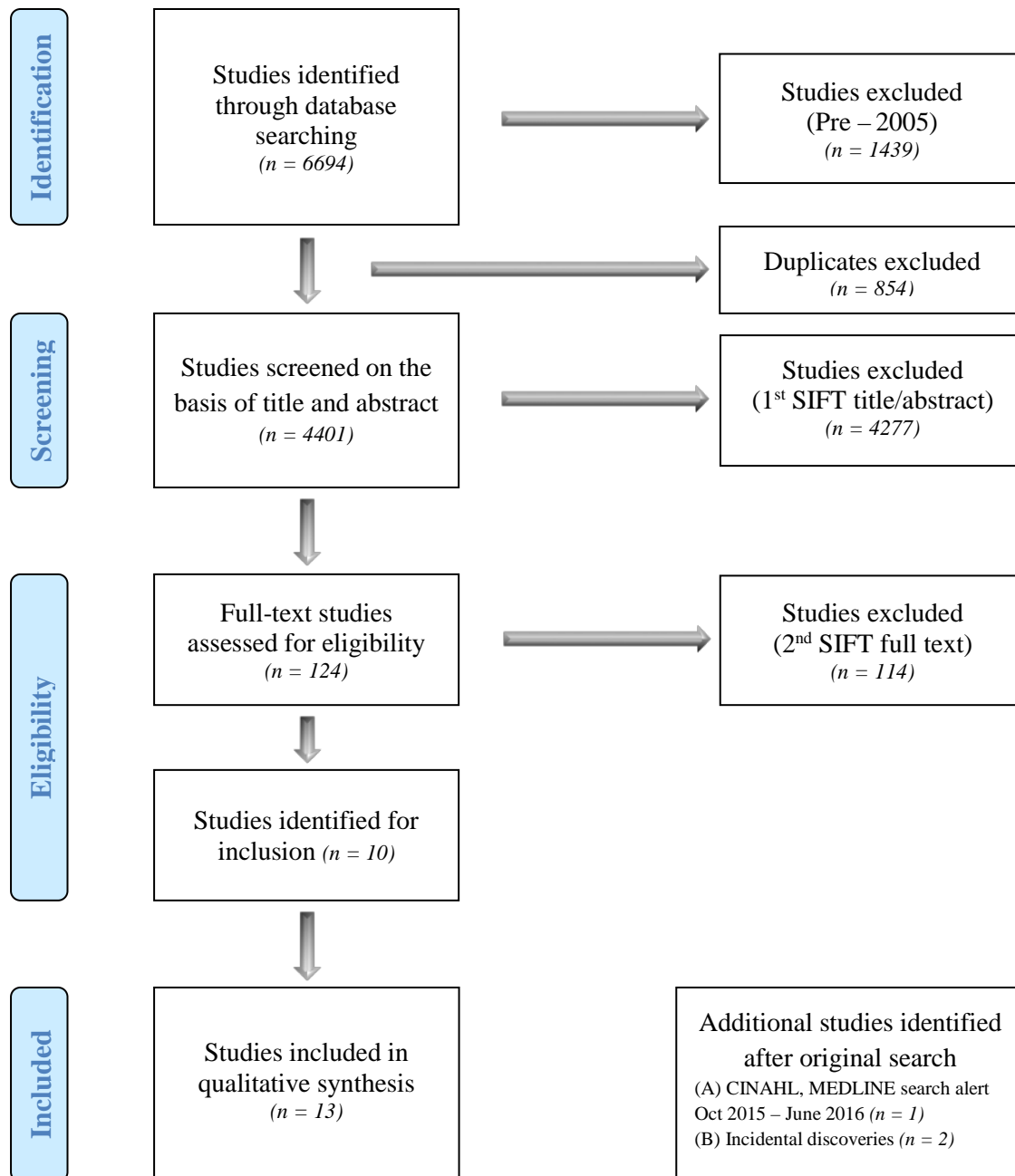
The first section of this chapter presents the results of the search, sifts and a PRISMA flow diagram of study selection (see Figure 4).

### **5.2 Search and sifting results**

This qualitative synthesis aimed to identify the key components of EOLC considered important by families and to identify where care might be improved. The initial search of 17 databases for published and unpublished literature, run in 2010, revealed 6694 potentially relevant studies. Duplicates and publications prior to 2005 were discarded and irrelevant studies were excluded on the basis of title and abstract. One hundred and twenty four full-text studies were assessed for relevance against the inclusion/exclusion criteria, and two Thai papers were excluded (see section 6.5) (Aramrom, 2007; Aramrom, Nilmanat, & Chailungka, 2009).

After the initial search in 2010, search alerts were setup in CINAHL and MEDLINE, and the search was formally re-run in these two databases in October 2015 and June 2016. A final total of 13 studies were included in the qualitative synthesis, which included 11 primary research studies and two doctoral theses (see Appendix D). None of the included studies were conducted in an Australasian setting. Appendix E provides a summary of the 114 excluded studies with reasons. A PRISMA flow diagram is provided in Figure 4 below to illustrate the study identification and selection process.

**Figure 4: PRISMA Flow Diagram of Study Selection**



Note. Reproduced from Moher, Liberati, Tetzlaff and Altman, The PRISMA Group (2009)

The following section reports the characteristics of the included studies.

### **5.3 Characteristics of included studies**

The included studies were from countries with diverse cultures and healthcare models, namely, the UK ( $n = 4$ ), USA ( $n = 5$ ), Netherlands ( $n = 1$ ), Sweden ( $n = 1$ ), Thailand ( $n = 1$ ) and South Africa ( $n = 1$ ). Authors used a variety of qualitative methodologies and analysis techniques, most prominently phenomenological investigations ( $n = 9$ ) and thematic analyses ( $n = 8$ ). The most common data collection method was one-on-one interview ( $n = 8$ ) followed by focus groups ( $n = 3$ ). Two authors published twice from the same data; one of these was a thesis followed by a publication.

In all studies, participants were family members, however in some studies, others were included and at times it was not clear which particular participant voice was presented. This included a lack of clarity between: (1) the perceptions of family members of survivors of critical illness versus those of patients who died after the withdrawal of life-sustaining modalities (Lloyd-Williams et al., 2009; Nelson et al., 2010); (2) the perceptions of family members of patients who died after the withdrawal of life-sustaining treatments versus those who died from other causes (Fridh et al., 2009; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Nelson et al., 2010; Pattison, 2011; Pattison et al., 2013; Wiegand, 2016); and (3) where a paper presented data from both before and after the withdrawal of life-sustaining treatments (Wiegand, 2006; Wiegand & Petri, 2010). Four studies demonstrated unclear reporting when the perceptions of patients (Nelson et al., 2010; Pattison, 2011; Pattison et al., 2013) and clinicians (Pattison, 2011; Pattison et al., 2013; Wiegand, 2006) could not be distinguished from those of the families. As discussed in Chapter 4 (see section 4.5), a study was considered for inclusion if it was clear that life-sustaining treatment was withheld or withdrawn, and where the perceptions of family members on EOLC delivered in the ICU were reported. In the presentation and discussion of findings, participants and their relationship to the patients will be identified as they were in the original studies.

One paper investigated the lived experience of Thai Buddhists and their EOLC was culturally distinct from the other studies identified (Kongsuwan & Chaipetch, 2011). One paper reported the EOLC experiences of families of brain dead ICU patients, the inclusion of which presents challenges to the delivery of EOLC given that some patients may die in the operating theatre and not ICU (Lloyd-Williams et al., 2009). However, perceptions of organ

donor families were also considered for inclusion, as this is considered to be care delivered at the end of life in the ICU.

The next section reports on the results of the quality appraisal of the included studies, when assessed against the standardised 10-item criteria from the JBI critical appraisal tool for qualitative research (see Appendix C).

#### **5.4 Appraisal of methodological quality**

The methodological appraisal revealed considerable variation in quality between the 13 studies (see Table 5). Most studies articulated a clear purpose, used an appropriate methodology, represented the voices of all participants and used analysis techniques that demonstrated congruence to the research methodologies. Few authors however, articulated their philosophical or theoretical position, or provided a clear reflexivity statement (Fridh et al., 2009; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Pattison, 2011). When appraised against the standardised 10-item JBI critical appraisal tool for qualitative research (see Appendix C), shortcomings in methodological robustness and trustworthiness were identified in some studies, as follows:

1. The research methodology was not clearly stated (Lloyd-Williams et al., 2009; Nelson et al., 2010; Wiegand & Petri, 2010);
2. The interpretation of results was not congruent with the research methodology or the presented aims (Nelson et al., 2010; Wiegand & Petri, 2010);
3. Results were presented without illustration from the data or any indication of where that result originated (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Wiegand, 2006);
4. Conclusions drawn did not appear to flow from the findings (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009); and some researchers did not critically examine and explain their pre-suppositions (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Wiegand & Petri, 2010).

**Table 5: Results of Appraisal of Methodological Quality of Included Studies**

	Q1 <sup>a</sup>	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Dependability Rating <sup>b</sup>
<b>Kociszewski, 2005</b>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High (5)
<b>Wiegand, 2006</b>	U	Y	Y	Y	Y	N	Y	Y	Y	N	High (4)
<b>Fridh et al., 2009</b>	Y	Y	Y	Y	Y	N	N	Y	Y	N	Moderate (3)
<b>Lloyd-Williams et al., 2009</b>	N	U	Y	U	Y	N	N	Y	Y	N	Low (1)
<b>Nelson et al., 2010</b>	N	Y	Y	Y	Y	N	Y	Y	Y	Y	High (4)
<b>Wiegand &amp; Petri, 2010</b>	N	Y	Y	Y	N	N	N	Y	N	Y	Moderate (3)
<b>Kongsuwan &amp; Chaipetch, 2011</b>	Y	Y	Y	Y	Y	N	N	Y	Y	N	Moderate (3)
<b>Pattison, 2011</b>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	High (5)
<b>Pattison et al., 2013</b>	U	Y	Y	Y	Y	N	Y	Y	Y	Y	High (4)
<b>Coombs, 2015</b>	N	Y	Y	Y	Y	N	N	Y	Y	Y	Moderate (3)
<b>Kisorio &amp; Langley, 2016</b>	N	Y	Y	Y	Y	N	U	Y	Y	Y	Moderate (3)
<b>Noome et al., 2016</b>	N	Y	Y	Y	Y	N	N	Y	Y	Y	Moderate (3)
<b>Wiegand, 2016</b>	N	Y	Y	Y	Y	N	N	Y	Y	Y	Moderate (3)

*Note.* Table Key: Y=Yes; N=No; U=Unclear.

<sup>a</sup>See Appendix C for the 10-item JBI Critical Appraisal Tool for Qualitative Research.

<sup>b</sup>The ConQual dependability rating calculation represents a totalled number of *Yes* responses from the following quality appraisal questions: Q2, Q3, Q4, Q6, Q7. Also see Figure 2 for dependability ranking system.

The next section presents the results of ConQual, the approach recommended for use with the meta-aggregative method, to assess and report confidence in the results of this qualitative synthesis, based on the concepts of dependability and credibility.

## 5.5 Results of ConQual

The ConQual approach was used to assess and report confidence in the results of this qualitative synthesis, based on the concepts of dependability and credibility that were described in section 4.9 (Munn et al., 2014). This was implemented in order to provide an overall ConQual ranking for each synthesised finding.

All studies were initially assigned a ranking of *high* on a scale of *high*, *moderate*, *low* and *very low* (Munn et al., 2014). First, the 13 studies in this review were assessed individually for dependability using five questions from the 10-point criteria of the JBI critical appraisal tool for qualitative research (see section 4.9). This initial dependability rating is regarded as a representation of the dependability of the findings in each paper.

Second, studies were downgraded for dependability when the five quality appraisal criteria were not met (see Chapter 4, Figure 2). Five studies addressed four or five of the dependability questions and maintained the initial ranking of *high*, seven studies addressed two or three dependability questions, and were downgraded to *moderate* and one study addressed only one dependability question, this paper was downgraded to *low* (see Table 5).

Third, overall dependability of the five synthesised findings was assessed based on the dependability rating of the studies that contributed to each synthesis. Four synthesised findings comprised a majority *moderate* ratings for the dependability of the extracted findings, thus were rated *moderate* for dependability, and one synthesised finding comprised a majority *high* ratings, thus was rated *high* (see Table 6).

**Table 6: ConQual Calculation for Dependability of Synthesised Findings**

Dependability Rating (see Table 5) <sup>a</sup>	Synthesis 1: The dying person: valued attributes of patient care	Synthesis 2: Communication with the family and within the healthcare team	Synthesis 3: Preparing the family and promoting a family-centred death	Synthesis 4: Family-centred support and care	Synthesis 5: Bereavement care
<b>Kociszewski, 2005 (High<sup>a</sup>)</b>	✓	✓	✓	✓	✓
<b>Wiegand, 2006 (High<sup>a</sup>)</b>		✓	✓	✓	
<b>Fridh et al., 2009 (Moderate<sup>a</sup>)</b>		✓	✓	✓	✓
<b>Lloyd-Williams et al., 2009 (Low<sup>a</sup>)</b>	✓	✓	✓	✓	✓
<b>Nelson et al., 2010 (High<sup>a</sup>)</b>	✓	✓	✓	✓	✓
<b>Wiegand &amp; Petri, 2010 (Moderate<sup>a</sup>)</b>	✓		✓		
<b>Kongsuwan &amp; Chaipetch, 2011 (Moderate<sup>a</sup>)</b>	✓	✓	✓	✓	
<b>Pattison, 2011 (High<sup>a</sup>)</b>	✓	✓	✓	✓	
<b>Pattison et al., 2013 (High<sup>a</sup>)</b>			✓	✓	✓
<b>Coombs, 2015 (Moderate<sup>a</sup>)</b>	✓		✓		
<b>Kisorio &amp; Langley, 2016 (Moderate<sup>a</sup>)</b>	✓	✓	✓	✓	
<b>Noome et al., 2016 (Moderate<sup>a</sup>)</b>	✓	✓	✓	✓	✓
<b>Wiegand, 2016 (Moderate<sup>a</sup>)</b>	✓	✓	✓	✓	
<b>Synthesised Finding Dependability Calculation<sup>b</sup></b>	High = 3/10 Moderate = 6/10 Low = 1/10 <b><sup>b</sup> = Moderate</b>	High = 4/10 Moderate = 5/10 Low = 1/10 <b><sup>b</sup> = Moderate</b>	High = 5/13 Moderate = 7/13 Low = 1/13 <b><sup>b</sup> = Moderate</b>	High = 5/11 Moderate = 5/11 Low = 1/11 <b><sup>b</sup> = Moderate</b>	High = 3/6 Moderate = 2/6 Low = 1/6 <b><sup>b</sup> = High</b>

<sup>a</sup>The ConQual dependability rating was calculated in Table 5

<sup>b</sup>Dependability of each synthesised finding is based on the dependability rating of the majority of the extracted findings (Munn et al., 2014)



Fourth, the credibility of the evidence (findings) in each synthesised finding was evaluated at the point-of-extraction (see section 4.8.3, Table 4 and Table 7).

**Table 7: Summary of the Credibility of Evidence for Synthesised Findings**

Synthesised Finding	Unequivocal	Equivocal <sup>a</sup>	Unsupported	Total
<b>Synthesis 1: The dying person: valued attributes of patient care</b>	24	1	0	25
<b>Synthesis 2: Communication with the family and within the healthcare team</b>	23	1	0	24
<b>Synthesis 3: Preparing the family and promoting a peaceful family-centred death</b>	53	3	0	56
<b>Synthesis 4: Family-centred support and care</b>	39	3	0	42
<b>Synthesis 5: Bereavement care</b>	13	0	0	13

<sup>a</sup>The term equivocal is equivalent to the term credible from the levels of credibility reproduced from the JBI Reviewers Manual (2014a) (see Table 4)

When not all findings included in a synthesis were considered *unequivocal*, a synthesised finding was downgraded for credibility (see Chapter 4, figure 3). Four synthesised findings comprised a mix of *unequivocal* and *equivocal* findings, thus they were downgraded one level for credibility to *low*, and all the findings in one synthesised finding were considered *unequivocal* (see Table 7), thus this synthesised finding maintained its *high* rating. At the conclusion of this process an overall score of *high*, *moderate*, *low* or *very low*, was applied to each synthesised finding, as expressed in the ConQual Summary of Findings Table (see Table 8).

**Table 8: ConQual Summary of Findings**

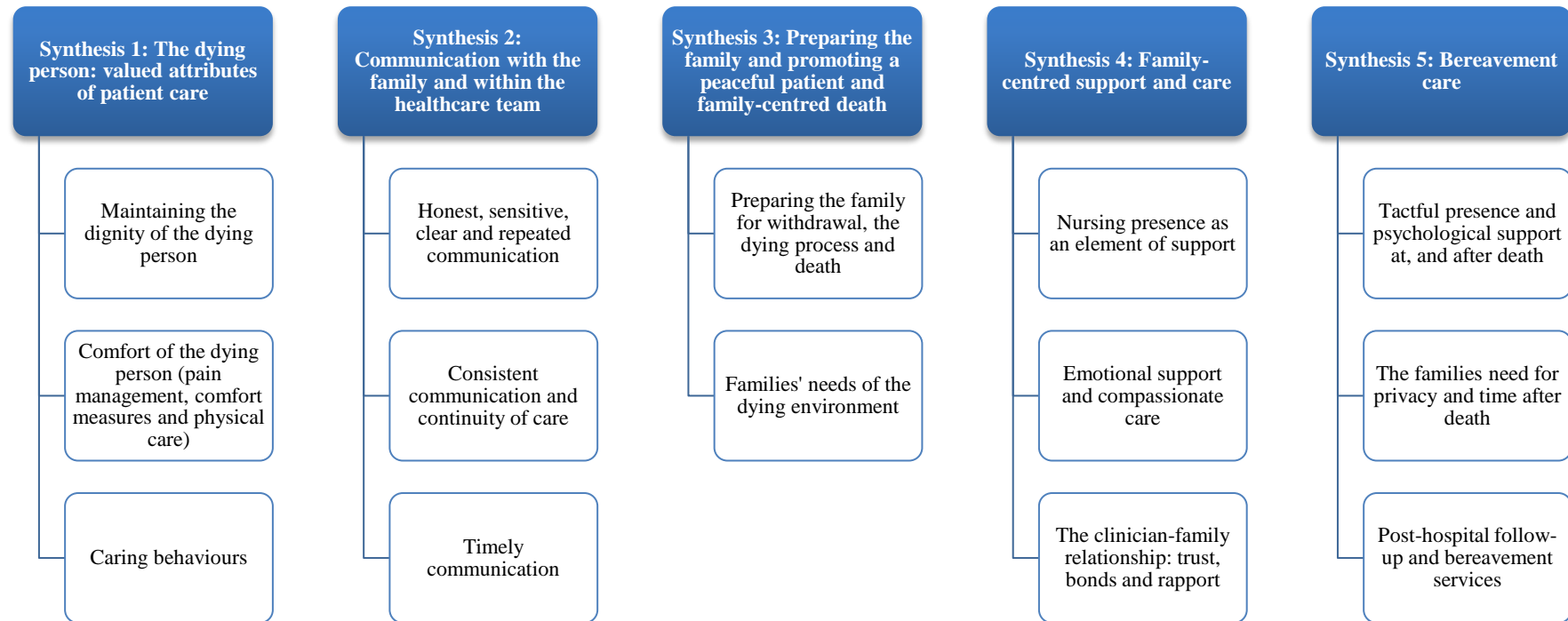
Synthesised Finding	Type of research	Dependability	Credibility	ConQual Score <sup>a</sup>	Comments
<b>Synthesis 1: The dying person: valued attributes of patient care</b>	Qualitative	Downgrade 1 level*	Downgrade 1 level **	<b>LOW</b>	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
<b>Synthesis 2: Communication with the family and within the healthcare team</b>	Qualitative	Downgrade 1 level*	Downgrade 1 level **	<b>LOW</b>	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
<b>Synthesis 3: Preparing the family and promoting a peaceful family-centred death</b>	Qualitative	Downgrade 1 level*	Downgrade 1 level **	<b>LOW</b>	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
<b>Synthesis 4: Family-centred support and care</b>	Qualitative	Downgrade 1 level*	Downgrade 1 level **	<b>LOW</b>	*Downgraded one level due to dependability of primary studies **Downgraded one level due to equivocal findings
<b>Synthesis 5: Bereavement care</b>	Qualitative	Unchanged	Unchanged	<b>HIGH</b>	Unchanged

<sup>a</sup>A ConQual score was calculated for each synthesised finding (see Section 4.9) (Munn et al., 2014)

## 5.6 Synthesised Findings

A total of 120 findings were extracted from the 13 studies. Findings were synthesised into 14 categories on the basis of similarity of meaning, then aggregated into 5 synthesised findings that represented families' experiences and perceptions of EOLC delivered in the ICU. These synthesised findings were: (1) the dying person: valued attributes of patient care; (2) communication with the family and within the healthcare team; (3) preparing the family and promoting a peaceful family-centred death; (4) family-centred support and care; and (5) bereavement care. A summary of extracted findings (with a level of credibility assigned), categories and syntheses is provided in Appendix F. A visual representation of the structure of the synthesised findings is presented below (see Figure 5).

**Figure 5: Visual representation of the synthesised findings**



In the presentation of results, interpretive statements from authors of the included studies are distinguished from the narrative excerpts of participants. Verbatim author statements are presented within paragraphs and single parentheses and with reference to the publication. Where large narrative excerpts, or multiple quotes from family members are required, quotes are presented in italics in stand-alone, indented paragraphs, within double parenthesis and notated with participant identity and publication details. Small narrative excerpts from family members are sometimes contained within the text of the paragraph, again in italics within double parenthesis and notated with participant identity and publication details. The following five sections present the results of this qualitative synthesis.

Finally, in-line with meta-aggregation methods, participant illustrations have been extracted verbatim, which includes spelling errors, if these have not been corrected in the original or if the author uses American English.

#### **5.6.1 Synthesis 1: The dying person: valued attributes of patient care**

This synthesised finding represents the attributes of patient care valued by family members that are considered features of high-quality EOLC. A majority of studies reported the attributes of patient care most highly valued by families (Coombs, 2015; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). When the needs of families were met with regard to care of the dying person, this was associated with perceptions of a good death, comfort and reduced anxiety.

This synthesised finding is represented by the meta-aggregation of three categories: (1) maintaining the dignity of the dying person; (2) comfort of the dying person (pain management, comfort measures and physical care); and (3) caring behaviours. These are presented below.

##### ***Maintaining patient dignity***

Families regarded maintaining the dignity of the dying person as a highly valued attribute of patient care (Kociszewski, 2005; Nelson et al., 2010; Pattison, 2011; Wiegand, 2016). In one paper, all participants reported caring as synonymous with maintaining dignity, privacy and

comfort (Pattison, 2011). Families associated a variety of caring behaviours with dignity, including talking to the dying person and calling him/her by name, using therapeutic touch to demonstrate compassion, showing concern for the person's wellbeing and delivering care that was personal and individualised (Kociszewski, 2005; Pattison, 2011; Wiegand, 2016). The terms "*respect*" and "*genuine*" were also used to describe care that preserved the dying person's dignity (Wiegand, 2016, p. 163).

In two studies, families reported that staff preserved patients' dignity with small acts of kindness, as illustrated below:

*"The nurse went in after my mother had passed and put her teeth in and put her socks on before we went to see her, which I thought was wonderful"* (Family member) (Wiegand, 2016, p. 163).

*"... the nurses were trying to do everything to make him comfortable, like turning him and covering him up because he felt cold and putting extra socks on him..."* (Family member 02) (Pattison, 2011, p. 178).

When the dying person's dignity was not maintained, for example when they were exposed without efforts to shield private areas of the body, families in two studies reported feeling distressed and angry (Kociszewski, 2005; Nelson et al., 2010).

Families in one paper focused on the importance of "*treating the patient as a person*" (Nelson et al., 2010, p. 8), noting that each person is unique and deserving of respect regardless of their circumstances. The author referred to this concept as personhood (Nelson et al., 2010). Physicians responded to the needs of one family member after being prompted to provide care that was centred on dignity and personhood:

*"My mother had a team of doctors ... and I thought some had a blank face, looking at my mother as just a number... I said, my mother is not just an old lady, my mother had a life... I brought in pictures of my mother when she was born, and when she got married to my father... And they saw her differently... That is 100% important"* (Son) (Nelson et al., 2010, p. 8).

In another example, a family member became distraught when her mother's personhood was not maintained:

*"That was my mother. They need to realize that that's somebody's loved one in there..."* (Family member) (Nelson et al., 2010, p. 8).

#### Patient Comfort (pain management, comfort measures and physical care)

Families in eight studies reported effective pain management as an essential element of patient comfort and a valued attribute of high-quality care (Coombs, 2015; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Nelson et al., 2010; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). In most cases, families felt that clinicians did everything they could to make sure that the dying person's pain was appropriately managed (Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010):

*"I don't think she [wife] suffered once they started the morphine"* (Husband) (Wiegand & Petri, 2010, p. 432).

*"There were a couple of occasions when I went out and said, "You know she seems to be a little restless," and a nurse came in and gave her a little bit more [morphine]... It was [morphine] being administered at a rate that was certainly enough to ease whatever discomfort she had"* (Family member) (Wiegand & Petri, 2010, p. 432).

*"... he died in the way that he would've wanted to die, which was very quickly and no pain..."* (Family member 02) (Pattison, 2011, p. 178).

Families in several studies needed assurance of the dying person's comfort, and this meant that control of pain needed to be perceived as a priority (Coombs, 2015; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). Further, two studies reported that all participants who perceived the dying person to be comfortable described this as an element of a good death (Kisorio & Langley, 2016; Wiegand & Petri, 2010). It was reported that families could not feel comfortable themselves without the assurance of the dying person's comfort, assurance on this issue lessened family anxiety (Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010):

*“Because of a lot of the cords and everything that was going in him ... I told [the doctor] I need to know that [my husband] is not hurting...”* (Widow) (Nelson et al., 2010, p. 7).

*“I just told nurses to make her as comfortable as possible even if we are going to lose her, do everything possible to reduce the pain she might feel in the process, not to leave her suffering”* (Peter) (Kisorio & Langley, 2016, p. 61).

Signs of discomfort were distressing for family members to watch. A family member was distressed by the comments of a physician, who said he was 75% sure that his mother didn't feel any pain. The son responded, *“That's not good enough!”* (Family member) (Kociszewski, 2005, p. 110). In another paper, a family member described a bad death when she perceived that her mother was uncomfortable:

*“For us [her family], maybe she didn't feel anything, so maybe it was good for her, but I never felt that, until she was so far under the morphine”* (Daughter) (Wiegand & Petri, 2010, p. 233).

Families in one paper were not always certain if the dying person was comfortable (Pattison, 2011). This identifies a potential tension between family and patient-centred care, where care practices are undertaken in an attempt to make patients comfortable, but it is not known if these help when patients are unconscious.

Comfort was also described in terms of personal comforts and hygiene care, and family members valued those nurses who prioritised these elements of care. Families reported many personal comforts that were facilitated by nursing staff including moistened lips, personal bedding, personal clothing, positioning, pressure-relieving devices, regular mouth, eye and skincare and providing warmth (Kisorio & Langley, 2016; Kociszewski, 2005; Pattison, 2011). The value of hygiene care as an element of EOLC and its association to family perceptions of comfort in the dying person is demonstrated in the following illustrations:

*“They changed his bedding frequently, which was nice. And I remember one nurse really cleaning his face really well... and brushing his hair. Just little things”* (Family member 04) (Pattison, 2011, p. 174).

*“Every time we come to visit he is clean and lying comfortably in bed like somebody that was well cared for”* (Ryan) (Kisorio & Langley, 2016, p. 61).

At odds with the perceptions expressed above, one family member reported feeling that *“comfort and hygiene care might be painful for their loved one”* and this was *“distressing to watch”* (Family member 07) (Pattison, 2011, p. 174).

### *Caring Behaviours Valued by Families*

Families observed a variety of caring behaviours from clinicians toward the dying person, but when it came to the delivery of EOLC, care that was compassionate, respectful, kind, genuine and holistic was the most highly regarded. In four studies most families reported satisfaction with directly observed caring behaviours toward the dying person (Kociszewski, 2005; Lloyd-Williams et al., 2009; Noome, Dijkstra, et al., 2016; Wiegand, 2016). In the following two excerpts, family members describe the attentive and personalised care provided to the dying person, and one family member labels this “the best care possible” (Family member) (Kociszewski, 2005, p. 114):

*“I feel like the people who were there treated her like a family member. It’s like she got the best care possible. She was paid every attention in the world you know. It’s like she was in a five-star hotel in a penthouse suite...”* (Family member) (Kociszewski, 2005, p. 114).

*“... it was a good experience... What a wonderful thing they do. You know and that’s aside from any of the care giving for my mom I guess...and physical care giving...”* (Family member) (Kociszewski, 2005, p. 121).

In some studies, dissatisfaction was expressed with the caring behaviours of clinicians toward the dying person (Kociszewski, 2005; Kongsuwan & Chaipetch, 2011). In the excerpt below, a family member has sympathy for clinicians’ work pressures but remains unimpressed by a lack of compassion and kindness expressed toward the dying person:

*“I felt unimpressed... They [clinicians] have responsibility to care for patients but why they don’t talk to the patients sweetly and softly? ... I know that they had many patients to care for... but why... Why they don’t sustain [the] patient’s mind? Maybe they are*



*moody because they have to respond to many things... I empathized and understood them in that way...*” (P4) (Kongsuwan & Chaipetch, 2011, p. 332).

Another family member became distressed when clinicians demonstrated a lack of compassion toward the dying person, and felt unprepared for this perceived lack of genuine caring:

*“... In, out, doing what they had to do. Technical for their records. I didn’t feel as though they did a thing for my mother”* (Family member) (Kociszewski, 2005, p. 112).

In this synthesised finding the value of maintaining the comfort and dignity of the dying person and important caring behaviours is presented from the perspective of the family. These valued attributes of patient care encompass pain management, comfort and hygiene care, acknowledgement of dignity and caring behaviours such as compassion, respect and kindness. When observed by the family, this high-quality EOLC was perceived to provide comfort to the dying person, thus reducing family anxiety, contributing in some cases to perceptions of a good death.

### **5.6.2 Synthesis 2: Communication with the family and within the healthcare team**

Adequate and appropriate communication with the family and within the healthcare team was identified as an important element of high-quality EOLC across a majority of studies (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2006). Poor communication however was too, often reported by families in relation to negative experiences of care delivery (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2006). The following three categories represent the elements of effective communication as perceived by families: (1) honest, sensitive, clear and repeated communication; (2) consistent communication and continuity of care; and (3) timely communication.

#### **Honest, sensitive, clear and repeated communication**

Findings from several studies suggest communication that was both honest and open was highly valued by family members (Fridh et al., 2009; Lloyd-Williams et al., 2009; Nelson et

al., 2010; Pattison, 2011). In three studies, participants considered honesty in communication as an element of good quality care (Lloyd-Williams et al., 2009; Nelson et al., 2010; Pattison, 2011). Honest and timely information about the seriousness of a prognosis enabled families in three studies to move through their shock, prepare psychologically for the anticipated death and even become involved in care (Fridh et al., 2009; Lloyd-Williams et al., 2009; Nelson et al., 2010).

When informed that a family member was not expected to survive, some families experienced emotional distress and anxiety (Fridh et al., 2009; Kisorio & Langley, 2016; Nelson et al., 2010). Communication between clinicians and family members that was not honest and clear resulted in families being psychologically unprepared for the possibility that the dying person's life would end, and their psychological distress is made clear:

*"It would have been advantageous for me and my family if, at a point... we could have had some kind of counselling on end of life issues... I believe I would have benefited greatly, if previous to this, I had been told by the doctor that this [death] is the possibility... I just wasn't ready for it ... We got a call at 5 AM and my brother was gone... I've agonized over this... I wasn't aware until that last day ... [Discussing the prognosis sooner] might have helped me prepare mentally"* (Brother) (Nelson et al., 2010, p. 5).

*"It is very painful to hear that because we were thinking he was going to come up and recover... you get worried, confused and it is really painful, it is so much stress, I am so frustrated"* (Jack) (Kisorio & Langley, 2016, p. 61).

Sensitive communication was also highly valued by family members as an essential element of effective communication, but this element was often missing (Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010). In one study there was broad agreement that communication should be sensitive, provided with compassion, empathy, and honesty:

*"She's going to tell you, she's not going to give you a line, but she's still sensitive. That's the key"* (Family member) (Nelson et al., 2010, p. 6). In another, a lack of sensitive communication left a family feeling like their wishes were being ignored when a physician said that they were just *"stalling"* because they couldn't let their mother go (Family member) (Kociszewski, 2005, p. 103). In the following two excerpts, shock and disbelief is evident

when communication about prognosis and death lacked a sensitive approach, and these family members were left feeling unprepared for the grief they experienced:

*“The doctor said, ‘You know your wife is going to die.’ I was staggered”* (Tom) (Lloyd-Williams et al., 2009, p. 661).

*“It was terrible being told that my son’s brain was ‘scrambled.’”* (Eleanor) (Lloyd-Williams et al., 2009, p. 661).

Families in several studies also consistently identified the need for clear, non-medicalised language that they could understand (Fridh et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2006). Information that was provided this way decreased anxiety, assisted families to come to terms with the prognosis and helped to prepare them for the dying process:

*“... using terms that a person that’s not a doctor could understand ... you did not need to go get a dictionary to look it up ... they explained themselves well”* (Unknown participant) (Nelson et al., 2010, p. 4).

*“I do not have a medical background... so ... I would be saying, please, tell me in English”* (Unknown family member) (Nelson et al., 2010, p. 4).

A failure to repeat key information was associated with feelings of confusion and frustration among participants (Fridh et al., 2009; Nelson et al., 2010). One author reported that several families had not been informed clearly when the patient had actually died (Lloyd-Williams et al., 2009). In one example, a family member struggled to comprehend brain death, reporting a need for clear and honest communication. Ignorance of the family member’s need for, and right to, information is evident in the excerpt below:

*“I was never told actually - I had to infer it. They said, ‘From the tests we have never seen anyone come back from this stage.’ ... I couldn’t believe, because the body was warm and moving - they were going to take things from the body... it is hard not knowing if she is dead. Is she? I knew in a way, but was not told. They should have said, ‘F is now dead’ - told you straight... I would have got my thoughts straight. I needed to be told”* (Alice) (Lloyd-Williams et al., 2009, p. 662).

### Consistent communication and continuity of care

Families in three studies reported the need for communication that provided consistent information (Kisorio & Langley, 2016; Nelson et al., 2010; Wiegand, 2006). A family member who had a very positive experience attributed consistent communication with the family to continuity and quality of care:

*“So many different teams of doctors and nurses were involved ... but those people were all communicating ... were all on the same page”* (Family member) (Nelson et al., 2010, p. 5).

However, consistent communication and continuity of care was not observed by all family members; in some cases, families were provided with conflicting information, which left them feeling confused and questioning whether members of the healthcare team were communicating with each other and if there was anyone directing the care of the dying person:

*“A lot of times, we did not know who was in charge... Do they ever sit down and have somebody leading the discussion that’s the patient’s main doctor? You had all kinds of specialists”* (Family member) (Nelson et al., 2010, p. 4).

*“... you meet different people all the time you come, with all this different information, it is difficult, it is confusing. They must communicate among themselves and report one thing”* (Ryan) (Kisorio & Langley, 2016, p. 61).

One family member demonstrated empathy toward the healthcare team, but perceived that a lack of communication between team members resulted in fragmented care for the dying person:

*“They’ve done the best they can, but the fragmentation of care is scary as hell”*  
(Daughter) (Wiegand, 2006, p. 182).

### Timely Communication

Being provided with timely access to information from physicians was recognised by all focus group members in one paper, as a basic care need (Nelson et al., 2010). In two studies, families' anxiety and stress levels were reduced when provided with timely information from clinicians (Kisorio & Langley, 2016; Nelson et al., 2010). The high value placed on timely communication is clear in the excerpts below:

*"Nothing, nothing was important to me as much as just being able to talk to the doctor and to get the information there"* (Widow) (Nelson et al., 2010, p. 4).

*"The more we got answers to what we wanted to know, the more relieved we got"* (Gloria) (Kisorio & Langley, 2016, p. 61).

In several studies timely communication with families in the ICU did not occur (Fridh et al., 2009; Kisorio & Langley, 2016; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2006). Poor communication shaped families' lasting memories of the dying process and death and provoked anxiety, distress and anger (Fridh et al., 2009; Kisorio & Langley, 2016; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2016).

In one example, the absence of timely communication was evident when a family member was not informed that death had occurred (Fridh et al., 2009). On witnessing the removal of monitors and lines, the participant believed the nurse had caused the person's death, a preventable negative experience:

*"... what was awful was that... somebody came and shut down all the monitors and, having no experience of medical things, I thought that they switched him off... she explained to me later that he was already dead... but I didn't understand that and it was sickening...I can still see it, I'll never forget it..."* (I: 16) (Fridh et al., 2009, p. 115).

Untimely or absent communication was also highlighted as a factor that left family members in three studies without the opportunity to say goodbye (Fridh et al., 2009; Nelson et al., 2010, p. 5; Noome, Dijkstra, et al., 2016). In the excerpt below, a family member was left

unaccompanied and uninformed in the waiting room and was denied the opportunity to be present while their family member's condition deteriorated:

*“And then I had to wait again for a very very long time... and then two nurses appeared, or a nurse and a doctor, and said that nothing could be done and that... that is my only complaint because I'm sure it took at least one or two hours and I had no idea what was happening and then they came and told me that it was too late” (I: 12)* (Fridh et al., 2009, p. 114).

The distress experienced by a family member kept in ignorance of his brother's poor prognosis is evident in the excerpt below. This family member was also not afforded the opportunity to say goodbye due to untimely communication:

*“Right up until the last time that the doctor called me, I always thought my brother was gonna get better and come home...”* (Family member) (Nelson et al., 2010, p. 5).

In this synthesised finding, families' views on the elements of effective communication that are valued as a feature of high-quality EOLC are presented. Findings indicate that when families were provided with prognostic information that was honest, sensitive, clear and repetitive, this allowed them to come to terms with the seriousness of the situation, begin to prepare psychologically for the anticipated death and become more involved in the process. Conversely, when communication was not provided in a manner that was honest, sensitive, clear and repetitive, families experienced uncertainty and misunderstanding, leading to a heightened emotional response including psychological distress, frustration, worry and shock. A link between consistent communication and continuity and quality of care was clear in this synthesised finding. Families became anxious when they viewed poor communication within the ICU team. Finally, timely communication was perceived by families as a most basic care need during their time in the ICU. When timely communication did not occur many families experienced psychological distress and some missed the opportunity to say goodbye to the dying person.

### 5.6.3 Synthesis 3: Preparing the family and promoting a peaceful family-centred death

This synthesised finding describes the care and information required to prepare families for the withdrawal of life-sustaining treatments, the dying process and death of their family member. This synthesis involved the aggregation of two categories: (1) Preparing the family for treatment withdrawal, the dying process and death; and (2) families' needs of the dying environment.

#### *Preparing the family for treatment withdrawal, the dying process and death*

In this category, elements fundamental to the preparation of families for the processes of treatment withdrawal, dying and death in the ICU are reported. If families were prepared, they knew what to expect, which helped them to navigate as best they could a difficult process and the inevitable death of their family member (Coombs, 2015; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010).

Families in four studies appreciated honesty regarding what they might see and hear during the dying process, even though the information was difficult for them to hear (Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison et al., 2013; Wiegand, 2006).

*“Be prepared [physician]. It’s gonna be harder than you think and probably not like you think... it’s not going to be easy... No [family member], it’s going to be a big relief and it’ll be okay. But, she [physician] was right... It was hard...”* (Family member) (Kociszewski, 2005, p. 109).

Witnessing death was important to some family members, providing they felt supported through the process. In one paper, all family members valued empathy as an important caring trait, when “*sadness was unfolding before them*” and clinicians acknowledged, “*how hard it is to witness the death*” (Family member 02) (Pattison, 2011, p. 177). This helped them to feel prepared. The perception that dying and death was “*very visually shocking*” (Family member 05) (Pattison, 2011, p. 177) was common, and lingered in the memories of some family members (Coombs, 2015; Kociszewski, 2005; Wiegand & Petri, 2010). Families in one study reported feeling unprepared for the dying process (Wiegand, 2016). In one example, the dying process distressed a family member:

*“It was really very difficult to watch her under the morphine and slip away and not really herself and gasping for breath” (Daughter) (Wiegand & Petri, 2010, p. 433).*

In another example, a physician provided a family with information about the confronting nature of extubation and suggested that they step out of the room, however it is unclear if these actions contributed positively to the family’s preparation or experience:

*“[The physician] suggested us not to be in the room when they...shut her...took it (endotracheal tube) out because sometimes they [the dying person] make sounds and it’s not very nice” (Family member) (Wiegand, 2016, p. 162).*

In the following two additional excerpts, family members who were unprepared recalled the dying person’s face in death as a painful memory:

*“... I wished that I hadn’t walked in at the time, cause I relive that every minute I remember... Her face was sort of distorted. Her eyes were all glazy. She was sweating up a storm. She was drooling... She looked dead but her heartbeat was just going so slow and slower and slower...” (Family members) (Kociszewski, 2005, p. 111).*

*“... his eyes were still open, his mouth was all distorted and it was quite a horrific sight... that’s our lasting image of him. I see it every day, every night when I go to bed I see that...” (Case 6) (Coombs, 2015, p. 3).*

Families were appreciative and felt supported when the nurse provided information about the care that would be delivered after death (Noome, Dijkstra, et al., 2016; Pattison et al., 2013, p. 1449; Wiegand, 2016).

*“What they were going to do [withdraw the ventilator] and how they were going to do it” (Family member) (Wiegand, 2016, p. 162).*

*“...And I asked what, um, what exactly would happen, um. So, she sort of explained...” (Family member 06) (Pattison et al., 2013, p. 1449).*

In three studies, families frequently reported an inability to understand and prepare for the unpredictable nature of the dying process (Kociszewski, 2005; Wiegand, 2006, 2016).



Families had either not been told what to expect, or if they had been told, the dying process still took much longer than expected, as they had hoped for a quick death (Kociszewski, 2005; Wiegand, 2006, 2016).

*“It isn’t what I expected... When you think of removing life-support you think it’s going to happen quickly”* (Family member) (Wiegand, 2006, p. 184).

*“After taking the ventilator out and increasing the morphine, I had no idea it would take that long. That was pretty gruelling”* (Family member) (Wiegand, 2016, p. 163).

In some cases, families felt uninformed and/or misinformed about the length of the dying process:

*“No one told us how much time it would take”* (Family member) (Wiegand, 2016, p. 163).

*“The weakened condition she was in he [the physician] felt that she would die within a few hours. And she took 3 days to die. I guess he didn’t really... They don’t really know”* (Family member) (Wiegand, 2016, p. 163).

Feeling prepared was also associated with the timing of treatment withdrawal. In one paper, families reported that managing the timing of withdrawal contributed to perceptions of a good death (Pattison et al., 2013). Some families requested that withdrawal of life-sustaining treatments be delayed to facilitate the presence of additional family members, which helped them to feel prepared:

*“... father was going to pass away that morning and he was being kept alive until the five kids could be assembled”* (Son) (Kociszewski, 2005, p. 109).

Another family felt their needs were ignored when their request for more time was denied, and as a result they experienced high levels of anxiety, a sense of helplessness and unpreparedness for their mother’s death:

*“We knew that we had to give her up. We knew that. We just wanted a little more time. My mother loved it when all of us were together. And that’s all we wanted her to see is*

*all of us together and then they could have done whatever needed to be done. But they didn't wait...*" (Daughter) (Kociszewski, 2005, p. 104).

After a decision to withdraw life-sustaining treatment had been made, any delay in the procedure provoked anxiety in families and worsened their grief (Coombs, 2015; Pattison et al., 2013; Wiegand, 2006). In one paper, delays in withdrawal were reported when medical paperwork was incomplete, qualified physicians were unavailable or infusions were delayed from pharmacy, in these examples families expected withdrawal to happen quickly, but were made to wait several hours, and this was described as "*unbearable*" (Family member) (Wiegand, 2006, p. 183). For one family, anxiety was especially high as withdrawal was delayed while they waited for the organ donation coordinator to attend and perform an assessment for donation after cardiac death (Wiegand, 2006). In another paper, family members associated delays in withdrawal with increased suffering and distress for the dying person:

*"... by elongating it, it was just going to prolong his suffering... the longer we kept him the more pain he was going through and so just the knowledge of that and being told that"* (Case 9) (Coombs, 2015, p. 2).

After life-sustaining treatments were withdrawn some families struggled, perceiving time and their grief in 'slow motion' during the dying process. This contributed to frustration for some family members as they believed the dying person to be suffering (Kociszewski, 2005; Wiegand, 2016). In the following excerpt, a family member exhibits frustration with the slow nature of the dying process, a likely expression of loving concern for the dying person:

*"Give the man an injection and let him go for Christ's sake. Don't keep coming in and checking things"* (Family member) (Wiegand, 2016, p. 163).

In the excerpt below, a son reports that he was unprepared for the nature of the dying process. His distress is clear:

*"So the ventilator was turned off and my mom just kept breathing. We all cried when the ventilator was turned off. And then she kept breathing and we thought 'Oh no, we got all prepared for this and she's still going. How long is it going to be?' This is so*

*hard. And she (the nurse) said 'Sometimes it takes up to two hours.' And I remember thinking two hours is forever"* (Son) (Kociszewski, 2005, p. 110).

### Family needs of the dying environment

In this second and final category of synthesis three, the fundamental needs of families with regard to the dying environment are reported, namely: (1) to be close to the dying person - the bedside vigil; (2) to have flexible, unrestricted access; (3) to experience grief in privacy; (4) to have a peaceful dying environment; and (5) to have respect for family rituals.

The first element of this category is related to the family's need for closeness. When time was perceived to be short and families understood the seriousness of the situation, they experienced a strong need to feel close to the dying person and to have other family members involved. This was described by one author as the *bedside vigil* (Fridh et al., 2009, p. 114). When this need was met it was associated with decreased anxiety (Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison et al., 2013):

*"... the fact that [patient's name] was so near death, I had to be there for as much as I could"* (Patient 06's spouse) (Pattison et al., 2013, p. 1450).

One family member described that just seeing the dying person made it easier to cope:

*"You feel you should see her face more often than when you sit at home because you will keep worrying"* (Gloria) (Kisorio & Langley, 2016, p. 62).

During the bedside vigil, families appreciated the opportunity to spend uninterrupted time with the dying person and described nurses as compassionate and supportive in facilitating this (Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016). In one example a family member described the importance of maintaining the vigil so that the dying person knew someone was with him until the end:

*"... I mean I was with him and he also knew that I was with him ... he knew that we didn't leave him..."* (P1) (Kongsuwan & Chaipetch, 2011, p. 333).

In a further two excerpts, the importance of uninterrupted and private time with the dying person was associated with closure for family members, who were able to reminisce about time spent together and also verbalise their grief in private:

*“What I liked, between the moment I called the family and their arrival in the ICU, I was able to spend some time alone at the bedside. The nurses left me in peace, so I was able to say the things I wanted to say”* (Family member 26) (Noome, Dijkstra, et al., 2016, p. 61).

*“... so I just sort of sat there just sort of talking to [him]. And she [nurse]... left me alone with him... and I was just sort of, you know, just talking to him about, you know, things we’d done together”* (Family member 06) (Pattison et al., 2013, p. 1449).

Flexible access to the dying person is identified as the second family need of the dying environment. In eight studies, families indicated an overwhelming need for flexible, unrestricted and open visiting hours in order to facilitate the bedside vigil (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2016). In six studies, families appreciated open visitation and the support gained from the presence of additional family members (Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2016). In two studies, restrictions on visitation were lifted when treatment was withdrawn, and this was a source of relief for some families (Kisorio & Langley, 2016; Wiegand, 2016). One family member highlights the importance of the bedside vigil as an opportunity for the family to create lasting positive memories of the death and the dying person, made possible by unrestricted access:

*“... every extra moment spent in the last days of my dad will count to all of us as family, we will maximise our togetherness knowing that these might be his last days with us, every second we spend with him is worth it and it will remain in our memories. Even though it doesn’t take away memories and thoughts of going to lose him but still you can see that he is well cared for and does not suffer in any way”* (Peter) (Kisorio & Langley, 2016, p. 62).

Other family members in the same paper expressed fear of the impending death, but gathered courage in order to stay with the dying person until the end in order to fulfil their spiritual beliefs:

*“... he doesn’t stay alone, even if he cannot look or speak he can sense that someone is there for him and because this may be our last times to see each other, it is good to make peace with one another so that you can leave in peace otherwise, the ancestors may not be so happy (Peter) (Kisorio & Langley, 2016, p. 62).”*

*“... it is a little bit uncomfortable to see him suffer and to watch him go... But when he dies, the soul will come out and it will just sit by his side, it will not go anywhere because it is waiting for us family to do what we have to do. We must talk to it and send this soul to where it belongs and then we are at peace to know that everything is done in the correct manner (Violet) (Kisorio & Langley, 2016, p. 62).”*

In one paper, although most families took advantage of open access, a few said they were satisfied with shorter visits, as expressed in the excerpts below:

*“I don’t see the reason for staying for long because he cannot speak, see or open his eyes, sometimes it doesn’t even take 10 minutes to be with him” (John) (Kisorio & Langley, 2016, p. 62).*

*“... It is hard for me to stay until she dies but I can come and check on her for a few minutes and then go because I am not comfortable when I see someone who is almost dying or dead” (Dave) (Kisorio & Langley, 2016, p. 62).*

For most family members, interruptions to the bedside vigil were experienced as very frustrating (Fridh et al., 2009; Kisorio & Langley, 2016).

*“... and then they said, you’ll have to leave us for a while, which I did...and then...I don’t remember very well but...what was difficult for me was having to wait outside for a really long time...” (I: 12) (Fridh et al., 2009, p. 114).*

*“It is not so easy, you don’t even sleep, and then you have to wait from now up to the following day to come and visit again, you think and think and think” (Jack) (Kisorio & Langley, 2016, p. 62).*

The third need of families regarding the dying environment was to be able to experience grief in a quiet and private place (Fridh et al., 2009; Lloyd-Williams et al., 2009; Pattison, 2011; Wiegand, 2006). This related to the provision of a private space away from the bedside and the availability of a private room, in some cases the layout of the facility created a barrier to staffs’ ability to meet this family need.

In three papers, small vacant spaces were made available by nurses so that families could remain together in privacy away from public waiting areas or shared rooms, and this was appreciated (Fridh et al., 2009; Lloyd-Williams et al., 2009, p. 661; Noome, Dijkstra, et al., 2016). However, limited access to private spaces away from the bedside was difficult for a majority of families, as it impacted on their ability to grieve (Fridh et al., 2009; Lloyd-Williams et al., 2009; Pattison, 2011; Wiegand, 2006).

*“... I was using the pay phone by the elevators, and I’m standing there crying, and there is no quiet little room that I can go into and talk with a family member... I was standing there crying and carrying on, and people are getting on and off the elevator...” (Daughter) (Wiegand, 2006, p. 184).*

Many dying persons did not have a private room, and as a result some families were troubled that others could hear their grief (Fridh et al., 2009; Lloyd-Williams et al., 2009; Noome, Dijkstra, et al., 2016; Pattison, 2011).

*“I entered the room... and her bed was there with all the equipment and then... the only thing that had an effect on me was when I realised that there was another person [patient] in the room//I believed that one had a private room on such occasions...” (I: 15) (Fridh et al., 2009, p. 116).*

Families of organ donors felt the layout of the facility afforded them no privacy, which was particularly distressing in the period preceding transfer to the operating theatre:

*“... There weren’t any separate rooms. There were curtains with privacy; it wasn’t good enough. Didn’t really have the opportunity to be alone, not really, it was a bit public. I would have liked to have a room. You were aware of others being around so you had to cry really quietly”* (Eunice) (Lloyd-Williams et al., 2009, p. 661).

Similarly, families in another paper reported anguish due to the “dreaded 7pm” visiting hour (family member 04) (Pattison, 2011, p. 174), during which they were witness to other families’ happy moments. In some cases, the physical layout of facilities impacted on clinicians’ ability to provide privacy. For example, families in three studies expressed dissatisfaction with the waiting area (Fridh et al., 2009; Lloyd-Williams et al., 2009; Wiegand, 2006).

*“Rooms like this (waiting rooms) are nice, but then you end up hearing about someone recovering, and I just want to say, shut up...”* (Daughter) (Wiegand, 2006, p. 184).

*“... The amenities were very basic... It [the waiting area] certainly was too small, too busy and it wasn’t acceptable”* (Nesta) (Lloyd-Williams et al., 2009, p. 661).

Conversely, families in three studies felt close physically, psychologically, and spiritually despite shared rooms and limitations in space, and valued being together during the bedside vigil (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Pattison, 2011).

The fourth element of this category relates to the family’s need to perceive a peaceful dying environment, which involved the preparation of the dying person and also the physical environment. Nurses prepared the dying person when life-sustaining treatment was withdrawn, which involved the removal of invasive lines and equipment. This contributed to some families’ perceptions of the peacefulness of death and the dying environment, helping them build positive memories of the dying person at the end of life (Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Wiegand, 2016).

*“They took everything off... She didn’t have that thing in her head, she didn’t have all of that stuff...and they took the respirator out of the room, like it was very... human”* (Family Member) (Wiegand, 2016, p. 163).

In another example, when the nurse prepared the dying person, this provided an opportunity to say goodbye to help families remember the person in a positive manner, the death was described as peaceful:

*“They took the tube out, together with all other lines, so they took everything. So, yeah, he was there in bed, just like a normal person in bed”* (Family member 6) (Noome, Dijkstra, et al., 2016, p. 61).

Participants reported mixed emotions regarding the continuation of patient monitoring after the withdrawal of life-sustaining modalities (Fridh et al., 2009; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison et al., 2013). Some families found comfort in the monitor as it diverted them from the distress of the dying process, while others used the monitor to help their understanding of the death as it unfolded (Fridh et al., 2009; Kociszewski, 2005):

*“I thought it was good that it was switched on, because I could see, I saw the slow decline, otherwise I would not have known, I would not have had any inkling as to whether there were ten minutes or hours left, but I saw very clearly that the pulse dropped and that the frequency declined and suchlike”* (I: 13) (Fridh et al., 2009, p. 115).

In one paper, family members became distressed when the patient monitor was turned away (Kociszewski, 2005). In this case, clinicians had presumed that the monitors were distressing or not wanted by the family:

*“Medical staff trying to turn her machines so that people were not focusing on the machines... That was helping to divert their attention. A type of coping mechanism, if you will, for them to be able to get out of the pain of looking at my mother and looking at the machine. But I think the machines were actually calming and created a little diversion”* (Family member) (Kociszewski, 2005, p. 110).

In three studies participants reported feeling relieved after the decision was made to turn off the monitor (Fridh et al., 2009; Kociszewski, 2005; Noome, Dijkstra, et al., 2016). Some families were observed to experience stress at the sound of the alarm (Fridh et al., 2009). In one paper the author observed a family member ‘could not look at the monitor or her loved



one and focused her attention out the window and on family photos (Kociszewski, 2005, p. 111).

Establishing a peaceful dying environment involved not only the preparation of the patient, but also the preparation of the physical environment. In some cases the nurses prepared and adapted the physical environment, which impacted positively on families' perceptions of a peaceful family-driven death (Pattison, 2011; Wiegand, 2016). In one paper, a nurse played personalised music to comfort the dying person and to add a sense of their personality to the room for the family; one family member spoke of this nurse going "*the extra mile*" (Family member 06) (Pattison, 2011, p. 177). In another paper, the author observed nurses position dying people comfortably, dimming lights, drawing curtains, bringing in additional chairs and removing unnecessary equipment to provide more space for family and to reduce the impact of technology on the peacefulness of the dying environment (Wiegand, 2016). However, despite the efforts of staff, some participants in this paper felt the environment was uncomfortable, and not a "*homey*" environment to die (Family member) (Wiegand, 2016, p. 163).

Families, who perceived a peaceful dying environment also drew associations to the presence of family and the peacefulness of the death, described by some as a good death (Fridh et al., 2009; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Wiegand, 2016; Wiegand & Petri, 2010). Families in one paper appreciated that they were able to be present at the bedside with the entire family (Noome, Dijkstra, et al., 2016). Several family members were present at the moment the person died and spoke of it as a wonderful moment, where the dead person looked peaceful and their suffering was over (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Wiegand & Petri, 2010). In the two examples that follow, family presence and togetherness around the dying person is experienced as a defining quality of a good death:

*"I think that she did have a good death... she had everybody around her"* (Daughter)  
(Wiegand & Petri, 2010, p. 432).

*"She had a peaceful death. She had her family around her..."* (Family member)  
(Wiegand & Petri, 2010, p. 432).

In addition to presence and togetherness, a lack of fear appears as a further quality of a good death:

*“Comforting, in that I was allowed to be there for the time that my dad had in the unit. Frustrating, because I wasn’t there when he died. Peaceful, in his death process because I truly believe it was a beautiful death: because he wasn’t afraid, we weren’t afraid, and the family was with him when he died”* (Family member) (Kociszewski, 2005, p. 112).

Families in two studies were disappointed that there was not enough room for all family members to be at the bedside at once, this was considered a negative aspect of the dying environment (Lloyd-Williams et al., 2009; Wiegand, 2016).

Place of death was a discussion point in three studies, with family expressing a mix of feelings regarding the suitability of the hospital environment. Ultimately, family members conceded that the hospital was the right place for their family member to die (Kociszewski, 2005; Pattison, 2011; Wiegand & Petri, 2010). One relative conveyed her desire to take her family member home to die *“To make him comfortable, to hold him, to take away his pain”* (Wife) (Kociszewski, 2005, p. 113). The idea that dying at home would be impractical or psychologically challenging (on either the dying person or the family) was clearly defined in all three studies (Kociszewski, 2005; Pattison, 2011; Wiegand & Petri, 2010). In one example, a daughter expressed sadness that her mother was not able to die at home, but acknowledged that she had a good death and that they all received the support and care that they needed:

*“I wish my mom hadn’t died in the hospital and that she was able to be at home... But we couldn’t have cared for her... I don’t want to think about the hospital... but it was full of compassion... in her circumstance... it was the only place for her to die”* (Daughter) (Kociszewski, 2005, p. 114).

One family member described the death in hospital as peaceful, suggesting that a death at home would have been harder:

*“... she [the patient] certainly knew that had she gone home it would have been harder on everybody, and it certainly would have not been easy on her”* (Family member) (Wiegand & Petri, 2010, p. 432).

In the excerpt below, a family member reported strong feelings against a death at home:

*“I don't think in the end he worried about the fact that he wasn't at home, which would've been his choice. But it wouldn't have been my choice... I think there's always this dilemma between the patient's wishes and the families'... I just don't really like the idea of someone dying in my house... I don't care who it is... the nursing staff were absolutely excellent... I have no criticism at all of anything that happened in fact...”* (Family member 02) (Pattison, 2011, p. 178).

The fifth element of the category family needs of the dying environment is respect for family rituals inclusive of participation in care. This is a key factor identified by families as contributing to their experience of a peaceful family-driven death and dying environment. In one paper a family member who had a positive experience described the *“ICU death as family driven”* (Family member) (Kociszewski, 2005, p. 112), and this illustration seems to align the sentiments identified in many other studies, wherein the families felt that they had some level of control in the preparation of the dying environment to achieve a peaceful death (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). In the excerpts below, the families felt that their needs were respected and that they were able to contribute to the dying environment:

*“... she [nurse] stood in the background and said that ‘It was an honour for her to be there.’ And that’s how she made us feel, feel like we were in charge and she was just there to help. And it wasn’t, wasn’t medically driven. It was more family driven”* (Family member) (Kociszewski, 2005, p. 112).

*“... it was recognizable that as a family, we were really the most important part”* (Daughter) (Kociszewski, 2005, p. 114).

Families in one paper appreciated when personal rituals were invited during the dying process, which included singing at the bedside or getting into bed with the dying person (Noome, Dijkstra, et al., 2016). Family involvement in care during the dying process was also important to some, identified in four studies with reference to a peaceful or a good death (Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison, 2011). In a Thai Buddhist paper, expressions of caring by the families played an important role in achieving a peaceful death; care was enacted in partnership with the nurses, and the strength of this relationship influenced families' perceptions regarding high quality care:

*"While being here, we feel warm. We receive lots of support from nurses"* (P2) (Kongsuwan & Chaipetch, 2011, p. 331).

*"While he was in the hospital, I helped nurses bathe him ... massaging and applying body lotion for his skin care. This made me feel good..."* (P1) (Kongsuwan & Chaipetch, 2011, p. 331).

In three other studies, being invited to participate in the care of the dying person throughout the time of the bedside vigil gave a sense of wellbeing and peace of mind to families (Kisorio & Langley, 2016; Noome, Dijkstra, et al., 2016; Pattison, 2011). One family member identified that being asked without feeling pressured provided a satisfying sense of purpose:

*"... the nursing staff got you involved and they told you what they were doing all the time. Erm, I liked it when they... they cleaned him and washed him down and that was really nice and then we'd help"* (Family member 05) (Pattison, 2011, p. 160).

In another example, a family member described participation in care as mutually beneficial; an action that provided comfort and fulfilled needs of both the dying person and the family member:

*"I can do the care because it is another method of saying goodbye in a nice way, of not dying alone. At least the family is there doing this, doing that. To my side I must be satisfied that I did something for him. The patient needs us as family as much as we need him and he becomes more comfortable when he is with us as family"* (Maria) (Kisorio & Langley, 2016, p. 62).

Kisorio and Langley (2016) reported similar perceptions, where most family members believed that the dying person was aware of their presence during the bedside vigil, and also ‘that they [the family] would experience a sense of belonging and of being needed while their ill relatives would be reassured and, in fact, happy if they [the patient] were cared for by one of their own’ (p. 62). However, in one paper, some family members were not aware of this possibility and in hindsight felt excluded, suggesting they would have liked to assist in care giving, or to have been invited to be present during care (Noome, Dijkstra, et al., 2016). A family member in another paper experienced care giving as challenging due to the technological nature of the environment, noting that support and engagement from the nurse would have been welcome:

*“... you will come and she has all these things attached to her, the machines, and you are scared to touch because you think, what if I mess, what if I switch the machine off accidentally? But if I can do whatever under supervision, then it would be great”*  
(Purity) (Kisorio & Langley, 2016, p. 62).

This synthesised finding involved the aggregation of two categories: (1) Preparing the family for treatment withdrawal, the dying process and death; and (2) Families’ needs of the dying environment. In the first category, families’ needs with regard to the process of withdrawal, dying and death in the ICU are reported. Both positive and negative care experiences are described. These experiences emphasise the need for complete and individualised preparation of the family. Families report that this preparedness positions them to deal better with the dying process, their grief and the immediate aftermath of the death. In this second category of this synthesised finding, the fundamental needs of families with regard to the dying environment are reported.

#### **5.6.4 Synthesis 4: Family-centred support and care**

Findings in this qualitative synthesis revealed that nurses, physicians and other members of the healthcare team play a central role in providing care, psychological support and guidance to the grieving family, when life-sustaining treatments has been withheld or withdrawn, and family members valued their contribution highly (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2006, 2016). In

this context, although the dying person is the main recipient of care, there is a perceptible shift of focus from the patient to the family, as the needs of the family with regard to support and care intensify. This synthesised finding involved the aggregation of three categories: (1) nursing presence as an element of support; (2) emotional support and compassionate care; and (3) the clinician-family relationship: trust, bonds and rapport.

#### *Nursing presence as an element of support*

The focus of this category is the constant presence of nursing staff as an element of family-centred support and care. Nursing presence encompasses a broad range of direct and indirect actions to support the perceived practical needs of the family. Families in five studies referred to the importance of the support they gained from nurses in terms of their reassuring presence (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison, 2011). In particular, the findings of several studies revealed family members valued nurses who made themselves available to answer questions, provide frequent updates and advocate for them, and these actions invariably bridged the gap between families and clinicians (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Noome, Dijkstra, et al., 2016). Families appeared to value nursing presence highly as a means to gather information (Kisorio & Langley, 2016; Kociszewski, 2005; Noome, Dijkstra, et al., 2016).

*“They told me exactly what is happening, they spoke to me nicely, when we had questions, they explained anything we needed” (Gloria) (Kisorio & Langley, 2016, p. 60).*

Positive experiences of nursing presence and availability were reported in two other studies, again this was valued highly by family members (Fridh et al., 2009; Pattison, 2011). Pattison (2011) narrated a description of presence from a patient’s wife ‘... she talked of the support encountered from nursing staff and their palpable, reassuring presence’ (p. 174). Fridh et al. (2009) observed that nursing presence and availability was also valued when the families were away from the bedside, ‘they could phone at any time of the day or night to inquire about their loved one’s condition and were met at the door and accompanied into the patient’s room’ (p. 114).

The presence of nurses during family meetings and their ability to advocate competently was means by which families felt supported and could obtain information (Noome, Dijkstra, et al., 2016). This included situations where nurses rephrased physicians' explanations and also assisted family members to ask questions:

*"During the family meeting, the ICU nurse added information sometimes, but most of the time she did not speak... when she thought we did not understand what the doctor was telling, she explained it to us in a clear way"* (Family member 24) (Noome, Dijkstra, et al., 2016, p. 61).

However, in one paper, most family members reported dissatisfaction with the lack of nursing presence, information sharing and advocacy for their needs:

*"... we need to understand what is happening in the process. Nurses must explain things so that we can understand... most of the time is like we are in the darkness because we don't know what is happening"* (Pinky) (Kisorio & Langley, 2016, p. 61).

*"When we asked nurses they wanted us to ask the doctor because they didn't want to divulge. With the doctors not being around and the nurses not divulging the information, I can say we have not received quite enough information as to what is happening and we still have some question marks that I may want to ask"* (Purity) (Kisorio & Langley, 2016, p. 61).

The presence and availability of nurses was also highly valued by families when associated with clinical competence (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011). Family members in three studies reported that nurses who were perceptive and made themselves available when needed inspired reassurance and a sense of security in the care provided (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005). Families described the security instilled by competent care as trust in the care, which made families feel important, empowered and welcome (Fridh et al., 2009; Kociszewski, 2005). This sense of feeling welcome was reinforced when staff reassured relatives that they were not in the way, an important element of practical support according to families (Fridh et al., 2009; Kisorio & Langley, 2016).

### Emotional support and compassionate care

The experiences and perceptions of families with relation to the receipt of emotional support and compassionate care was reported in nine studies (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2016). When needs were met, participants reported feeling cared for and emotionally supported; some directly described compassionate care, some experienced empathy, and some provided indirect descriptions (Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Lloyd-Williams et al., 2009; Pattison, 2011). These experiences and perceptions convey clearly that nurses play a highly visible and integral role in this care provision.

Families in one paper reported that their emotional needs were met, and perceived this as a responsibility of staff, illustrated by the excerpt below:

*“I think that while their focus is medical and saving lives and, you know, the science, I think also, along with that comes the responsibility of some kind of support to a relative or a family, that patient’s loved one or caregiver. Yeah, and they actually did that, and that is part of high-quality care”* (Family member) (Nelson et al., 2010, p. 9).

Where nurses showed interest that was perceived to be genuine and personal this was associated with respectful, competent and compassionate care, and in some cases a good death (Fridh et al., 2009; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Pattison, 2011). According to Pattison (2011), a husband who experienced compassionate care and emotional support ‘talked of seeing the nurses in tears at the death of his wife and how that positively impacted on his experience’ (p. 177). In the excerpt below, the compassion expressed by nurses resonated strongly for one family member:

*“... They were mostly women [nurses]. These women were truly amazing – the strength and the fortitude of the personality that they have, the compassion...”* (Family member) (Kociszewski, 2005, p. 121).

Families described nurses’ compassion in terms of their therapeutic touch, sincere and respectful care, personal and genuine interest, and simple acts of kindness. Families also



reported satisfaction with emotional support and perceived the care to be compassionate when clinicians demonstrated concern for their wellbeing on a personal level, and did *“everything possible to uphold or enhance this”* (Family member) (Pattison, 2011, p. 159). One author observed the importance of simple yet compassionate gestures, such as ‘smiling after 12 hours on duty and doctors sitting at family level, rather than standing’ (Pattison, 2011, p. 177), which contributed to a family member’s perception of being cared for with compassion. In the excerpt below, a family experienced emotional support in association with compassionate care:

*“We were looked after so well, staff cared for us so well... [they] let the children hold their mother’s hand”* (John) (Lloyd-Williams et al., 2009, p. 661).

In six studies, nurses were present to provide practical support, identified by families as compassionate care, that addressed the basic needs of families, such as a comfortable chair or a drink (Fridh et al., 2009; Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison, 2011). In one paper when nurses offered drinks, food or a place to sleep this was unexpected, and families felt that their practical needs were met with compassion (Noome, Dijkstra, et al., 2016). However, nurses did not always maintain sensitivity to families’ needs in this way, and omissions of such basic support and care remained in the forefront of some participants’ memories (Kisorio & Langley, 2016; Pattison, 2011, p. 175).

*“I didn’t talk with them... they just asked if I wanted a cup of tea, wanted to wash, or wanted toast”* (Alice) (Lloyd-Williams et al., 2009, p. 661).

Family members in three studies spoke of receiving little in the way of emotional support from nurses (Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010). In the excerpts below, two family members were psychologically fragile and needed emotional support while coming to terms with changing events:

*“I would have liked someone to put an arm around me, to look after me, to ask if I wanted tea, seeing the state I was in, I was out of my mind”* (Edith) (Lloyd-Williams et al., 2009, p. 661).

*“... It’s not like they need to have an emotional bond with each and every one of our relatives, but they need to have some compassion for these people”* (Family member) (Nelson et al., 2010, p. 8).

Difficulty with perceived emotionally detached care from clinicians was a feature in many studies, where negative experiences influenced the families’ experiences of emotional support and compassionate care (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Pattison, 2011). In one paper, it was reported that participants were ‘resentful, angry and hurt when the nurses were dispassionate and remote’ (Kociszewski, 2005, p. 120). Family members perceived a disregard for their emotional needs and a lack of compassion in the two excerpts below:

*“Hurt. I’m hurt. I feel like these people took something away from me. Not because my mother died. It seemed like they just didn’t care... I know that... these people aren’t supposed to get emotionally involved, but I do believe they should have some kind of compassion for the family, and for what the family wants, what the family needs...”* (Family member) (Kociszewski, 2005, p. 120).

*“... The staff was cold... No feeling... No emotion... Lack of emotion. Lack of feelings... If you change the way people are feeling – it’s not how it looks. It’s how a room and an environment makes someone feel. And that ICU was just cold... just cold”* (Family member) (Kociszewski, 2005, p. 118).

In another paper, family members expressed a need for empathy and compassion from the nurses, and someone to talk to and express their feelings, but when this need was unmet, they felt emotionally unsupported:

*“Nurses must be a little bit more compassionate, they must speak to the families nicely... I mean little things matter, in such situations you must put yourself in somebody else’s shoe and say, wait a minute, if this is me how do I want to be treated”* (Ryan) (Kisorio & Langley, 2016, p. 62).

*“... sometimes you come and you don’t talk to anyone because nurses don’t come. They were sitting at the reception and I was thinking, maybe if it is time for visitors it is their time to relax”* (Pinky) (Kisorio & Langley, 2016, p. 61).

In a rather atypical situation, a distinct lack of empathy and compassion on the physician's part was reported, and a family was left to tell their dying mother that treatment was being withdrawn:

*“Even though her body's shutting down... her mind – She was still talking to us and she was asking for things. We had to explain to her that they were going to stop treatment cause they couldn't do anything else for her. They were going to put her in a Hospice...”* (Son) (Kociszewski, 2005, p. 103).

Family members in three studies perceived a tension in nurses who seek to provide individualised compassionate care and emotional support, but also understood that clinicians maintained some emotional detachment as a defence mechanism (Fridh et al., 2009; Nelson et al., 2010; Pattison, 2011).

*“Their job is very hard ... So that is the way of saying, I am not going to get involved. I am not going to feel it. Because, you know, they see people die every day. And if they get involved emotionally, they could not function”* (Family member) (Nelson et al., 2010, p. 8).

In a number of studies families showed no empathy for clinicians who delivered emotionally detached care; these families had a very negative care experience and indicated that they were frequently left feeling unsupported (Fridh et al., 2009; Kociszewski, 2005; Nelson et al., 2010). These insights highlighted the importance of care that addressed the emotional needs of family members:

*“They do it all with rote knowledge with no feeling (and) no emotion what so ever. And that's how staff was... like Stepford wives or robots... I didn't feel as though they did anything for the family... To show no empathy. To just disregard the family as though the family wasn't there... It was like this meant nothing to them...nothing...there was just a lack of. The entire experience was technically driven...”* (Family member) (Kociszewski, 2005, p. 112).

In two studies, families perceived a clear distinction between the emotional support provided by the nurses and the emotional distance apparent in the behaviours of the physicians (Fridh et al., 2009). The following excerpt demonstrates that where emotional support and

compassionate care was upheld, these valued elements of high-quality family-centred care were most often attributable to the actions of the nurses:

*“Quite a few doctors who I didn’t know were in the room, and it felt as if there was some kind of distance, I don’t know if it’s due to their professional jargon or that they are overworked or their responsibility, but they are a bit distant, they talk in a professional manner//they (nurses and nursing assistants) are more likely to embrace you, a bit closer, a bit warmer in some way...” (I: 7) (Fridh et al., 2009, p. 115).*

Another highly valued aspect of care within this category was nurses’ provision of care that encompassed the spiritual needs of families (Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2016). In one paper, focus group participants across a spectrum of religions and cultures identified that attention to families’ spiritual needs was achieved, and regarded this as an element of “high-quality ICU care” (Family member) (Nelson et al., 2010, p. 9). In another paper, the author reported that many family members made arrangements to have clergy from the hospital to visit patients and perform ‘final rituals’ before treatment was withdrawn, and sometimes this happened at the suggestion of the nurse (Wiegand, 2016, p. 162).

However, while spiritual support was identified as potentially valuable in five studies (Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2016), no studies provided illustrations directly from participants to demonstrate how and why spiritual support was valued.

Families in five studies reported that their spiritual needs were rarely met (Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Wiegand, 2016). In three studies, families reported that they relied on each other for spiritual support, even though in most cases referral to a hospital chaplain or clergy was desired (Kisorio & Langley, 2016; Kociszewski, 2005; Noome, Dijkstra, et al., 2016). In one paper, a family member highlighted that nurses did not offer spiritual support:

*“I will say not spiritually, I have not seen this service provided by nurses to us as family or to the patient, we just pray for him as a family” (Maria) (Kisorio & Langley, 2016, p. 63).*

### *The clinician-family relationship - trust, bonds and rapport*

This category is the third and final in the synthesis ‘Family-centred support and care’, and refers to families’ need for clinicians (specifically nursing and medical staff) to establish relationships that maintain trust, bonds and rapport in order to feel supported and cared for from admission, through to the bereavement period. Staff familiarity and consistency was regarded as important in order to establish trust and rapport, and in several studies families reported such a supportive relationship, where clinicians knew both the family and the patient (Fridh et al., 2009; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison et al., 2013; Wiegand, 2006, 2016).

*“... if certain nurses were working, I could go to sleep. I could just lie down and trust them and go to sleep”* (Mother) (Wiegand, 2006, p. 181).

Where nurses showed personal interest in families and patients it was appreciated and unexpected, by some this was associated with establishing trust and rapport (Fridh et al., 2009; Noome, Dijkstra, et al., 2016). This was described in terms of nurses inquiring about the lives of the patient and their family on a personal level and by listening to family members (Noome, Dijkstra, et al., 2016). In one paper ‘almost half of the family members mentioned they did not expect any interest from nurses in their situation’ (Noome, Dijkstra, et al., 2016, p. 61). The sharing of experiences was also associated with trust (Fridh et al., 2009).

When life-sustaining treatment was being withdrawn, families in three studies reported the benefit of having familiar nurses, those who had had time to develop a rapport with the dying person and family, involved in care (Kociszewski, 2005; Pattison et al., 2013; Wiegand, 2016). Wiegand (2006) observed in one facility ‘... the Lyle family wanted Mrs Lyle’s primary nurse, Ally, to be there the day that life-sustaining therapy was withdrawn because they had a close connection with her’ (p. 181). In another example, a family member suggested that the withdrawal of life-sustaining treatment was easier under these circumstances:

*“Having the same nurse was really nice, especially the day that he died”* (Family member) (Wiegand, 2016, p. 163).

However, in some circumstances even though trust and rapport was established between a family and clinicians, the trust could be disrupted. Several families experienced broken bonds with clinicians (Kociszewski, 2005; Wiegand, 2006). Broken bonds were experienced when clinicians rotated, didn't provide ongoing support after treatment was withdrawn, or in some cases where the dying patient was transferred. Families struggled, often psychologically to adjust to such changes:

*"Dr. Jones... he was wonderful, but then after 3 or 4 weeks, he was gone, and we never saw him again... Dr. Jones should have at least had the new guy with him and say, 'look I'm going off, but this is the new guy'" (Daughter) (Wiegand, 2006, p. 181).*

*"... we bonded with them [nurses], and then all of a sudden, boom, we're out of there... just like ejected to here... we didn't know anybody and nobody knew us and that was hard" (Daughter) (Wiegand, 2006, p. 181).*

In another negative experience, a family member feels abandoned after his mother is transferred; he expresses anxiety and desires the comfort of the previous trusting family-clinician relationship to support his grief:

*"I knew the nurses. I knew the doctors. I had a relationship with them... [my mother] was just being pushed out of the ICU to die... I don't know the nurses. I don't know anybody here. I don't know how often they're going to come in and check on her. There are no familiar faces... leaving tonight, I don't have the sense of comfort because I don't know the people. I don't know the nurses taking care of my mom" (Son) (Wiegand, 2006, p. 185).*

Broken bonds were avoided by the compassionate actions of one clinician, as reported by Wiegand (2006) 'the physicians who acted as attending ICU physicians in the units usually changed monthly. Although Mrs Keefer's attending ICU physician technically was no longer on service in the unit, he remained Mrs Keefer's attending physician because he thought it was 'the right thing to do' for Mrs Keefer's family' (p. 181), however this is an uncommon practice.

In this synthesised finding, three categories have been aggregated: (1) nursing presence as an element of support; (2) emotional support and compassionate care; and (3) the clinician-

family relationship: trust, bonds and rapport. The findings demonstrate that although the dying person is the main recipient of care, once life-sustaining treatments have been withheld or withdrawn, the needs of the family with regard to support and care intensify, and there is a perceptible shift of focus from the patient to the family. During this time the healthcare team, particularly nurses, play a central role in providing care, emotional support and guidance to the grieving family.

### **5.6.5 Synthesis 5: Bereavement care**

Findings from the studies in this synthesis show that bereavement care for the family has two distinct elements: (1) the care that occurs throughout the dying period until death (when death is imminent, at the time of death and immediately after death); and (2) bereavement support after hospital (Fridh et al., 2009; Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison et al., 2013). This synthesised finding comprises three categories: (1) tactful presence and psychological support at, and after death; (2) the families' need for privacy and time after death; and (3) post-hospital follow-up and bereavement services.

#### *Tactful presence and psychological support at, and after death*

Families' need for emotional support extends to the actual moment of death and the period of time immediately after death; an essential part of bereavement care. For families, this time is associated with intense manifestations of grief and anguish, demonstrated by the mixture of positive and negative experiences reported (Fridh et al., 2009; Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010; Pattison et al., 2013).

The ability of a nurse to anticipate imminent dying reflected positively on the experience of several families, at a time when they were extremely sensitive and dependent on having someone to lean on (Fridh et al., 2009; Pattison et al., 2013).

*"... she was brilliant... She was obviously aware that, you know, it was going to be very soon, so she came back in and sat with me...that was very good, she was tremendous"* (Family member 06) (Pattison et al., 2013, p. 1449).

*“... but then I noticed that the beats per minute were becoming fewer I just sat there and actually followed it and... yes, it went down to 20 and then that line and it scared me a bit. I mean it was so final... it felt so... but then all of a sudden the staff were at our side... somehow it felt like a support... the fact that they came and took care of us too” (I: 1) (Fridh et al., 2009, p. 115).*

Further, in one paper, a family was very appreciative when they were accompanied from the ward, which was perceived as a compassionate gesture and an extension of the emotional support they received:

*“In the end J [nurse] came to see us off. This helped a lot” (Tom) (Lloyd-Williams et al., 2009, p. 662).*

In a number of studies, families described the challenges of coping without timely presence or psychological support from staff at, and after death. These very negative experiences created lasting memories for family members (Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010). In the following two excerpts, participants reported feeling psychologically unprepared, unsupported and abandoned; in reflection the family members felt staff failed to provide the support and care they needed to manage their grief:

*“At 8:00 PM, I went out there and felt like I was going into a war zone. I was put out like, out on the street. No one told me anything. They knew several days beforehand that I had arranged the date [for ventilator withdrawal], but nobody approached me...Nothing was addressed at all...Nobody asked, ‘Are you able to take care of yourself; are you able to find a place to go to, as far as for grief, for death of your mother?’ Where do you go, what do you do? ... Prepare one for it a little bit. Not to walk out into the cold night” (Son) (Nelson et al., 2010, p. 10).*

*“While I was in hospital I had loads of care and attention, but at the end I needed someone to take time with me. At the end, somebody could have asked, ‘How are you getting home? Who is taking you home?’ They didn’t and I don’t know how I did” (Irene) (Lloyd-Williams et al., 2009, p. 662).*

In another example, a family member voiced her distress, as nobody was there to provide psychological support when the patient died; this was associated with a lack of compassion:



*“There should have been somebody there... How do they feel you know when somebody that they love passes away? Don’t they want the same kind of compassion and a little understanding?”* (Family member) (Kociszewski, 2005, p. 120).

### *The families’ need for time and privacy after death*

The grief experienced by families when a person died in the ICU manifested in diverse and unique ways. It is clear that, regardless of the circumstance surrounding death, supporting the needs of families is essential, particularly in terms of providing time to come to terms with death. In two studies, families stressed the need for time to grieve immediately after death, or to prolong the moment (Fridh et al., 2009; Nelson et al., 2010).

Few reported being granted the time they needed to grieve after death. In two studies, families reported feeling forced by staff to leave the room in order to allow them to prepare the remains (Fridh et al., 2009; Nelson et al., 2010). The following excerpts exemplify care that promotes a sense of abandonment in family members, where their psychological need for time with the deceased person were not met:

*“I think that I did get very good attention and my father had the best of care, but... they just came and closed his eyes, started doing whatever they do when somebody dies, and basically just said to move. And, I just left. I did not know what else to do...”* (Daughter A) (Nelson et al., 2010, p. 10).

*“After he died, they just came in there and pronounced him dead, and started covering him up and moving him, and pulling out all these things. And, I thought, do they need the room right now? They do not give me a minute to just kind of get up and grab my stuff and get out? So, I just left”* (Daughter B) (Nelson et al., 2010, p. 10).

In two other studies, families expressed the need for a private place to express their grief while they waited for nurses to prepare the body, as they did not want to distress other family members by their suffering (Fridh et al., 2009; Kociszewski, 2005). This excerpt paints a very stark picture of one woman’s sense of feeling abandoned and alone:

*“So they told me to go down and sit in the corridor and I have to say that it was probably the worst thing I ever experienced... when I sat down I just felt that, oh my*

*God, I'm sitting here all alone, and I've never felt so lonely in all my life" (I: 5) (Fridh et al., 2009, p. 116).*

In one paper, family members reported a complex interplay of emotions after the death, namely, 'relief, sadness, shock, confusion, doubt, pain, anger, numbness and blame' (Kociszewski, 2005, p. 124). In the same paper, one family requested to keep their deceased mother in a room for two hours, to allow time for others to arrive from interstate, however, their request was denied due to a need for the ICU bed to be vacated. The family eventually made their final visit in the morgue, which was very distressing, and created lasting memories of a very negative experience:

*"That was awful. That was terrible. I thought it was... I don't know, humiliating... I mean they treated my mother like garbage" (Daughter) (Kociszewski, 2005, p. 115).*

#### Post-hospital follow-up and support services

After the death of a family member, many participants reported a need for follow-up and support services, such as a return visit to the ward, a follow-up conversation with staff, and information about available support services, support groups and social workers (Fridh et al., 2009; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016).

Participants in two studies valued the opportunity for a return visit (Fridh et al., 2009; Noome, Dijkstra, et al., 2016). Where family members were afforded this opportunity, they could reconcile with their loss and achieve closure (Fridh et al., 2009). In the same paper, participants reflected that their profound grief might have hindered their ability to comprehend an offer of support, however two other participants appreciated the follow-up they received:

*"We received a condolence card a few days later, so thoughtful. And if we wanted to schedule a follow up meeting, this was possible. That was also written in the card. And I was called for a follow up meeting twice, yes, we appreciated that" (Family member 15 and 16) (Fridh et al., 2009, p. 62).*

In two other studies, many family members experienced an unmet need for bereavement follow-up after hospital and for some, this had long-lasting consequences, including psychological distress (Lloyd-Williams et al., 2009; Nelson et al., 2010):

*“... I would’ve liked a piece of follow-up, somehow. A call: ‘Ms.\_\_\_\_, I know your father just recently died, how are you doing? Did you know there’s a group? Would you be interested in talking to someone?... It’s important for people who have recently lost their loved ones,’ or something like that”* (Daughter A) (Nelson et al., 2010, p. 10).

*“... I would have appreciated some follow-up or grief support or social work or anything. Because I did not cry over my father... I did not cry at all, until 2 months ago, I finally had myself a good little fit. I did not know that I was so messed up. I wished that I had spoken with someone. Or someone had reached out to me. In some way”* (Daughter B) (Nelson et al., 2010, p. 10).

Similarly in another example, a family member identified that they needed further psychological support, but were not provided with information on such services:

*“A letter after the event, saying something like, ‘We understand how things are. In the meantime, here is a number.’ You are on your own afterwards. You have got time to think. It would be nice if they would see if you would like to attend a support group or answer questions, to know that you are not on your own. It would be good if they let you know straight away”* (Ethel) (Lloyd-Williams et al., 2009, p. 662).

It was also identified in one paper that participants felt uncomfortable contacting the ICU themselves for a follow-up meeting, as opposed to being contacted by the hospital directly (Fridh et al., 2009).

This synthesised finding has aggregated three categories: (1) tactful presence and psychological support at and after death; (2) the families’ need for privacy and time after death; and (3) post-hospital follow-up and bereavement services. The findings demonstrate that families have unmet bereavement needs when death is imminent, at the time of death and immediately after death.

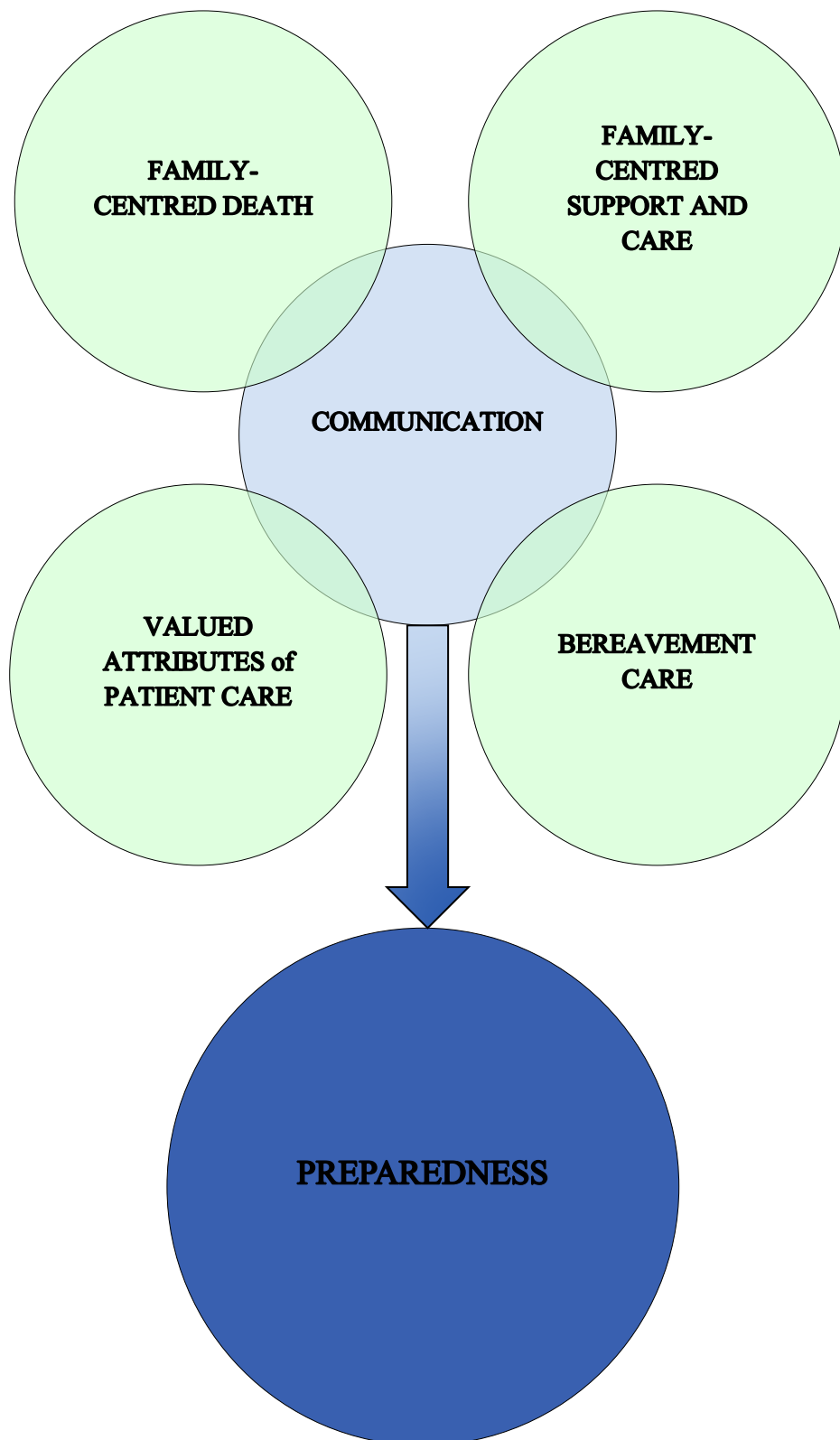
In the next section, the findings of this synthesis are presented conceptually in a model of care for the delivery of high-quality family-centred EOLC in the ICU.

### **5.7 Conceptual representation of the meta-synthesis**

The synthesised findings have generated robust evidence on families' experiences and perceptions of the EOLC delivered in the ICU, when life-support treatment is withheld or withdrawn. Most valuable is new knowledge on how these key components of care can contribute to a state of *preparedness* in families. A conceptual model of care was developed to explain the key findings of this qualitative synthesis (see Figure 6). The model arranges four synthesised findings around the core synthesis of communication, and from this the central concept of preparedness has evolved. A state of preparedness explains the circumstance in which the family of the dying person can manage, in the best way possible for them, the death and their sadness, loss and grief. This can be used to guide future practice, inform policy development and clinical decision-making.

The syntheses are: (1) the dying person: valued attributes of patient care; (2) communication with the family and within the healthcare team; (3) preparing the family and promoting a peaceful family-centred death; (4) family-centred support and care, and; (5) bereavement care. The conceptual model of preparedness is helpful in conferring a structure on the reported findings and will be utilised to in guiding the discussion in Chapter 6.

**Figure 6: Preparedness: A model of care for the delivery of high-quality family-centred EOLC in the ICU**



## 5.8 Summary

This qualitative synthesis aimed to identify the experiences and perceptions of patients' families, of the EOLC delivered in the ICU setting, when life-sustaining treatments are withheld or withdrawn. The inclusion of 13 international studies (from the UK, USA, Netherlands, Sweden, Thailand and South Africa) has provided rich data for meta-synthesis. Meta-aggregation and thematic analysis resulted in five synthesised findings: (1) the dying person: valued attributes of patient care; (2) communication with the family and within the healthcare team (3) preparing the family and promoting a peaceful family-centred death; (4) family-centred support and care; and (5) bereavement care. The synthesised findings contribute to the establishment of preparedness, which is depicted in the model for care delivery (see Figure 6).

Overall the synthesised findings showed that families experienced both positive and negative aspects of EOLC. However, if key components of care are in place, preparedness is more likely to be facilitated, and families may experience EOLC in the ICU as a more positive experience, despite their anticipatory sadness, loss and grief. It is acknowledged that the unique nature of each end-of-life experience and the reality of a sudden death in the ICU may not make possible thorough preparation and thus the establishment of preparedness for all families. It appears that these families are more likely to experience EOLC in the ICU negatively. Nonetheless, providing care that meets the needs, values and wishes of families is essential. The key components of care that contribute to the preparedness of families are summarised below.

First, families reported their need to witness caring behaviours from the healthcare team toward the dying person. This was demonstrated in synthesis one, in particular behaviours focused on maintaining dignity and comfort were considered priorities of high-quality EOLC. The presence of these behaviours was associated with perceptions of a good death, and also contributed to the perceived peacefulness of the death and the dying environment, shown in synthesis three.

Second, families considered adequate and appropriate communication an essential element of high-quality EOLC, however, synthesis two showed that this did not occur consistently. Families valued honest, sensitive, clear, consistent, timely, and repeated communications

with clinicians. When high-quality EOLC was facilitated, clinicians demonstrated effective communication skills, thus communication is considered a core synthesis. In the absence of a coordinated approach to communication, preparedness could not be established. Families also associated consistent communication with continuity of care.

Third, when families knew what to expect during treatment withdrawal, the dying process and death, they perceived a more peaceful and family-centred death. Perceptions of a peaceful and family-centred death relied on a number of care elements relating to the dying environment, namely, removal of medical paraphernalia, protection of physical space and privacy, respect for personal rituals and family participation in care for the dying person.

Fourth, families' needs for support and care increased throughout the duration of EOLC. A lack of emotional support and the presence of emotionally detached care were reported in an array of negative experiences. The findings indicate that nurses in particular have a significant role to play in the delivery of emotional support. ICU nurses' abilities to provide compassionate, empathic and individualised care appeared to be key to meeting the support and care needs of families, bridging the gap between family members and other members of the multidisciplinary team to facilitate a family-centred model of care.

Fifth, families' needs for support and care continue into the bereavement period, however a perceived lack of bereavement care was expressed strongly in synthesis five. Families viewed bereavement care as the responsibility of the nurse, including that nurses: (1) anticipate the support required as death approached; (2) provide privacy and time, and; (3) offer information and referral to after-hospital support. There is some overlap between the elements of care established in synthesis four (see 6.4.4) and families' needs for bereavement care in synthesis five (6.4.5). That is, high-quality EOLC in the ICU involves effective bereavement care, which also requires nursing presence, emotional support, compassionate care and an established clinician-family relationship, as described in synthesis four.

Overall, the qualitative synthesis has demonstrated families have unmet needs for *communication, support and care* and *bereavement care*, reflecting a lack in some cases of a family-centred model of care. The conceptualisation of preparedness describes the circumstance in which families can manage, in the best way possible for them, death, and the sadness, loss and grief experienced during EOLC in the ICU. Preparedness was found to play

an important role in family member satisfaction with care, and where this occurred, a trusting relationship between families and clinicians was evident. Preparedness could not be facilitated without effective communication. Despite the unmet needs reported, many of the key findings were associated with mixed family experiences and variable needs, indicating the importance of an individualised approach. Thus, there is an opportunity for ICU clinicians, particularly nurses, to align support and care with the values, needs and wishes of families and family members during EOLC.



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## **CHAPTER 6**

### **DISCUSSION AND CONCLUSION**

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## **Chapter 6: Discussion and Conclusion**

### **6.1 Introduction**

In this chapter key findings of this qualitative synthesis are presented and discussed in relation to research literature, current policy and guidelines. The strengths and potential limitations of this synthesis will also be presented, as well as implications and recommendations for future research, policy, training and practice.

### **6.2 Meeting the thesis aim**

Chapters 1 and 2 set the scene and context for the development of the aim of this thesis. The practical and methodological barriers inherent in conducting end-of-life research in the ICU were highlighted, as were the development of policy, guidelines, position statements and standards, which have not been informed by a robust evidence base. The variability of withdrawal, withholding and EOLC practices in the ICU was also discussed. The complexities of delivering quality EOLC in the ICU were highlighted, in relation to the often unpredictable and potentially short dying phase following treatment withdrawal. This context provided strong justification of the need to consolidate the available research evidence about families' views of EOLC in the ICU, in order to improve evidence-based clinical guidelines and EOLC practice standards.

Chapter 3 provided a comprehensive critique of the synthesis methods of most methodological relevance for delivering the thesis aim. The critique provided an informed basis, with rationales and justification for selecting meta-aggregation as the qualitative synthesis method, taking into consideration the epistemological frameworks, assumptions strengths and limitations of the main methods used for qualitative synthesis. Meta-aggregation is the most appropriate method to meet the thesis aim because it: (1) is an established, well published method; (2) provides a validated framework, tools and checklists; (3) is suited to the synthesis of experiential aspects of healthcare phenomena; (4) provides recommendations that take into account the strength and quality of the evidence, and; (5) is linked to an online best-practice database, which supports the dissemination of research and knowledge directly to clinicians (see section 3.5).

A comprehensive overview of how meta-aggregative method and thematic analysis was to meet the aim of this thesis was provided in Chapter 4.

The aim of this systematic review was met as described in Chapter 5 through: (1) conducting a comprehensive search of the literature to identify relevant studies; (2) selecting relevant studies according the published protocol; (3) extracting data relating to the synthesis aim; (4) analysing and synthesising data, and; (5) reporting findings that identify the key components of EOLC considered important by families and thus where care of patients and their families could be improved.

### **6.3 Key findings**

The aim of this thesis was to identify and synthesise qualitative studies that capture the experiences and perceptions of patients' families, of the EOLC delivered in the ICU setting, when life-sustaining treatment was withheld or withdrawn. This qualitative synthesis is the first to have synthesised qualitative research in this area of study.

The synthesised findings offer new knowledge in understanding the key components of care considered important to meet the needs of families, when life-sustaining treatments were withheld or withdrawn in the ICU. The five synthesised findings were conceptualised as a model of care for the delivery of high-quality family-centred EOLC in the ICU (see Figure 6). Communication was established as a core synthesis, and from this the central concept of preparedness evolved. On the basis of this synthesis it is seen that preparedness influences family members' experiences of death, dying and bereavement, and thus satisfaction with EOLC in the ICU environment. However, due to the unique nature of each end of life experience, it is unlikely that every family will achieve a state of preparedness. The synthesised findings suggest that when families felt prepared, they knew what to expect, felt supported by staff in a trusting family-clinician relationship, and felt their needs were being met. Feelings of preparedness also appeared to influence the experience of grief. For example, when a family member felt unprepared, they expressed a high emotional response to the impending death and their anticipated sadness, loss and grief.

As shown in the synthesised findings, preparedness requires a coordinated approach to communication. This important domain of care has the potential to influence families'

perceptions of all aspects of care delivery. Effective communication assisted families' preparedness for the death of their family member and the ensuing, sadness, loss and grief. Effective communication also facilitated individual support and care and bereavement care. Families valued honest, sensitive, clear, consistent, timely, and repeated communications with clinicians. An important finding for translation into practice is that families need communication that is readily available, timed appropriately to the changing status of the patient, and decipherable and easily remembered.

*Family-centred support and care*, presented in synthesis four, resonates throughout the entire care experience, and encompasses the practical, psychological and spiritual support provided by clinicians to meet the needs of families. Families expressed satisfaction with support and care when it was compassionate, conveyed empathy, and recognised and provided to their individual needs and preferences. Families had high expectations of nurse-initiated support and care. Families reported that nurses could assist them to bridge the communication gap with medical staff for example, by advocating for them or assisting them to comprehend difficult information.

Families also had needs associated with *preparing for and promoting a peaceful family-centred death*, described in synthesis three. This included families' needs to maintain a bedside vigil, to have flexible and unrestricted access, to experience grief in privacy with extended family, for a peaceful dying environment and to feel involved in the preparation of the dying environment when death was imminent. When families witnessed dignified and compassionate care for the dying it contributed to their perception of a peaceful death.

Families had unmet needs for *bereavement care*, in which nurses play a central role. According to the synthesised findings, families felt satisfied when bereavement care provided the family with time and privacy after death, when psychological support was timed appropriately, and when nurses anticipated the needs of the grieving family after the death and once they resumed their normal life outside the hospital.

In summary, these key findings contribute new knowledge in understanding the key components of high-quality EOLC in the ICU, considered important by families. The synthesised findings provide rich illustrations of families' positive and negative experiences of care. In the 13 studies under review there were many instances of poor care standards

exhibited by clinicians in the ICU, predominantly in the domains of communication, family-centred support and care and bereavement care. Thus, whilst it has been suggested that EOLC in the ICU can be a positive experience for families, the reported inconsistencies highlight potential inadequacies in current policy and practice standards.

In the next section, these findings are discussed and compared with the findings of related research literature from other clinical settings to ascertain if there are common and/or unique issues in relation to EOLC in ICU.

## **6.4 Comparison to related literature**

Due to the under-representation of families' views in current policy and guidance documents as shown in Chapter 2, it is pertinent to consider the key findings of this qualitative synthesis in relation to the existing research. Accordingly, this section discusses the key findings of the current study, highlighting commonalities and contrasts with relevant research, and policy and practice guidelines.

### **6.4.1 The dying person: valued attributes of patient care**

When the needs of the family were met in regard to care of the dying person, this was associated with perceptions of a good death, a peaceful dying environment, feelings of preparedness and decreased anxiety.

This qualitative synthesis found that families could not feel comfortable themselves without assurances of the dying person's comfort. In most cases these assurances were communicated effectively and families experienced a reduction in anxiety. These findings confirm earlier palliative care research, which considered family satisfaction from seeing the patient contented, as a powerful mediator in the protection of caregiver-wellbeing (Hudson, 2003). Hudson (2003) developed a model for conceptualising supportive interventions for family caregivers and identified satisfaction as a coping resource, with decreased anxiety and preparedness as favourable resolutions.

In this qualitative synthesis, basic humane responses to the dying person and family were also important, such as, respect, empathy, truth, dignity and competence in clinical care. When these responses were not observed, families reported distress, sometimes anger. This distress

prevented families from focusing on their own need to prepare for the death, anticipated sadness, loss and grief. National and international standards and guidance documents consider dignity and compassionate care essential elements of high-quality EOLC in all settings (ACSQHC, 2015; Neuberger, 2003; PCA, 2005; Truog et al., 2008). Additionally, these values are embedded in nursing practice standards worldwide (American Nurses Association; International Council of Nurses, 2012; Nursing and Midwifery Board of Australia, 2016; Nursing and Midwifery Council, 2015). The American Association of Critical Care Nurses Scope and Standards for Acute and Critical Care Nursing Practice advocate caring behaviours that create a compassionate environment that is responsive to each unique patient/family dyad (American Association of Critical Care Nurses, 2015). Early comment by Liaschenko and Fisher (1999) noted the challenges faced by clinicians in making their compassion visible. More recently, attributes of clinician compassion are defined as recognising vulnerability and suffering, relating to needs and feelings and preserving integrity and dignity in interactions (Dewar, 2011).

The reported synthesised findings relating to the importance of dying with dignity confirm earlier findings of an integrative review on EOLC in hospice and palliative care settings:

... Dying with minimal symptom distress and limited invasive treatment, being human and being self, maintaining autonomy and independence to the greatest extent, achieving existential and spiritual goals, having self-respect and being respected by others, having privacy, maintaining meaningful relationships with significant others, and receiving dignified care in a calm and safe environment (Guo & Jacelon, 2014, p. 937).

This definition clarifies valued attributes of EOLC, and should underpin future ICU policy development. Further research is needed to establish barriers that limit clinician's capacity to provide EOLC in the ICU.

#### **6.4.2 Communication with the family and within the healthcare team**

An important finding in this study and one that is immediately relevant to clinical practice, is families' expressed need for honest, sensitive, clear, consistent, timely and understandable communication from clinicians. However, ineffective and absent communication was frequently reported by families in this study, with regard to both the information that was provided during EOLC, and how it was delivered. This finding confirms earlier research, which identified the need for effective communication between families and clinicians in the ICU, especially during EOLC (Nelson et al., 2006; Scheunemann, McDevitt, Carson, & Hanson, 2011; Shannon, Long-Sutehall, & Coombs, 2011).

Families in this qualitative synthesis were dissatisfied with care and reported increased anxiety relating to the impending death and the anticipated sadness, loss and grief, when clinicians communicated little or no information. This finding corroborates earlier palliative care research, which suggests anxiety may be minimised if caregivers are well informed (Ramirez, Addington-Hall, & Richards, 1998). Family-centred care is the accepted framework for care delivery in many ICUs (see 6.4.4) (M. L. Mitchell & Chaboyer, 2010), however, communication between families and clinicians continues to be neglected, particularly regarding withdrawal of life-sustaining treatments and EOLC (ACSQHC, 2015; NHS National End of Life Care Programme, 2010; Office for National Statistics, 2015).

In the current study, families reported satisfaction with care when nurses also communicated through touch, hugs, facial expressions and being present. Similar findings have been reported in other research, in which nurses were highly important communicators (Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2012; Wong, Liamputtong, Koch, & Rawson, 2015). A qualitative descriptive study found good communication involves both verbal and nonverbal skills, "and these are as important and fundamental to family-centred care and effective communication as what is communicated" (Bloomer et al., 2016, p. 7). A recent Australian qualitative study found families' needs regarding communication to centre on: (1) access to information; (2) method of delivery, and; (3) supportive interactions (Wong et al., 2015).

The synthesised findings show that clinicians need to maintain an open dialogue and provide honest yet sensitive information about the seriousness of the situation to facilitate family preparedness for the impending death and the ensuing sadness, loss and grief. The ACSQHC

(2013) report that potentially preventable emotional, spiritual or physical distress can occur if EOLC does not meet the needs of families.

Communication is identified in current EOLC policy and literature as a priority of high-quality EOLC (ANZICS, 2014; ACSQHC, 2015; Curtis, Treece, et al., 2016; Neuberger et al., 2013; PCA, 2005; Truog et al., 2008). What this qualitative synthesis adds to the knowledge base is that families have dynamic and complex communication needs, and nurses may not have the required verbal and non-verbal skills to meet this need. Education and role support is needed to assist ICU nurses to learn, and incorporate into practice, very high-level communication skills (Bloomer et al., 2016). Further, these findings on communication can be used to inform the development of policy and evidence-based clinical guidelines in the future.

#### **6.4.3 Preparing the family and promoting a peaceful and family-centred death**

A key finding of this study was that families found the unpredictable nature of the dying process difficult to comprehend. Families reported their need for precise information regarding withdrawal, the dying process and death. In the event that these processes didn't proceed as expected, families experienced stress and frustration and their desire for peace at this time was not realised. Preparedness was also not facilitated. This key finding confirms findings from a recent integrative review of family preparation for treatment withdrawal, wherein a model with a central theme of equipping families through information and communication is clarified (Coombs et al., 2016). The model makes an important contribution to the evidence base, as it provides a framework to guide education and professional development for nurses regarding withdrawal of life-sustaining treatments in the ICU (Coombs et al., 2016). The North American Clinical Practice Guidelines for Support of Family in the Family-Centred Intensive Care Unit (Davidson et al., 2007) also recommend ICU staff receive training on how to assess family needs and family members' psychological distress. Further research is needed to establish the effect on families of targeted preparation for withdrawal of life-sustaining treatments and the dying process in the ICU.

In the current study families sought a predicted time of death, in reality this information is unknowable. Coombs et al. (2016) review found nurses experience difficulties in their role of information provider to families during the difficult period between the decision to withdraw



or withhold life-sustaining treatment and death of the patient. Authors reported that the type of information provided to families was informed by nurses' assessments of family need and understanding (Coombs et al., 2016). Current palliative care guidance documents assert that individualised clinical assessment is essential to meet the psychological needs of families at the end of life (Hudson et al., 2012; PCA, 2005; Truog et al., 2008). Family meetings are recognised as an effective avenue for patients, family members and clinicians to give and receive information and align goals of care in both palliative and intensive care settings (Singer et al., 2015). Earlier research suggests that proactive family meetings can align delivered care with the needs and expectations of families (Lautrette et al., 2007), reduce anxiety among bereaved family members (Singer et al., 2015) and improve family satisfaction with EOLC (Billings, 2011; Glavan et al., 2008). A number of healthcare tools are available to aid in the conduct of family meetings in the ICU (Singer et al., 2015).

The current study also identified key family needs of the dying environment, namely, to be close, to experience privacy, to have flexible and unrestricted access to the dying person, and to have accommodation made for family rituals and participation in care. When met these fundamental elements of high-quality EOLC contributed to a peaceful family-centred dying environment. This synthesised finding confirms earlier research, which identified that a family-centred approach to care is entirely appropriate during treatment withdrawal in the ICU (ACSQHC, 2015; Bloomer et al., 2016; Coombs et al., 2016; Hinkle et al., 2015). However, family-centred care is not the accepted framework for care delivery in all adult ICUs (G. K. Mitchell, 2012). Families' desire for nurses to engage with them in planning individualised care within the dying environment was made clear in the current study, and this requires stronger representation in future policy and guidance documents. The preparedness of a family is once again pertinent here, since observing the physical signs and symptoms of the dying patient can cause stress and may be associated with suffering (Kirchhoff, Conradt, & Reddy Anumandla, 2003). Where nurses make assessments about family needs in the ICU and allowed this to inform the withdrawal process, a family-centred approach to care is facilitated (Coombs et al., 2016).

The synthesised findings add to the knowledge base that when families are adequately prepared for the withdrawal of life-sustaining treatment, the dying process and death with effective individualised assessment and communication, a family-centred model of care can

be facilitated. As was identified in the previous synthesised finding (see section 6.4.2), education and training is needed to support nurses to develop high-level communication skills. Further, a peaceful family-centred death can be achieved when key family needs relating to the dying environment are incorporated into care.

#### **6.4.4 Family-centred support and care**

Families in this qualitative synthesis derived considerable support from nurses through their constant reassuring presence. Key aspects of nursing care and support were reported to include advocacy, communication, trust and rapport, empathy, respect and, most importantly, compassion. Those who perceived their emotional, spiritual and practical needs were met reported satisfaction with this care. The synthesised findings support findings from a seminal work, which identified that the needs of families of critically ill ICU patients were most often fulfilled by nurses, in particular emotional support (Molter, 1979). Emotional support and addressing information needs for caregivers is considered to be a critical element of social support, as identified in EOLC research (Hudson, 2003). Relating this to the current study findings, ICU nurses can be considered to be well placed to facilitate social, emotional and informational support (Hudson, 2003).

The information, support and communication needs of families reported in the current study suggest that a family-centred model of care contributes to feelings of preparedness. Family-centred care recognises the essential role that families play and has been defined as:

... An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families... that [acknowledges] emotional, social, and developmental support are integral components of health care... [and] promotes the health and well-being of individuals and families and restores dignity and control to them (Institute for Patient- and Family-Centred Care, 2010).

This definition embodies the essence of the synthesised findings and should be adapted by clinicians to guide care of dying patient in the ICU. In this qualitative synthesis the support

and care expected of nurses was integral to the delivery of family-centred EOLC, and nurses are ideally situated to bridge the gap between families and other members of the multidisciplinary team.

Families felt prepared for the impending death, and their sadness, loss and grief when nursing care met expectations, however this was not always experienced. The reason for this is unclear. Basic care needs are mandated within professional standards defining the practice and behaviour required for nursing registration in the UK, North America and Australia (American Nurses Association, 2015; Nursing and Midwifery Board of Australia, 2016; Nursing and Midwifery Council, 2015) and also by the International Council of Nurses (International Council of Nurses, 2012). An influencing factor may be the educational qualifications and experience of ICU nurses.

A recent review of critical care nursing education and practice standards in North America, the UK, New Zealand and Australia identified variation in the practice and educational requirements of a critical care qualification (Gill, Leslie, Grech, & Latour, 2012). Governing bodies in the UK require 25% of nurses to hold a critical care qualification, while North America has no recommended minimum requirement (Gill et al., 2012). In Australia and New Zealand, at least 50% of nurses providing ICU patient care must hold a critical care qualification and the remaining 50% must be in pursuit of one (Australian College of Critical Care Nurses, 2016).

Postgraduate nursing degrees in Australia have been identified as inadequate to prepare nurses to care for the dying patient and their family (Bloomer et al., 2012; Parish et al., 2006; Pincombe, Brown, & McCutcheon, 2003). One study demonstrated a link between survival in neonatal care for very low birth weight infants ( $n = 2585$ ) and the proportion of nurses with specialist neonatal qualifications (Hamilton, Redshaw, & Tarnow-Mordi, 2007). Although outside the adult ICU setting, this study suggests that the expertise of specialist registered nurses improves outcome. The findings of a small Australian study of 220 ICU nurses found a link between a nurse's level of education and experience and the self-reported quality of EOLC delivered in the ICU (Rattu, 2013). It would be useful to compare the recently released Workforce Standards for Intensive Care Nursing (Australian College of Critical Care Nurses, 2016) to the findings of an Australasian study that examines families' experiences and

perceptions of the EOLC delivered in the ICU setting, to determine if expertise impacts on the quality of care delivered. This remains a gap in the current literature.

Consistency in the content of critical care postgraduate courses is required to prepare nurses to care for the dying patient in a family-centred model of care. Further, as in Australia and New Zealand (Australian College of Critical Care Nurses, 2016), governing bodies should mandate minimum levels of qualified nurses working in critical care areas, which improve the quality of care delivered to the dying in ICU, although further research is needed in this area. What the current study adds to the knowledge base is that when nurses align care and support with the values, needs and wishes of families during EOLC, families feel prepared for the impending death, their sadness, loss and grief and this can facilitate a family-centred model of care. A family-centred model of care can facilitate high-quality EOLC in the ICU, and this can be used to inform the development of policy, evidence-based clinical guidelines and also training and education resources.

#### **6.4.5 Bereavement care**

The final synthesised finding is bereavement care. Broadly, families had unmet needs in this area, and the findings strongly suggest a need for nurses to provide further bereavement support to families. An exploratory cross-sectional survey conducted in the ICU setting had similar findings, authors reporting that 35% of family members wished for follow-up bereavement services (van der Klink et al., 2010). The World Health Organisation (2002) supports a focus on enhancing families' quality of life during bereavement. Despite national and international guidance providing recommendations for bereavement care as part of high-quality family-centred EOLC in all healthcare settings, specific details on what comprises bereavement care and who should deliver it in practice is lacking (ACSQHC, 2015; Neuberger et al., 2013; PCA, 2005; Truog et al., 2008). Critical care societies have identified bereavement support as a clinical and research priority (ANZICS, 2014; Davidson et al., 2007; Truog et al., 2008). In particular, the ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill (2014) provides recommendations and process detail on all elements of bereavement support and post-hospital follow-up as identified by families in this qualitative synthesis. Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients (Hudson et al., 2012) provide similar detailed recommendations for bereavement care, many of which can be applied in ICU settings, in

particular that each family should have a customised bereavement care plan. It is recommended that these documents (ANZICS, 2014; Hudson et al., 2012) are used as they were intended, as frameworks to guide the development of local policy, which consider “organisation and legal issues, as well as religious, ethnic, cultural diversity” (ANZICS, 2014, p. 6).

A unique aspect of the guidelines by Hudson et al. (2012) that the ANZICS Statement does not address, is the link between preparedness and bereavement care. The current study findings confirm the palliative care guidelines that acknowledge the importance of family preparedness, including: (1) assisting the family to recognise death; (2) assess the family’s preparedness for death, and (3) determining the type of support the family may need when death is imminent and immediately after (Hudson et al., 2012). The palliative care guidelines make an important contribution to the evidence base, as they provide a framework to guide the establishment of preparedness in families. These guidelines should be considered to support policy and guideline development for ICU setting in the future.

This study adds evidence to the existing knowledge base regarding families’ unmet needs for bereavement care in the ICU. Recent critical and palliative care guidance documents can be used to as a framework to develop local policy, which acknowledges the importance of preparedness, to inform guideline and policy development and evidence-based clinical practice in the future.

In the next section, key aspects of preparedness will be discussed in relation relevant literature.

#### **6.4.6 A conceptualisation of preparedness in the ICU**

The concept of preparedness was established from the findings of this qualitative synthesis, and describes the circumstance in which families can manage, in the best way possible for them, death, and the sadness, loss and grief experienced during EOLC in the ICU.

Preparedness is reliant on effective communication between families and clinicians. Families in this qualitative synthesis often felt unprepared as a result of the communication, support and care they received, and experienced heightened grief, anxiety and stress.

The concept of preparedness is well described in palliative care literature. Preparedness is defined as “something done before a crisis to improve the response” (Henriksson et al., 2015, p. 534), or “the degree to which a caregiver is ready for death” (Hebert, Schulz, Copeland, & Arnold, 2009, p. 1165). Studies in palliative care settings show that family carers who experience preparedness tend to have more favourable experiences, in particular with relation to their health and wellbeing during the caregiving experience (Funk et al., 2010; Hudson, 2003; Schumacher, Barbara, & Archbold, 2007). No studies have directly examined the association between the preparedness of family members and manifestations of grief during EOLC in the ICU. Nevertheless, earlier palliative care research confirms that bereaved caregivers who feel insufficiently prepared for their caregiver role and the anticipated death are less satisfied and experience poor mental health (Funk et al., 2010; Hebert, Dang, & Schulz, 2006; Hebert et al., 2009; McNamara & Rosenwax, 2007).

Symptoms of depression, sadness and anger are normal manifestations of grief expected in bereaved family members, which usually resolve within six months (Downar, Barua, & Sinuff, 2014). Complicated grief is defined as a syndrome of grief manifestations persisting for greater than six months after bereavement (Downar et al., 2014; Kentish-Barnes et al., 2015). In a prospective, observational study, timely treatment withdrawal, psychological support, effective communication, and bereavement care were reported to have significant association with decreased complicated grief symptoms up to one year after a death in the ICU (Kentish-Barnes et al., 2015). Effective communication occurred when the family: (1) understood that death was imminent; (2) had an opportunity to say goodbye; and (3) were allowed to witness death (Kentish-Barnes et al., 2015). These findings support the idea that when a family member feels unprepared, they may experience a prolonged emotional response to grief, or intensified psychological fragility, as identified in the findings of this qualitative synthesis. The connection between effective communication and the establishment of preparedness identified in the current study are also confirmed by Kentish-Barnes et al. (2015) findings.

Instruments to measure preparedness in community and home-based palliative care settings have been evaluated (Henriksson et al., 2015). However, there is no instrument that measures the preparedness of family members for EOLC in the ICU. The Quality of Death and Dying (QODD) questionnaire is considered the most reliable validated measure of the quality of

death and dying and has been used widely to evaluate the experiences of bereaved families in ICU settings (Glavan et al., 2008; Long et al., 2014; Mayland, Williams, & Ellershaw, 2008; Mularsky, Heine, Osborne, Ganzini, & Curtis, 2005; Osborn et al., 2012). A recent landmark study resulted in the development and validation of a new instrument, CAESAR, a 15-item questionnaire designed specifically to assess the EOLC experience of relatives of patients who die in the ICU (Kentish-Barnes et al., 2016). Kentish-Barnes et al. (2016) suggest that the CAESAR scale complements the QODD questionnaire; however others disagree and suggest that both questionnaires are limited (Curtis, Downey, & Engelberg, 2013; Downey, Curtis, Lafferty, Herting, & Engelberg, 2010; Gerritsen et al., 2013; Wall, Engelberg, Downey, Heyland, & Curtis, 2007). There is a need for further development and testing of instruments that measure preparedness and the quality of EOLC in the ICU.

Current EOLC guidelines provide little direction for clinicians on which components of EOLC contribute to a state of preparedness in order to best prepare family members for grief and bereavement in ICU (ACSQHC, 2015; Davidson et al., 2007; Downar et al., 2016; NICE, 2015; Neuberger, 2003; Sprung et al., 2014; Truog et al., 2008). In a seminal work by Lazarus and Folkman (1984), the transactional stress and coping framework was proposed. This framework has been broadly cited and promoted in palliative care family caregiver research (Hudson, 2003; Kinsella, Cooper, & Picton, 2000; Wilborn-Lee, 2015; Yates & Stetz, 1999), and used to inform intervention development for family caregivers in palliative care settings (Hudson, 2003). Hudson (2003) explored key variables, including preparedness, to further explain responses to the family caregiver experience for intervention development. Drawing on the work of Lazarus and Folkman (1984), the model of care for the delivery of high-quality family-centred EOLC in the ICU developed to explain the key findings of this qualitative synthesis (see Figure 6) could be used to support the future development of interventions targeting families' needs during EOLC.

The synthesised findings show that when preparedness is established, a unique combination of care and support from clinicians is required. This uniqueness extends to the needs, values and wishes of families during EOLC in the ICU setting. In home based palliative and hospice settings, preparedness relates to the caregivers capacity to deliver direct physical and emotional care to the dying person (Henriksson et al., 2015). Further, family and caregivers in these settings are usually aware that the recipient of care is dying. Preparedness in the ICU

describes the circumstances in which families can manage, in the best way possible for them, death, and the sadness, loss and grief experienced during EOLC in the ICU. Furthermore, families in this setting are reliant on clinicians, particularly nurses, to provide care and support that reinforces the establishment of preparedness. The reality of a sudden death can evoke overwhelming shock, emotional distress and helplessness in a family member, a scenario quite often observed in the ICU, a setting where the usual approach to care is curative (Worden, 2009). In this setting, it is not always possible to facilitate the thorough preparation for death that is encouraged in palliative care settings (Bloomer, Lee, et al., 2010; Trankle, 2014). Thus, EOLC in the ICU needs to be appropriately planned and implemented, with specific guidelines based on the best available evidence.

In ICU, family members are optimally positioned to identify key components of care at the end of life, however their views and needs are under-represented in current guidance documents. Therefore, the experiences and perceptions of patients' families of EOLC reported in this qualitative synthesis will provide policy-makers, clinicians and researchers with robust evidence to: (1) inform the development of future policy and evidence-based clinical guidelines; (2) promote quality and consistency of EOLC delivery, and; (3) assist with optimising the EOLC experiences of the patient's family in the ICU. The proposed conceptual model (see Figure 6) can be used as a framework to inform policy and guideline development, clinical decision-making and guide practice in the future. The findings of this qualitative synthesis need to be seen in reference to methodological strengths as well as limitations, presented in the next section.

## **6.5 Strengths and limitations**

This qualitative synthesis was undertaken using meta-aggregation and thematic analysis. The following processes can be considered strengths of the chosen approach:

1. An exhaustive search strategy was used with guidance from Bates' Model of Berry picking to maximise recall and sensitivity (see sections 4.3 and 4.4). Both subject and broad-based terms across a range of electronic databases were used to overcome the inconsistent indexing of qualitative studies in online databases (Barroso et al., 2003; Bates, 1989; Flemming & Briggs, 2007). This ensured that most relevant papers were identified, and contributed to the dependability and transferability of the



synthesised findings (see section 4.10.4 and 4.10.4). Two studies were later identified, that were missed by the primary search strategy.

2. Thematic analysis (Boyatzis, 1998; Thomas & Harden, 2008) provided comprehensive detail on line-by-line coding, developing themes and constant comparative techniques used to analyse and synthesise data during the analysis (see section 4.8). The resultant synthesis was richer and more in-depth, than a synthesis using meta-aggregation alone, allowing translation into a theoretical model for practice (see Figure 6). This technique contributed to dependability and confirmability during the synthesis process (see sections 4.10.2 and 4.10.3).
3. ENTREQ reporting guidelines were followed in the reporting of this qualitative synthesis (Tong et al., 2012). This strength has contributed to dependability in the conduct of this qualitative synthesis (see section 4.10.2), as comprehensive reporting adds transparency and may increase the likelihood that it will be used to influence future healthcare research, policy and practice (France et al., 2014; D. Moher et al., 2009);
4. A pilot extraction was undertaken, and a secondary reviewer was consulted during difficult data decisions. This contributed to the credibility and transferability of the research methods (see section 4.10.1 and 4.10.4).

ConQual was used to establish confidence in the synthesised findings; however the output of this technique was not felt to enhance the conduct of this qualitative synthesis, thus is considered a limitation. The following experiences can be reported:

1. The procedures were difficult to follow due to a lack of detail;
2. The ConQual calculations rely on the results of quality appraisal and the evaluation of findings via the application of a level of credibility. These are debated processes in qualitative synthesis (see sections 4.3 and 4.8.3). These calculations are also based on averages. For example, if ten studies provide data on a phenomenon, and not all are considered dependable or credible, that synthesised finding may still be downgraded;
3. The output of ConQual (see Table 6) reflects an attempt to quantify and rate the findings of a qualitative synthesis, which may skew the readers' understanding of the usefulness of the results. For example, the quality of a synthesised finding is

downgraded for dependability based on selected critical appraisal items (see section 4.9).

The JBI v5.0 computer software is intended to facilitate a systematic process during data extraction and subsequent analysis. However, due to its limited compatibility with syntax and punctuation marks, the online module required the manual input of all data and did not allow the reviewer to copy and paste text directly. Furthermore, the online module did not allow the reviewer to input codes during the data extraction phase of the analysis. For these reasons the computer software was ceased during data analysis (see section 4.8). Future versions of this software would benefit from a copy and paste function.

Potential methodological limitations of this qualitative synthesis include aspects of the inclusion/exclusion criteria, which are discussed below. Language restrictions may be considered a limitation for two reasons: (1) the synthesised findings may not be transferable to ICU settings where cultural contexts may differ; and (2) important studies printed in other languages may have been missed. Two non-English Thai studies (Aramrom, 2007; Aramrom et al., 2009) were excluded (see section 5.2), however included papers were conducted in the UK, USA, Netherlands, Thailand and South Africa providing rich and diverse data from many different cultures and healthcare models with sufficient scope to address the aim of this qualitative synthesis. Also, language limitations were not applied to the search strategy, which increases confidence that no non-English papers were missed.

Another limitation was that quantitative studies, such as surveys were excluded. Such studies may also provide insights into families' experience of EOLC in the ICU. However, as discussed in Chapter 2 (see section 2.3), quantitative studies exploring factors associated with family satisfaction with EOLC in the ICU have already been synthesised (Hinkle et al., 2015). In addition, this qualitative synthesis did not synthesise the views of other key stakeholders, for example nurses, physicians or patients, which have the potential to deepen understanding of EOLC in the ICU and of offering another perspective. The next section presents recommendations for future research based on research gaps identified by the synthesis.

Potential shortcomings of the included papers were discussed in Chapter 5 (section 5.3 and 5.4). Quality appraisal revealed variable study quality (see section 5.4). As an additional

measure of authenticity (see section 4.10.1) a level of credibility was assigned to each finding at the point of extraction to demonstrate the congruency between the primary author's interpretation and the supporting data, and no included data was deemed unsupported (see Table 4 and Table 7). The 13 included studies provided valuable insights with sufficiently rich scope and depth to contribute to the synthesis aims. The next section presents recommendations for future research.

## **6.6 Recommendations for future research**

Drawing on the synthesised findings, and through consideration of the broader research literature, several recommendations for future research are made that will address the most pertinent research gaps and help to inform policy and practice:

1. No study has been conducted in Australasia that captures the experiences and perceptions of patients' families on this phenomenon. An Australasian, qualitative, multi-centre investigation would provide robust experiential data on family's needs in relation to EOLC in the ICU. This study will assist researchers, clinicians and policy-makers in this geographical location to understand what families need to feel adequately prepared for death, sadness, loss and grief during EOLC in the ICU;
2. A qualitative synthesis that broadens the scope of the current qualitative synthesis will add depth to the current findings. This will add valuable and relevant insight to the findings of this qualitative synthesis and provide a more holistic view of the barriers and facilitators associated with the delivery of care in this context. This could be achieved by including the experiences and perceptions of:
  - Family members of ICU patients who survived EOLC and/or critical illness;
  - Patients who survived critical illness;
  - Family members of patients who died in the ICU where withdrawal of life-sustaining treatment is not explicit, and;
  - Clinicians involved in delivering EOLC in the ICU;
3. A randomised controlled trial of preparedness is warranted. Participants in the intervention arm of the trial (families of patients receiving EOLC in the ICU) would receive a communication and bereavement care package, while the control group would receive normal care. A secondary outcome of this study would be an evaluation

of the CAESER and QODD questionnaires as measures of the death and dying experience of families.

The next section presents recommendations for policy and practice.

## **6.7 Recommendations for policy, training and practice**

Drawing on the synthesised findings several recommendations are provided that focus on the importance of aligning the quality of EOLC with the values and needs of families in the ICU. These recommendations focus on creating a culture of care that supports preparedness and the delivery of high-quality family-centred EOLC in the ICU.

First, the roles and responsibilities of all members of the healthcare team should be clearly outlined by national governing critical care nursing/medical agencies in order to define a standardised level of care. It is recommended that these roles and responsibilities:

1. Be defined to suit the individual nature and structure of each healthcare system;
2. Reflect the needs of families;
3. Promote a family-centred framework for healthcare delivery;
4. Be mandated as an extension of the basic standards of care set out by registration bodies and governing agencies, to encourage translation into practice and dissemination to clinicians.

Second, EOLC in the ICU is highly contextual. Generic guidelines such as the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care (ACSQHC, 2015) are not sufficient to support EOLC practice in the ICU, as they do not address the specialised nature of care that is required to meet the needs of patients and their families in this setting. Healthcare facilities need to be appropriately resourced in order for changes to meet defined standards of care, inclusive of the following recommendations:

1. A practice standard on the delivery of EOLC in the ICU should be developed alongside key performance indicators, and mandated by registration bodies and governing critical care nursing/medicine agencies. This document could be developed as an extension of the ANZICS Statement on Care and Decision-Making at the End of Life for the Critically Ill (ANZICS, 2014) to Include: (1) roles and responsibilities of

each member of the healthcare team; and (2) guidance on how to establish preparedness in family members for the withdrawal of life-sustaining treatment, the dying process, grief and bereavement;

2. Extension of the National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care (ACSQHC, 2015) to include guidance on how to establish preparedness in family members for the withdrawal of life-sustaining treatment, the dying process, grief and bereavement;
3. Mandated integration of specialised content into undergraduate nursing degrees, which include:
  - Registration based competencies and curricular-based education in caring for the dying person and their family, including effective end of life communication and bereavement care;
  - Communication tools to facilitate effective communication in high stress scenarios as a basic minimum standard for undergraduate nurses;
4. Specialist critical care postgraduate degrees should, as a minimum, provide nurses with knowledge and skills relating to EOLC, specifically how to:
  - Prepare the dying person and their family for withdrawal of life-sustaining treatment, the dying process, grief and bereavement;
  - Care for the dying patient in a family-centred model of care;
  - Promote a peaceful death;
  - Communicate effectively and compassionately with the patient and the family about end-of-life issues;
  - Assess physical, psychosocial, social, and spiritual needs and provide individualised support and care to the grieving family, including bereavement care.

## **6.8 Conclusion**

The contribution of this research to existing knowledge lies in the provision of robust evidence on understanding the elements of high-quality family-centred EOLC in the ICU. Most valuable is new knowledge on how these key components of care can contribute to a state of preparedness in families. Important gaps in policy, practice and research have also been identified. This study was timely because numerous frameworks, position statements,

recommendations, quality measures and strategies were developed in Australia, the UK and North America to guide the overall delivery of EOLC without the support of a robust evidence base. The findings of this qualitative synthesis offer a complementary medium to fill the gaps apparent in these documents, specifically the under-representation of families' experiences and perceptions, which can be used for the future development of policy, guidelines and a framework for practice.

If core components of care are in place, preparedness can be facilitated, families can be equipped to manage, in the best way possible for them, the death, sadness, loss and grief. This may result in perceptions of satisfaction with EOLC delivery in the ICU. A conceptual model of preparedness for the delivery of high-quality family-centred EOLC in the ICU will assist clinicians to target areas for improvement in practice. A change in current practice standards is needed to address inconsistencies and deficiencies in clinical practice. Clinicians will need support and education to re-conceptualise their practice towards family-centred EOLC, which supports the values, needs and wishes of families in the ICU. A family-centred model of care is also recommended to support the delivery of high-quality EOLC that supports the values, needs and wishes of families in the ICU.

In summary, families have unmet needs for communication, support and care and bereavement care, reflecting a lack in some cases of a family-centred model of care. If a state of preparedness can be established in families, this will contribute to a peaceful family-centred death and in family member satisfaction with EOLC. The study found that an individualised approach to EOLC is necessary to meet the diverse needs of each family, and that nurses are optimally positioned to provide this care. Thus, there is an opportunity for healthcare teams, and particularly nurses, to align support and care with the values, needs and wishes of individual families during EOLC in the ICU.

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## **Appendix A: Detailed Search Strategy**

### ***CINAHL complete (EBSCO)***

#1 (MH "intensive care units") OR (MH "critical care") OR (MH "critical care nursing")

**AND**

#2 (MH "significant other") OR (MH "family") OR (MH "family attitudes") OR (MH "visitors to patients") OR (MH "extended family") OR (MH "caregivers") OR (MH "spouses") OR (MH "patient-family relations")

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying")

### ***MEDLINE (EBSCO)***

#1 ("intensive care units" OR "critical care" OR "intensive care")

**AND**

#2 ("family" OR "visitors to patients" OR "family relations" OR "spouses" OR "caregivers" OR "patient-family relations")

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

***Health Source – Nursing/Academic Edition (EBSCO)***

#1 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying")

**AND**

#2 ("Significant Others" OR "SPOUSES" OR "EXTENDED-families" OR "CAREGIVERS-attitudes" OR "CAREGIVERS" OR "Families" OR "PATIENT-family relations")

**AND**

#3 ("Intensive Care Units" OR "critical care medicine" OR "Intensive Care Nursing" OR "NEUROLOGICAL intensive care" OR "CARDIAC intensive care" OR "CRITICAL care medicine -- Social aspects")

***Academic Search Complete (EBSCO)***

#1 SU ("Intensive Care Units" OR "critical care medicine" OR "Intensive Care Nursing" OR "NEUROLOGICAL intensive care" OR "CARDIAC intensive care" OR "CRITICAL care medicine -- Social aspects")

**AND**

SU ("Significant Others" OR "SPOUSES" OR "EXTENDED-families" OR "CAREGIVERS-attitudes" OR "CAREGIVERS" OR "Families" OR "PATIENT-family relations")

**AND**

("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying")

***Health Collection (Informit)***

#1 SUBJECT ("Critical care medicine" OR "Intensive care nursing" OR "Intensive care units")

**AND**

#2 SUBJECT ("Caregivers" OR "Caregivers--Attitudes" OR "Caregivers--Family relationships" OR "Caregivers--Psychological aspects" OR "Families" OR "Families--Attitudes" OR "Families--Psychological aspects" OR "Family" OR "Spouses" OR "Spouses--Death" OR "Spouses--Death--Psychological aspects")

**AND**

#3 "end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life"

### ***CareSearch***

Main Page> Clinical Evidence>Patient Management>EOLC (17 articles in a reference list including systematic reviews to review)

Main Page> Clinical Evidence>Patient Management>EOLC> Patient and Family experience of receiving EOLC (6 guidelines, 1 overview article, 13 articles in a reference list including systematic reviews to review: total 20)

Main Page> Clinical Evidence>Patient Management>EOLC>EOLC in different settings & EOLC pathways (5 guidelines, 2 overview articles, 20 reference list)

Main Page> Clinical Evidence>Patient Management>Principles of good EOLC (3 guidelines, 15 in reference list)

### ***CareSearch GREY LITERATURE Database***

#1 ("ICU" OR "intensive care" OR "critical care")

**AND**

#2 ("end-of-life" OR "end of life" OR "EOLC" OR "EOL" OR "withhold" OR "withheld" OR "withdraw" OR "life sustain" OR "life support" OR "euthanasia" OR "terminal" OR "palliative" OR "palliate" OR "death" OR "dying")

***British Nursing Index (ProQuest)***

#1 (SU.EXACT("Intensive Care") OR SU.EXACT("Intensive Care Nursing"))

**AND**

#2 (SU.EXACT("Family") OR SU.EXACT("Nurse Patient Relations") OR SU.EXACT("Carers"))

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

***ProQuest Central (ProQuest)***

#1 su(Intensive Care OR "Critical Care" OR "Intensive Care Units" OR "Intensive Care" OR "Critical Care")

**AND**

#2 su(Caregivers OR "Families & family life" OR "Spouses" OR "Visitors to Patients" OR "Family" OR "Caregivers" OR "Family Relations")

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

***PsychINFO (Ovid)***

#1 (intensive care).sh.

**AND**

#2 (significant others OR family OR spouses OR caregivers OR extended family OR family relations OR family members).sh.

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life").af.

***Journals@Ovid***

#1 ("ICU" or "intensive ADj2 care" or "critical ADj2 care").ti,ab.

**AND**

#2 ("significant ADj2 other\*" or "loved ADj2 one\*" or "famil\*" or "spous\*" or "caregiver\*" or "carer\*").ti,ab.

**AND**

#3 ("end-of-life" or "end-of-life-care" or "withh\*" or "withdr\*" or "life ADj2 sustain\*" or "life ADj2 support" or "terminal\*" or "palliat\*" or "end ADj1 of ADj1 life" or "EOLC" or "EOL" or "death" or "dying").ti,ab.

***AMED (EBSCO)***

#1 SU ( intensive care OR critical care )

**AND**

#2 SU ( family OR spouses OR caregivers OR family relations )

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life" )

***Mednar (EBSCO)***

#1 ("ICU" OR "intensive care")

**AND**

#2 (Keyword "end-of-life" OR "end-of-life-care" OR "end of life" OR "EOLC" OR "EOL" AND "intensive care" OR "ICU")

***ProQuest Dissertations & Thesis Database (ProQuest)***

#1 su(Intensive Care OR "Critical Care" OR "Intensive Care Units" OR "Intensive Care" OR "Critical Care")

**AND**

#2 su(Caregivers OR "Families & family life" OR "Spouses" OR "Visitors to Patients" OR "Family" OR "Caregivers" OR "Family Relations")

**AND**

#3 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

***Australian Digital Thesis program***

#1 subject:("ICU" OR "intensive care")

**AND**

#2 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

### ***EThOS***

#1 free text:("intensive care")

**AND**

#2 ("end-of-life" OR "end-of-life-care" OR "withh\*" OR "withdr\*" OR "life sustain\*" OR "life support" OR "euthanasia" OR "terminal\*" OR "palliat\*" OR "end of life" OR "EOLC" OR "EOL" OR "death" OR "dying" OR "end of life")

### ***The Joanna Briggs Institute***

#1 intensive care

**AND**

#2 end of life

### ***Cochrane***

#1 "intensive care units" OR "intensive care" OR "critical care"

**AND**

#2 "spouse" OR "caregivers" OR "family relations" OR "family" OR "visitors to patients"

**AND**

#3 "end-of-life-care" or "end-of-life" or "withh\*" or "withdr\*" or "life sustain" or "euthanasia" or "terminal\*" or "palliat\*" or "end of life" or "EOLC" or "EOL" or "death" or "dying":ti,ab,kw



## **Appendix B: Expert Author Search Strategy CINAHL**

#1 AU("Pattison, Natalie A." OR "Pattison, N." OR "Pattison, Natalie" OR "Pattison, N. A.")

**OR**

#2 AU("Fridh, I." OR "Fridh, Isabell")

**OR**

#3 AU("Levy, M." OR "Levy, M. M." OR "Levy, Mitchell M." OR "Levy, M.")

**OR**

#4 AU("Wiegand, D." OR "Wiegand, D. L." OR "Wiegand, Debra L." OR "Wiegand, Debra Lyn-McHale")

**OR**

#5 AU("Kociszewski, C." OR "Kociszewski, C. E." OR "Kociszewski, Cynthia E.")

**OR**

#6 AU("Lloyd-Williams, M." OR "Lloyd-Williams, Mari")

**OR**

#7 AU ("Azoulay, E." OR "Azoulay, Elie")

**OR**

#8 AU("Lautrette, Alexandre" OR "Lautrette, A.")

**OR**

#9 ("Ellershaw, J." OR "Ellershaw, J. E." OR "Ellershaw, John E." OR "Ellershaw, John")

**OR**

#10 AU(“Kirchhoff, K. T.” OR “Kirchhoff, Karin T.” OR “Kirchhoff, Karin” OR “Kirchhoff, K.”)

**OR**

#11 AU(“Curtis, J. R.” OR “Curtis, J. Randall” OR “Curtis, J.”)

**OR**

#12 AU(“Mularski, R. A.” OR “Mularski, Richard A.” OR “Mularski, Richard” OR “Mularski, R.”)

**OR**

#13 AU(“Truog, Robert D.” OR “Truog, R. D.”)

## Appendix C: JBI Critical Appraisal Tool for Qualitative Research

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice- versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Note.* Reproduced from The Joanna Briggs Institute Critical Appraisal tools for use in JBI Systematic Reviews, Checklist for Qualitative Research (The Joanna Briggs Institute, 2016).

### Appendix D: Summary of Included Studies

Author(s), year, country	Design	Study aims	Participants	Design: data collection and analysis	Key findings
<b>Coombs et al. (2015)</b> <b>UK</b>	Interpretive qualitative	The experiences and needs of bereaved families during and after treatment withdrawal in the adult ICU.	Family members of deceased patients who received EOLC ( $n = 21$ )	Interview  Thematic analysis using a phenomenological iterative analysis approach	Three themes emerged: (1) alleviating further suffering; (2) re-establishing identity, and; (3) re-connecting with relationships.
<b>Fridh et al. (2009)</b> <b>Sweden</b>	Hermeneutic phenomenology	Close relatives' experiences of caring and the physical environment when a loved one dies in an ICU.	Close relatives who had been present in connection with the illness and death of 15 patients in ICU.  ( $n = 17$ )	Interview  Hermeneutic phenomenology inspired by Ricoeur (1976, 1992) and developed by Lindseth and Norberg (2004)	Seven themes emerged: (1) being confronted with the threat of loss; (2) maintaining a vigil; (3) trusting the care; (4) adapting and trying to understand; (5) facing death; (6) the need for privacy and togetherness, and; (7) experiencing reconciliation. The experience of a caring relationship was central, which the authors labelled as 'piloted' Vs. 'not being piloted'.
<b>Kisorio &amp; Langley (2016)</b> <b>South Africa</b>	Descriptive exploratory qualitative	Family members' experiences of end-of-life care in adult intensive care units.	Family members who had an adult relative in the ICU receiving EOLC ( $n = 17$ )	Interview  Tesch's (1990) steps of analysis	Five themes emerged: (1) most of the time we are in darkness; (2) emotional support; (3) involvement; (4) family presence; and (5) spiritual support. The findings appear to reflect less than adequate care to the families who had a relative at end-of-life, where the negatives far outweighed the positive.
<b>Kociszewski (2005)</b> <b>USA</b>	Descriptive phenomenology	The families lived experience of ICU bereavement.	Bereaved family members of ICU patients. 5 mothers, 3 fathers, 1 ex-husband, 1 sister and 1 fiancé.  ( $n = 13$ )	Interview  Descriptive phenomenology (Colaizzi, 1978)	Seven themes emerged: (1) shock and inertia; (2) all one's senses shut down, family institutions of foreboding; (3) hope as a driving force; (4) families' assessment and changing expectations; (5) the agony of decision-making; (6) a surreal death, and; (7) lingering memories. Professionals caring and uncaring behaviours profoundly affected these families' ICU bereavement experiences. A mid-range theory for compassionate

					communication between nurses and families in the ICU is proposed.
<b>Kongsuwan et al. (2011)</b> <b>Thailand</b>	Hermeneutic phenomenology	The meaning of Thai Buddhists' lived experiences caring for family members who died a peaceful death in ICUs.	Family caregivers who were Thai Buddhists, the main caregiver and believed that the patient had a peaceful death. ( <i>n</i> = 9)	Interview  Hermeneutic phenomenology (Van Manen's, 1990)	Nine themes structured the experiences and were reflected within the four lived worlds of rationality, corporeality, temporality and spatiality. The participants struggled when making decisions about their family member's life in the context of changing hope. Feelings of stress and exhaustion were common. Participants' valued empathetic understanding as a means for maintaining relationships with others in giving and receiving compassionate care. Caring for the self in order to give mindful care and doing one's best in the moment also significantly contributed to achieving a peaceful death.
<b>Lloyd-Williams et al. (2009)</b> <b>England</b>	Unknown qualitative	This paper focuses on the perceived palliative care needs of relatives of patients who died of brain death in the ICU.	Relatives of patients who died of brain death in the ICU ( <i>n</i> = 29)	Interview  Grounded theory (Strauss & Corbin, 1998)	Participants valued the physical care their relatives had received, but communication and breaking bad news was a cause for concern. The facilities on many ICUs, for example, cramped relatives' rooms and little privacy to be with the patients or to say the final goodbye, was a common theme to emerge. Bereavement follow-up did not routinely occur, and this was an identified factor noted by relatives.
<b>Nelson et al. (2010)</b> <b>USA</b>	Unknown qualitative	Ask important 'Stakeholders' (surviving patients, families of survivors, and families of patients who died) to define high quality Palliative Care in the ICU.	Family members of patients who died in the ICU ( <i>n</i> = 19) <sup>a</sup>	Focus groups  Qualitative; Grounded theory	A shared definition of high-quality ICU palliative care emerged; timely, clear, and compassionate communication by clinicians; clinical decision-making focused on patients' preferences, goals, and values; patient care maintaining comfort, dignity, and personhood; and family care with open access and proximity to patients, interdisciplinary support in the intensive care unit, and bereavement care for families of patients who died.

<sup>a</sup>Partial sample of relevance

<b>Pattison, N. (2011)</b> <b>UK</b>	Heideggarian phenomenology	Explore the provision of EOLC for cancer patients in a critical care unit.	Family members of patients who died after decisions to forgo life-sustaining treatment <i>(n = 12)<sup>a</sup></i>	Interview  Heideggarian phenomenological (Van Manen's coding frame and data synthesis techniques, Attride-Stirling thematic network analysis)	A continuum of dying in cancer critical illness is presented with different participants' experiences along that continuum. Three main themes included: Dual prognostication; The Meaning of Decision-Making; and Care Practices at EOL: Choreographing a Good Death.
<b>Pattison et al. (2013)</b> <b>UK</b>	Heideggarian phenomenology	To explore the meaning of end-of-life care for critically ill cancer patients at high risk of dying, bereaved families, oncologists, palliative care specialists, critical care consultants and nurses.	Bereaved family members <i>(n = 6)<sup>a</sup></i>	Interview  Phenomenology (Van Manen's analysis framework, 1990 with Attride-Stirling's thematic network analysis, 2001).	Interpretations have led to the essence of the findings: cancer critical illness as part of a continuum towards death and the pivotal and complementary roles the key players have within each stage. Nurses, in particular, had an important role in determining and enacting EOLC.
<b>Wiegand, D. (2006)</b> <b>USA</b>	Descriptive phenomenology	Describe the interactions between patients' family members, HCP, and the HCS during withdrawal of life-sustaining therapy after a sudden, unexpected illness or injury in the ICU.	Bereaved family members <i>(n = 6)</i>	Interview & observation  Inductive thematic analysis (Van Manan, 1990)	Interactions between patients' families, clinicians, and the healthcare system can greatly influence the families' experiences in participating in the process of withdrawal of life-sustaining therapy from a family member with an unexpected, life-threatening illness or injury. Understanding issues created by these interactions can help improve the process for patients' families.
<b>Wiegand, D. (2016)</b> <b>USA</b>	Hermeneutic phenomenology	Families' experiences during the process of withdrawal of life-sustaining therapy from a family member in an ICU with an unexpected, life-threatening illness or injury.	Bereaved family members <i>(n = 22)</i>	Interview  Inductive thematic analysis (Van Manan, 1990)	Six themes emerged: (1) preparing for the dying process; (2) the dying environment; (3) perceptions of patient comfort; (4) the death vigil; (5) essential aspects of care and (6) together as a family.

<sup>a</sup>Partial sample of relevance

<b>Wiegand et al. (2010)</b> <b>USA</b>	Unknown qualitative	Explore family members' perceptions of the withdrawal of life-sustaining therapy (was it a good death or a bad death?).	Family members ( <i>n</i> = 56)	Interview  Unknown inductive analysis approach	Family members defined a death as good if the patient was comfortable, the death was fast, the patient was not aware, and death was peaceful. A death was defined as bad if the patient had a prolonged hospital course with up and down periods, if death was premature, and if signs of discomfort were present. However, different members within the same family could perceive the same death as good and bad. Thus, healthcare providers should intervene to optimise the conditions that can be improved (especially symptom management) but also be aware that even optimal patient care does not preclude perceptions of a death as bad.
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## Appendix E: Summary of Excluded Studies with Reasons (*n* = 114)

Study Details	Reason for Exclusion
Adams, J. A. (2013). Family Perspectives of Nursing Strategies to Facilitate Transition from Curative to Palliative Care in the Intensive Care Unit. (Doctoral dissertation), Duke University, Ann Arbor. ProQuest Dissertations & Theses Global database.	– Not EOLC
Ågård, A. S., & Harder, I. (2007). Relatives' experiences in intensive care: Finding a place in a world of uncertainty. <i>Intensive and Critical Care Nursing</i> , 23(3), 170-177. doi:10.1016/j.iccn.2006.11.008	– Not EOLC
Al Mutair, A. (2014). Family needs and involvement in the intensive care unit in Saudi Arabia: mixed methods study (Doctoral dissertation), Monash University, Australia. Retrieved from <a href="http://arrow.monash.edu.au/vital/access/manager/Repository/monash:130379">http://arrow.monash.edu.au/vital/access/manager/Repository/monash:130379</a>	– Not EOLC
Allen, M. B., & Jesus, J. E. (2012). The language of goals of care: Framing preferences at the end of life. <i>Chest</i> , 141(4), 1126.	– Commentary
Anonymous. (2007). Guidelines help providers care for patients, families. <i>Health Care Strategic Management</i> , 25(4), 13.	– Commentary
Apatira, L., Boyd, E. A., Malvar, G., Evans, L., Luce, J., Lo, B., & White, D. B. (2008). Hope, truth, and preparing for death: perspectives of surrogate decision makers. <i>Annals of Internal Medicine</i> , 149(12), 861-868. doi:10.7326/0003-4819-149-12-200812160-00005	– Not EOLC
Anonymous. End-of-life care. (2008). <i>Psychologist</i> , 21(7), 610.	– Editorial
Aramrom, Y. (2007). Experiences of family of critically ill dying patient (Unpublished master's thesis). Prince of Songkhla University, Songkhla, Thailand. [In Thai].	– Thai language/ unable to obtain copy
Aramrom, Y., Nilmanat, K., & Chailungka, P. (2009). <i>Experiences of families whose family member were in critically dying stage in ICU [Conference Abstract Only]</i> . Paper presented at the Together! Cultural connections for quality care at the end of life, Palliative Care Australia and the Asia Pacific Hospice Palliative Care Network, Perth, Australia.	– Treatment not withheld or withdrawn



Aramrom, Y., Nilmanat, K., & Chailungka, P. (2009). Experience of family of critically ill dying patients. <i>Journal of Nursing and Health Sciences</i> , 32(4), 33-43. [In Thai].	– Thai language/ unable to obtain copy
Azoulay, E. (2005). The end-of-life family conference: Communication empowers. <i>American Journal of Respiratory and Critical Care Medicine</i> , 171(8), 803-804.	– Editorial
Baggs, J. G., Norton, S. A., Schmitt, M. H., Dombeck, M. T., Sellers, C. R., & Quinn, J. R. (2007). Intensive care unit cultures and end-of-life decision making. <i>Journal of Critical Care</i> , 22(2), 159-168. doi:10.1016/j.jcrc.2006.09.008	– Not EOLC
Bailey, J. J., Sabbagh, M., Loiselle, C. G., Boileau, J., & McVey, L. (2010). Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care. <i>Intensive and Critical Care Nursing</i> , 26(2), 114-122. doi:10.1016/j.iccn.2009.12.006	– Quantitative
Barber, K. (2008). Bereavement follow-up for families after a loved one's death in the intensive care unit. <i>Canadian Association of Critical Care Nurses</i> , 19(2), 35.	– Not EOLC
Billings, J. A. (2011). The end-of-life family meeting in intensive care part 1: Indications, outcomes, and family needs. <i>Journal of Palliative Medicine</i> , 14(9), 1042-1050.	– Literature review
Bocharov, M. V., & Kahn, J. M. (2012). New obstacles to improving the quality of end-of-life care in ICU. <i>Critical Care</i> , 16(1), 304-306.	– Commentary
Brandt, D. S., Shinkunas, L. A., Gehlbach, T. G., & Kaldjian, L. C. (2012). Understanding goals of care statements and preferences among patients and their surrogates in the medical ICU. <i>Journal of Hospice and Palliative Nursing</i> , 14(2), 126-132.	– Not EOLC
Browning, A. M. (2009). Empowering family members in end-of-life care decision making in the intensive care unit. <i>Dimensions of Critical Care Nursing</i> , 28(1), 18-23.	– Literature review
Bushinski, R. L., & Cummings, K. M. (2007). Practices of effective end-of-life communication between nurses and patients/families in two care settings. <i>Creative Nursing</i> , 13(3), 9-12.	– Nurses perspective
Byock, I. (2007). Caring well for the families of our patients. <i>Chest</i> , 132(5), 1420-1422.	– Commentary

Byock, I. (2008). PC-FACS issue 34 - February 5, 2008: Family satisfaction in the intensive care unit. <i>Journal of Palliative Medicine</i> , 11(4), 654-655.	–	Commentary
Chambers-Evans, J., & Carnevale, F. A. (2005). Dawning of awareness: The experience of surrogate decision making at the end of life. <i>Journal of Clinical Ethics</i> , 16(1), 28-45.	–	Not EOLC
Cook, D., & Rocker, G. (2007). A communication strategy and brochure reduced the burden of bereavement on relatives of patients dying in the intensive care unit. <i>ACP Journal Club</i> , 146(3), 69-69.	–	Commentary
Cox, S., Handy, J. M., & Blay, A. (2012). Palliative care in the ICU. <i>Journal of the Intensive Care Society</i> , 13(4), 320-326.	–	Literature review
Crighton, M. H., Coyne, B. M., Tate, J. M., Swigart, V., & Happ, M. B. (2008). Transitioning to end-of-life care in the intensive care unit: A case of unifying divergent desires. <i>Cancer Nursing</i> , 31(6), 478.	–	Not EOLC
Curtis, J. R., Downey, L., & Engelberg, R. A. (2013). The quality of dying and death: is it ready for use as an outcome measure? <i>Chest</i> , 143(2), 289-291. doi:10.1378/chest.12-1941	–	Not EOLC
Cutugno, C., Contillo, C., Chu, J., & Price, C. (2007). Communication at end-of-life for family members. <i>American Journal of Nursing</i> , 107(11), 72DD-72GG.	–	Commentary
Cypress, B. S. (2011). The lived ICU experience of nurses, patients and family members: A phenomenological study with Merleau-Pontian perspective. <i>Intensive and Critical Care Nursing</i> , 27(5), 273-280. doi:10.1016/j.iccn.2011.08.001	–	Not EOLC
Day, L. (2006). Family involvement in critical care: Shortcomings of a utilitarian justification. <i>American Journal of Critical Care</i> , 15(2), 223-225.	–	Literature review
Dibert, C. (2009). Families with loved ones on mechanical ventilation in the ICU found a way to face "living with dying". <i>Evidence-Based Nursing</i> , 12(3), 96.	–	Commentary
Dowling, J., Vender, J., Guilianelli, S., & Wang, B. (2005). A model of family-centered care and satisfaction predictors*: The critical care family assistance program. <i>Chest</i> , 128(3), 81S-92S.	–	Quantitative

Duong, J., Koegler, E., Peters, J., Aung, W., An, S. J., Redstone, L., & Aslakson, R. (2012). 901: Perceptions of high and low quality care in surgical intensive care units among patients and their families. <i>42nd Critical Care Congress of the Society-of-Critical-Care-Medicine, 40(12) Supplement(1)</i> , 328.	–	Not EOLC
Dy, S. M., Shugarman, L. R., Lorenz, K. A., Mularski, R. A., Lynn, J. R., & Southern California Evidence-Based Practice Center. (2008). A systematic review of satisfaction with care at the end of life. <i>Journal of the American Geriatric Society, 56(1)</i> , 124-129. doi:10.1111/j.1532-5415.2007.01507.x	–	Not ICU
Evans, L. R., Boyd, E. A., Malvar, G., Apatira, L., Luce, J. M., Lo, B., & White, D. B. (2009). Surrogate decision-makers' perspectives on discussing prognosis in the face of uncertainty. <i>American Journal of Respiratory and Critical Care Medicine, 179(1)</i> , 48-53.	–	Not EOLC
Farber, J. (2006). Compassionate care in the ICU: Creating a humane environment. <i>Geriatrics and Aging, 9(8)</i> , 589-590.	–	Not EOLC
Gallo, D., Palermo, N., Peruzzi, G., & Cassina, T. (2013). Opinion of families on end-of life (EOL) care in the ICUs. <i>SCENARIO: Official Italian Journal of ANIARTI, 30(2Sup)</i> , 45-45.	–	Quantitative
Guidelines for "end of life care". (2008). <i>Asian Biomedicine, 2(2)</i> , 89-90.	–	Not families' perspectives
Gutierrez, K. M. (2012). Experiences and needs of families regarding prognostic communication in an intensive care unit: Supporting families at the end of life. <i>Critical Care Nursing Quarterly, 35(3)</i> , 299-313. doi:10.1097/CNQ.0b013e318255ee0d	–	Not EOLC
Hallenbeck, J. (2005). Palliative care in the final days of life: "They were expecting it at any time". <i>JAMA, 293(18)</i> , 2265-2271. doi:10.1001/jama.293.18.2265	–	Not ICU
Henrich, N. J., Dodek, P., Heyland, D., Cook, D., Rocker, G., Kutsogiannis, D., & Ayas, N. (2011). Qualitative analysis of an intensive care unit family satisfaction survey. <i>Critical Care Medicine, 39(5)</i> , 1000-1005.	–	Not EOLC
Heyland, D. K., Allan, D. E., Rocker, G., Dodek, P., Pichora, D., & Gafni, A. (2009). Discussing prognosis with patients and their families near the end of life: impact on satisfaction with end-of-life care. <i>Open Medicine, 3(2)</i> , e101-110.	–	Not ICU

Hinkle, L. J., Bosslet, G. T., & Torke, A. M. (2015). Factors associated with family satisfaction with end-of-life care in the ICU: A systematic review. <i>Chest</i> , 147(1), 82-93 12p. doi:10.1378/chest.14-1098	– Quantitative systematic review
Hoban, V. (2006). Dying with dignity. <i>Nursing Times</i> , 102(22), 16-17.	– Editorial
Hoehn, K. S. (2006). Family satisfaction from clinician statements or patient-provider concordance? <i>Critical Care Medicine</i> , 34(6), 1836-1837.	– Commentary
Hoffman, L. A. (2008). A short written message: Improved satisfaction after withdrawal of life support. <i>Critical Care Alert</i> , 16(8), 57-58.	– Quantitative
Hughes, F., Bryan, K., & Robbins, I. (2005). Relatives' experiences of critical care. <i>Nursing in Critical Care</i> , 10(1), 23-30.	– Not EOLC
Ingleton, C., Gott, M., & Kirk, S. (2009). The beginning of the end (of life care strategy). <i>Journal of Clinical Nursing</i> , 18(7), 935-937. doi:10.1111/j.1365-2702.2008.02616.x	– Editorial
Jackson, A., Purkis, J., Burnham, E., Hundt, G. L., & Blaxter, L. (2010). Views of relatives, carers and staff on end of life care pathways. <i>Emergency Nurse</i> , 17(10), 22-26. doi:10.7748/en2010.03.17.10.22.c7616	– Not ICU
Jacoby, L. H., Breitkopf, C. R., & Pease, E. A. (2005). A qualitative examination of the needs of families faced with the option of organ donation. <i>Dimensions of Critical Care Nursing</i> , 24(4), 183-189.	– Not EOLC
Johansson, I., Fridlund, B., & Hildingh, C. (2005). What is supportive when an adult next-of-kin is in critical care? <i>Nursing in Critical Care</i> , 10(6), 289-298. doi:10.1111/j.1362-1017.2005.00136.x	– Not families' perspectives
Johnson, J., Engelberg, R., Nielsen, E. L., Kross, E., Smith, N., Hanada, J., ... Curtis, J. R. (2014). The Association of Spiritual Care Providers' Activities With Family Members' Satisfaction With Care After a Death in the ICU. <i>Critical Care Medicine</i> , 42(9), 1991-2000.	– Quantitative
Karlsson, C., Tisell, A., Engström, Å., & Andershed, B. (2011). Family members' satisfaction with critical care: A pilot study. <i>Nursing in Critical Care</i> , 16(1), 11-18. doi:10.1111/j.1478-5153.2010.00388.x	– Not EOLC

Kaufer, M., Murphy, P., Barker, K., & Mosenthal, A. (2008). Family satisfaction following the death of a loved one in an inner city MICU. <i>American Journal of Hospice &amp; Palliative Medicine</i> , 25(4), 318-325.	– Quantitative
Kentish-Barnes, N., & Azoulay, E. (2012). The vulnerable family. <i>Critical Care Medicine</i> , 40(5), 1667-1668.	– Commentary
Kjerulf, M., Regehr, C., Popova, S., & Baker, A. (2005). Family perceptions of end-of-life care in an urban ICU. <i>Dynamics: The Official Journal of the Canadian Association of Nurses</i> , 16(3), 22-25.	– Quantitative
Kock, M., Berntsson, C., & Bengtsson, A. (2014). A follow-up meeting post death is appreciated by family members of deceased patients. <i>Acta Anaesthesiologica Scandinavica</i> , 58(7), 891-896.	– Quantitative
Kongsuwan, W., Chaipetch, O., & Matchim, Y. (2012). Thai Buddhist families' perspective of a peaceful death in ICUs. <i>Nursing in Critical Care</i> , 17(3), 151-159. doi:10.1111/j.1478-5153.2012.00495.x	– Not EOLC
Kross, E. K., & Curtis, J. R. (2008). Burden of psychological symptoms and illness in family of critically ill patients: What is the relevance for critical care clinicians? <i>Critical Care Medicine</i> , 36(6), 1955-1956.	– Commentary
Langley, G., & Schmollgruber, S. (2006). End-of-life care in intensive care units. <i>Southern African Journal of Critical Care</i> , 22(2), 58-65.	– Not families' perspectives
Latour, J. M., & Haines, C. (2007). Families in the ICU: Do we truly consider their needs, experiences and satisfaction? <i>Nursing in Critical Care</i> , 12(4), 173-174. doi:10.1111/j.1478-5153.2007.00234.x	– Editorial
Lautrette, A. (2007). Innovations in practice: Better communication helps families handle grief. <i>RN</i> , 70(4), 18.	– Commentary
Lautrette, A. (2007). 10 extra minutes helps families cope. <i>Nursing</i> , 37(4), 34-34.	– Letter to the editor
Lautrette, A., Cioldi, M., Ksibi, H., & Azoulay, E. (2006). End-of-life family conferences: Rooted in the evidence. <i>Critical Care Medicine Improving the Quality of End-of-Life Care in the ICU</i> , 34(11), S364-S372.	– Literature review
Lederer, M. A., Goode, T., & Dowling, J. (2005). Origins and development: The Critical Care Family Assistance Program. <i>Chest</i> , 128(3), 65S-75S.	– Literature review

Levy, M. (2007). Including families in quality measurement in critical care. <i>Critical Care Medicine</i> , 35(1), 324-325.	– Editorial
Levy, M. (2007). A view from the other side. <i>Critical Care Medicine</i> , 35(2), 603-604.	– Opinion piece
Levy, M. M., & McBride, D. L. (2006). End-of-life care in the intensive care unit: State of the art in 2006. <i>Critical Care Medicine</i> , 34(11 Supplement), S306-S308.	– Literature review
Lind, R., Lorem, G. F., Nortvedt, P., & Hevrøy, O. (2011). Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions. <i>Intensive Care Medicine</i> , 37(7), 1143-1150.	– Treatment not withheld or withdrawn
Lind, R., Nortvedt, P., Lorem, G., & Hevroy, O. (2013). Family involvement in the end-of-life decisions of competent intensive care patients. <i>Nursing Ethics</i> , 20(1), 61-71. Doi:10.1177/0969733012448969	– Not EOLC
Mangram, A. J., McCauley, T., Villarreal, D., Berne, J., & et al. (2005). Families' perception of the value of timed daily "family rounds" in a trauma ICU. <i>The American Surgeon</i> , 71(10), 886-891.	– Quantitative
Mayland, C. R., Williams, E. M., & Ellershaw, J. E. (2012). Assessing quality of care for the dying: the development and initial validation of a postal self-completion questionnaire for bereaved relatives. <i>Palliative Medicine</i> , 26(7), 897-907. Doi:10.1177/0269216311424953	– Not families' perspectives
McAdam, J. L., Arai, S., & Puntillo, K. A. (2008). Unrecognized contributions of families in the intensive care unit. <i>Intensive Care Medicine</i> , 34(6), 1097-1101.	– Not families' perspectives
McKiernan, M., & McCarthy, G. (2010). Family members' lived experience in the intensive care unit: A phenomenological study. <i>Intensive and Critical Care Nursing</i> , 26(5), 254-261. Doi:10.1016/j.iccn.2010.06.004	– Not EOLC
Medina, J. (2005). A natural synergy in creating a patient-focused care environment: The critical care family assistance program and critical care nursing. <i>Chest</i> , 128(3), 99S-102S.	– Opinion piece
Meier, D. E., & Beresford, L. (2006). Palliative care/intensive care unit interface: Opportunities for mutual education. <i>Journal of Palliative Medicine</i> , 9(1), 17-20.	– Editorial

Mitchell, G. K. (2012). Facilitating better end-of-life care. <i>Medical Journal of Australia</i> , 197(2), 68-69.	– Editorial
Morrison, W. (2011). Does it help us to know what questions our patients families might want to ask? <i>Critical Care Medicine</i> , 39(6), 1572-1573.	– Editorial
Nelson, J. E., Kinjo, K., Meier, D. E., Ahmad, K., & Morrison, R. S. (2005). When critical illness becomes chronic: Informational needs of patients and families. <i>Journal of Critical Care</i> , 20(1), 79-89. Doi:10.1016/j.jcrc.2004.11.003	– Not families' perspectives
O'Mahony, S., McHenry, J., Blank, A. E., Snow, D., Karakas, S. E., Santoro, G., ... Kvetan, V. (2010). Preliminary report of the integration of a palliative care team into an intensive care unit. <i>Palliative Medicine</i> , 24(2), 154-165.	– Not EOLC
Obringer, K., Hilgenberg, C., & Booker, K. (2012). Needs of adult family members of intensive care unit patients. <i>Journal of Clinical Nursing</i> , 21(11-12), 1651-1658. Doi:10.1111/j.1365-2702.2011.03989.x	– Quantitative
Osborn, T. R., Curtis, J. R., Nielsen, E. L., Back, A. L., Shannon, S. E., & Engelberg, R. A. (2012). Identifying elements of ICU care that families report as important but unsatisfactory: Decision-making, control, and ICU atmosphere. <i>Chest</i> , 142(5), 1185-1192.	– Quantitative
Phillips, B. (2007). Improving access to diagnosis and treatment of sleep-disordered breathing. <i>Chest</i> , 132(5), 1418-1420. Doi:10.1378/chest.07-1793	– Commentary
Plost, G., & Nelson, D. (2007). Family care in the intensive care unit: The Golden Rule, evidence, and resources. <i>Critical Care Medicine</i> , 35(2), 669-670.	– Opinion
Reynolds, R. C. (2014). Last days. <i>Pharos Alpha Omega Alpha Honor Medical Society</i> , 77(1), 25-29.	– Not families' perspectives
Robert, R., Salomon, L., Haddad, L., Graftieaux, J. P., Eon, B., & Dreyfuss, D. (2014). End of life in the intensive care unit: Should French law be adapted? <i>Annals of Intensive Care</i> , 4(1), 1-13.	– Not EOLC
Robillard, D., Shim, S., Irwin, R., Katonah, J., & et al. (2005). Support services perspective: The critical care family assistance program. <i>Chest</i> , 128(3), 124S-127S.	– Not EOLC
Rusinova, K., Kukal, J., Simek, J., & Cerny, V. (2014). Limited family members/staff communication in intensive care units in the Czech and Slovak Republics considerably increases anxiety in patients' relatives-The DEPRESS study. <i>BMC Psychiatry</i> , 14(Jan).	– Quantitative – Not EOLC

Santiago, C., Lazar, L., Jiang, D., & Burns, K. E. (2014). A survey of the attitudes and perceptions of multidisciplinary team members towards family presence at bedside rounds in the intensive care unit. <i>Intensive and Critical Care Nursing</i> , 30(1), 13-21.	– Not families' perspectives
Schleyer, A. M., & Curtis, J. R. (2013). Family satisfaction in the ICU: why should ICU clinicians care? <i>Intensive Care Medicine</i> , 39(6), 1143-1145. Doi:10.1007/s00134-013-2939-3	– Editorial
Schulz, V., & Novick, R. J. (2013). The distinct role of palliative care in the surgical intensive care unit. <i>Seminars In Cardiothoracic And Vascular Anesthesia</i> , 17(4), 240-248. Doi:10.1177/1089253213506121	– Not families' perspectives
Schwarzkopf, D., Behrend, S., Skupin, H., Westermann, I., Riedemann, N. C., Pfeifer, R., ... Hartog, C. S. (2013). Family satisfaction in the intensive care unit: a quantitative and qualitative analysis. <i>Intensive Care Medicine</i> , 39(6), 1071-1079.	– Not EOLC
Sepúlveda Sánchez, J. M., Morales Asensio, J. M., Morales Gil, I. M., Canca Sánchez, J. C., Pérez Tueba, E., & Rueda Dominguez, A. (2014). Impact of a legislative framework on quality of end-of-life care and dying in an acute hospital in Spain. <i>International Journal of Palliative Nursing</i> , 20(5), 225-231.	– Not families' perspectives
Sessler, C. N. (2005). The Critical Care Family Assistance Program: Caring For Those Who Care. <i>Chest</i> , 128(3), 1101-1103.	– Opinion piece
Shander, A., Gandhi, N., & Aslakson, R. A. (2014). Anesthesiologists and the quality of death. <i>Anesthesia and Analgesia</i> , 118(4), 695-697.	– Opinion piece
Shaw, D. J., Davidson, J. E., Smilde, R. I., Sondoozi, T., & Agan, D. (2014). Multidisciplinary team training to enhance family communication in the ICU. <i>Critical Care Medicine</i> , 42(2), 265-271.	– Not families' perspectives
Sinuff, T., Giacomini, M., Shaw, R., Swinton, M., & Cook, D. (2009). "Living with dying": The evolution of family members' experience of mechanical ventilation. <i>Critical Care Medicine</i> , 37(1), 154-158.	– Not EOLC
Soares, M., Terzi, R. G. G., & Piva, J. P. (2007). End-of-life care in Brazil. <i>Intensive Care Medicine</i> , 33(6), 1014-1017.	– Literature review
Stapleton, R. D., Engelberg, R. A., Wenrich, M. D., Goss, C. H., & Curtis, J. R. (2006). Clinician statements and family satisfaction with family conferences in the intensive care unit. <i>Critical Care Medicine</i> , 34(6), 1679-1685.	– Quantitative – Not EOLC



Steinhauser, K. E., Voils, C. I., Bosworth, H., & Tulsky, J. A. (2014). What constitutes quality of family experience at the end of life? Perspectives from family members of patients who died in the hospital. <i>Palliative Supportive Care</i> , 13(4), 945-952. doi:10.1017/s1478951514000807	– Not ICU
Sundararajan, K., Sullivan, T. S., & Chapman, M. (2012). Determinants of family satisfaction in the intensive care unit. <i>Anaesthesia and Intensive Care</i> , 40(1), 159-165.	– Quantitative – Not EOLC
Thiers, M. (2006). End-of-life decision making in ICU. <i>Critical Care Nurse</i> , 26(2), 16-18.	– Letter to the editor
Tonetta-Stanker, S. (2009). Providing patient- and family-centered end-of-life care in the ICU. <i>Nursing Critical Care</i> , 4(5), 54-55.	– Opinion piece
Tong, A., Cheung, K. L., Nair, S. S., Kurella Tamura, M., Craig, J. C., & Winkelmayer, W. C. (2014). Thematic synthesis of qualitative studies on patient and caregiver perspectives on end-of-life care in CKD. <i>American Journal of Kidney Disease</i> , 63(6), 913-927. doi:10.1053/j.ajkd.2013.11.017	– Not ICU
Tsaloukidis, N. (2010). Treating ICU patients of final stage and dealing with their family. <i>Health Science Journal</i> , 4(3), 136-141.	– Literature review
Urizzi, F., & Corrêa, A. K. (2007). Relatives' experience of intensive care: The other side of hospitalization. <i>Revista Latino-Americana de Enfermagem (RLAE)</i> , 15(4), 598-604.	– Not EOLC
van der Klink, M. A., Heijboer, L., Hofhuis, J. G. M., Hovingh, A., Rommes, J. H., Westerman, M. J., & Spronk, P. E. (2010). Survey into bereavement of family members of patients who died in the intensive care unit. <i>Intensive and Critical Care Nursing</i> , 26(4), 215-225. doi:10.1016/j.iccn.2010.05.004	– Quantitative
VALUE process helps families cope with end-of-life choices in the intensive care unit. (2007). <i>H&amp;HN: Hospitals &amp; Health Networks</i> , 81(3), 68-70.	– Not families' perspectives
Vandall-Walker, V. (2006). Delineating the process of nursing support with family members of the critically ill adult. (Doctoral dissertation), University of Alberta (Canada), Ann Arbor. ProQuest Central database.	– Not EOLC
West, H. F., Engelberg, R. A., Wenrich, M. D., & Curtis, J. R. (2005). Expressions of nonabandonment during the intensive care unit family conference. <i>Journal of Palliative Medicine</i> , 8(4), 797.	– Not EOLC

White, D. B., & Curtis, J. R. (2006). Establishing an evidence base for physician-family communication and shared decision making in the intensive care unit. <i>Critical Care Medicine</i> , 34(9), 2500-2501.	– Editorial
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## Appendix F: Summary of Extracted Findings, Categories and Syntheses

Synthesis 1: Communication with the family and within the healthcare team		
Findings	Category	Synthesis
Caring was universally regarded as ensuring comfort, privacy and dignity. (U)	Maintaining patient dignity	Valued attributes of patient care
Comfort, privacy and dignity were considered universally paramount. (U)		
Perceptions of comfort also extended to after-death care. (C)		
Families could not always offer perspectives on whether patients were comfortable or not, highlighting how care practices are undertaken which contribute to what is thought to make patients comfortable, but in reality it is not known if these help when patients are unconscious, emphasising potential tensions between family and patient care. (U)		
Participants discussed the importance of assuring that patients were not in pain. (U)	Patient comfort (pain management, comfort measures and physical care)	
Families could not feel comfortable without assurance of the patient’s comfort. (U)		
Patient comfort was extremely important to family members (U)		
Family members described the dying process and the actual moments around the time of death as peaceful. (U)		
Signs of discomfort during the dying process were particularly distressing for family members. (U)		
Comfort, privacy and dignity were considered universally paramount. (U)		
One nurse found out from family that music comforted the patient (U)		
Perceptions of comfort also extended to after-death care. (C)		
Families could not always offer perspectives on whether patients were comfortable or not, highlighting how care practices are undertaken which contribute to what is thought to make patients comfortable, but in reality it is not known if these help when patients are unconscious, emphasising potential tensions between family and patient care. (U)		
All participants were concerned about their loved ones’ comfort. (U)		
Family members expressed hope that their loved ones were comfortable. (U)		
When the participants accepted the coming death, they then hoped for a peaceful death and also for a good new life for the dying person. (U)		
Attention to the patient’s comfort was acknowledged by all participants. Most wanted to be reassured that the patient would be kept pain free and as comfortable as possible up to the end. (U)		

An area of importance for bereaved families was to achieve a painless and comfortable death for the person. (U)	Caring behaviours valued by families	
Participants relied heavily on other family members for emotional support. (U)		
Two participants spoke of wanting their loved ones to die at home. (U)		
At the end of each interview, participants were asked to try to summarize their experience using one word. Each participant briefly paused, reflected, and then summarized their experience of having a loved one die in the ICU. (Gift). (U)		
They [family members] needed to witness nurses' physical comfort care provided their dying loved ones. (U)		
Some dissatisfaction was expressed about the caring behaviours of the health-care providers. In order to maintain good relationships, participants valued empathetic understanding. (U)		
Families were deeply appreciative when healthcare providers demonstrated respect and genuine care for their loved one and also for them as a family. (U)		
All family members appreciated the nursing care for the critically ill patient very well; they noticed the respect the nurses showed to the patients. Nurses cared for the patient as a whole person. (U)		
Generally, relatives were satisfied with the care the patient had received once on the ICU, and much of this same care was also shown to the relatives. (U)		
In every group, multiple participants stressed attention to personhood. (U)		

Synthesis 2: The dying person: valued attributes of patient care		
Findings	Category	Synthesis
This family requested everything be done until they could gather the rest of the children in from out of state at their dying mother's request. (U)	Honest, sensitive, clear and repeated communication	Communication with the family and within the healthcare team
Participants expressed confusion and frustration with clinicians' use of medical terminology. (U)		
Participants discussed implications of inadequate communication between ICU physicians and families. (U)		
There was broad agreement about the value of open and complete communication. (U)		
Being confronted with the threat of loss. (U)		
Generally, relatives were satisfied with the care the patient had received once on the ICU, and much of this same care was also shown to the relatives. (U)		
Communication About Death: It appeared that, sometimes, staff did not appreciate the suddenness and intensity of the event that had brought the patient to their unit, and did not communicate sensitively with the families. (U)		

Communication About Death: There were several issues of relatives not understanding when the patients had actually died. (U)		
Caring was universally regarded as ensuring comfort, privacy and dignity. (U)		
When the participants accepted the coming death, they then hoped for a peaceful death and also for a good new life for the dying person. (U)		
Family members expressed hope that their loved ones were comfortable. (U)		
Communication and information sharing between the nurses and the family was reported to be very important and should be done to enable the family to understand exactly what is going on and what to expect. (U)		
Following the decision to transition to palliative management, all participants expressed some form of distress because they were not prepared to hear this as they expected their loved ones would get better. (U)		
Having been informed of the possibility that their relative may not survive, they found the news hard to believe and most families held on to hope of recovery. (U)		
Coordination of care was especially important (U)	Consistent communication and continuity of care	
Many participants had interacted with caregivers from various specialties and disciplines. (U)		
Confusion occurred when the family received conflicting information from different staff they met working in different shifts. (U)		
<b>Maintaining a vigil:</b> When the close relatives understood the seriousness of the situation, they felt a great need to be close to the dying person. (U)	Timely communication	
The monitoring and medical-technical equipment. (U)		
Three family members were not able to say goodbye while the patient was still conscious. (U)		
Once the decision was made that treatment was no longer going to be aggressive, patients were sometimes transferred out of the ICU. (U)		
In all focus groups, communication was the dominant theme of the discussion by patients, families of ICU survivors, and bereaved families. (U)		
Participants discussed implications of inadequate communication between ICU physicians and families. (U)		
The doctor and families met only once when the move from curative to palliative management was discussed. Thereafter, no more family meetings took place unless requested by the family. (C)		
With the doctors being busy and the nurses not divulging information, other families concurred that they had to wait for the doctor in order to receive information. (U)		



Synthesis 3: Preparing the family and promoting a peaceful family-centred death		
Findings	Category	Synthesis
When the time came for life-sustaining therapy to be withdrawn, families expected the withdrawal to happen quickly. (U)	Preparing the family for treatment withdrawal, the dying process and death	Preparing the family and promoting a peaceful family-centred death
Some families were prepared for the dying process, and others were not. (U)		
The nurse directed withdrawal of treatment (U)		
Managing timeliness [timing of withdrawal] contributed towards feelings of a good death for families and many staff (p. 1449). (C)		
This family requested everything be done until they could gather the rest of the children in from out of state at their dying mother's request. (U)		
Death in the intensive care unit was frequently expected and planned for by family and staff (U)		
Most participants received an explanation from nurses about how death would unravel and what they could expect to see and hear (U)		
Most family members have strong visual and auditory recollections of their dying loved ones, although many participants said they tried to forget. (U)		
ICU nurses informed family about symptoms during the dying process, about care after death of the patient, and whom they had to contact about the funeral and further arrangements. (C)		
All family members appreciated the nursing care for the critically ill patient very well; they noticed the respect the nurses showed to the patients. Nurses cared for the patient as a whole person. (U)		
Signs of discomfort during the dying process were particularly distressing for family members. (U)		
Many family members began to make arrangements before withdrawal of LST. (U)		
Families described being prepared for the withdrawal of LST, but not prepared for the dying process. (U)		
The death vigil was very difficult for families. (U)		
When the time came for life-sustaining therapy to be withdrawn, families expected the withdrawal to happen quickly. (U)		
For all respondents, a good death included the acknowledgement of families' feelings, when sadness was unfolding before them. (U)		
Most participants wanted their situation to be recognised by the nurses. (U)		
An area of importance for bereaved families was to achieve a painless and comfortable death for the person. (U)		
Whilst most family members recalled affirming experiences about remembering the person at this time, some family members held negative memories. (U)		
The participants reported that they received compassionate care from the nurses, who also allowed them to be with their dying family member	Families' needs of the dying environment	

as long as they wanted. The nurses respected the participants as partners in care and gave them support. (U)		
When the participants accepted the coming death, they then hoped for a peaceful death and also for a good new life for the dying person. (U)		
The caregivers felt close physically, psychologically, and spiritually in this limited space. (U)		
When the close relatives understood the seriousness of the situation, they felt a great need to be close to the dying person. (U)		
The close relatives played down their own needs and overlooked and accepted deficiencies in the unit's physical environment. (C)		
The monitoring and medical-technical equipment. (U)		
Several of the participants who were present when their loved one died stressed that it was a wonderful moment. (U)		
Maintaining a vigil at a loved one's deathbed was a very private experience. (U)		
No informant felt prevented from being close to his/her loved one in the ICU (U)		
Many participants described how they focused on the monitor during their loved ones' dying moments. (U)		
In contrast, another participant described ICU death as "family driven". (U)		
The emotional responses that family members had at the time of death were diverse. (U)		
Two participants spoke of wanting their loved ones to die at home. (U)		
As death of his or her loved one became the anticipated outcome, family members emphasized the desire to constantly be with their dying loved ones and other family members. (U)		
All family members appreciated the nursing care for the critically ill patient very well; they noticed the respect the nurses showed to the patients. Nurses cared for the patient as a whole person. (U)		
All family members wished to stay with the patient. (U)		
Five family members were invited to assist in care for the patient. (U)		
Most patients died in a single room in the ICU, which was appreciated by the family. (U)		
The nurse directed withdrawal of treatment (U)		
Unrestricted access to patients was important. (U)		
Both patients and families placed high value on family access and proximity to the patient. (U)		
Being included – an insider in care-giving – gave a sense of wellbeing for families and patients...How nurses allowed or invited families to participate in minutiae of care both for patients who survived,		



and those at EOL, shaped families' feelings of being involved. (U)		
One nurse found out from family that music comforted the patient (U)		
Tension between conflicting patient and family wishes [to die at home]. (U)		
Maintaining sensitivity to families' need for presence and privacy was an important skill and fell predominantly to the nurses. (U)		
After a decision was made with the team to withdraw LST, family commonly opened visitation up to others. (U)		
Family members described both positive and negative aspects of the dying environment. (U)		
Most families wanted to be involved in the patient's direct care if allowed as this would bring about peace of mind even after death. (U)		
Following the decision to move to palliative care, most participants mentioned that just to see their relative lessened their worries and stress levels. (U)		
The participating ICUs restricted visiting hours except for those families where a relative had been deemed to be terminally ill. (U)		
Most families appreciated and took advantage of the open access policy. However, a few families said that they were satisfied with shorter visits. (U)		
It was evident that families were fearful of the impending death and of being present when it happened, nevertheless, most gathered courage and were willing to stay with the patient till the end. (U)		
An important issue for bereaved family members was how the dying person was remembered around the bedside during the final hours. (U)		
Finding privacy was important for families. (U)		
At such an emotional time, relatives described the need for a place where they could be away from the ICU. (U)		
The layout and facilities of the ICU also caused problems for families who felt they did not have any privacy with their loved one in the period of time preceding the machine being switched off or the relative going to the operating theatre for organ donation. (U)		
Family members described the dying process and the actual moments around the time of death as peaceful. (U)		
Although all of the patients were unconscious, several family members described death as occurring on the patient's terms. (U)		

Synthesis 4: Family-centred support and care		
Findings	Category	Synthesis
All participants were concerned about their loved ones' comfort. (U)	Nursing presence as an element of support	
In contrast, another participant described ICU death as "family driven". (U)		
Most appreciated was that ICU nurses were available at any time, and willing to answer questions. (U)		
All family participated in a family meeting. In each meeting an ICU nurse was present, but family did not remember the specific role. (U)		
Families appreciated seeing familiar nurses during the patients' stay in the ICU. (C)		
The participants reported that they received compassionate care from the nurses, who also allowed them to be with their dying family member as long as they wanted. The nurses respected the participants as partners in care and gave them support. (U)		
Comfort, privacy and dignity were considered universally paramount. (U)		
Maintaining sensitivity to families' need for presence and privacy was an important skill and fell predominantly to the nurses. (U)		
All energy and attention was focused on the dying person and the participants [close relatives'] could be totally preoccupied with the situation and spend many long hours at his or her bedside..(C)		
Trusting the care (U)		
Communication and information sharing between the nurses and the family was reported to be very important and should be done to enable the family to understand exactly what is going on and what to expect. (U)		
With the doctors being busy and the nurses not divulging information, other families concurred that they had to wait for the doctor in order to receive information. (U)		
Divided opinions about participants' reception to the ICU were reported. (U)		
All participants were concerned about their loved ones' comfort. (U)		
In contrast, another participant described ICU death as "family driven". (U)		
In every group, multiple participants stressed attention to personhood. (U)	Emotional support and compassionate care	
Support for families was identified by patients and family members as an important part of ICU care. (U)		
Families valued contributions not only of physicians and nurses but of other disciplines providing support in the ICU. (U)		
Emotional burden was placed on family members as the physicians left it to them to tell their mother that treatment was being stopped (U)		

Participants relied heavily on other family members for emotional support. (U)		
At the end of each interview, participants were asked to try to summarize their experience using one word. Each participant briefly paused, reflected, and then summarized their experience of having a loved one die in the ICU. (Cold). (U)		
At the end of each interview, participants were asked to try to summarize their experience using one word. Each participant briefly paused, reflected, and then summarized their experience of having a loved one die in the ICU. (Hurt). (U)		
At the end of each interview, participants were asked to try to summarize their experience using one word. Each participant briefly paused, reflected, and then summarized their experience of having a loved one die in the ICU. (Gift). (U)		
They [family members] needed to witness nurses' physical comfort care provided their dying loved ones. (U)		
Families appreciated seeing familiar nurses during the patients' stay in the ICU. (C)		
Some family members reported that the ICU nurses did not ask for a hospital chaplain, even though they had wished for one. (U)		
Many family members began to make arrangements before withdrawal of LST. (U)		
Most families needed someone to talk to and express their feelings but they did not always have somebody to talk to. (U)		
Most participants wanted their situation to be recognised by the nurses. (U)		
Religion and the importance of prayers during their relatives' critical illness were valued by most participants. (U)		
Generally, relatives were satisfied with the care the patient had received once on the ICU, and much of this same care was also shown to the relatives. (U)		
Although every attention was given to the practical needs of the relatives by staff, little attention was paid to their emotional needs. (U)		
Some relatives were left on their own once a decision had been made. (U)		
The participants reported that they received compassionate care from the nurses, who also allowed them to be with their dying family member as long as they wanted. The nurses respected the participants as partners in care and gave them support. (U)		
Caring was universally regarded as ensuring comfort, privacy and dignity. (U)		
For all respondents, a good death included the acknowledgement of families' feelings, when sadness was unfolding before them. (U)		
For families, seeing that staff became emotional about achieving good decisions and reaching a		

good death contributed to the overall perception of a good death. (U)		
Trusting the care. (U)		
Families found it helpful to see a consistent familiar face that they trusted and with whom they had developed a relationship. (U)	The clinician-family relationship: trust, bonds and rapport	
Families indicated that it was important that the nurses and the physicians know both the family member who was the patient and the other family members. (U)		
Several families experienced broken bonds and inconsistency with nurses and physicians. (U)		
Families described challenges they faced when the patient was transferred. (U)		
The presence of physicians was important for families. (U)		
Once the decision was made that treatment was no longer going to be aggressive, patients were sometimes transferred out of the ICU. (U)		
Trusting the care (U)		
The nurse directed withdrawal of treatment (U)		
Families appreciated seeing familiar nurses during the patients' stay in the ICU. (C)		
Family members agonized over changes in care and withdrawal of treatment (C)		
In contrast, another participant described ICU death as "family driven". (U)		
It was important to families that they have consistent nurses especially at the time of death. (U)		

Synthesis 5: Bereavement care		
Findings	Category	Synthesis
When the ventilator and other medical-technical equipment were turned off, death suddenly became very obvious. At that moment, the relatives were extremely sensitive and dependent on having someone to lean on. The staff members' tactful presence and support was described as much appreciated by more or less all participants. (U)	Tactful presence and psychological support at, and after death	Bereavement care
The nurse directed withdrawal of treatment (U)		
At the end of each interview, participants were asked to try to summarize their experience using one word. Each participant briefly paused, reflected, and then summarized their experience of having a loved one die in the ICU. (Hurt). (U)		
Some relatives were left on their own once a decision had been made. (U)		
Where staff did accompany relatives from the ward, this was greatly appreciated. (U)		
Families of patients who died in the ICU stressed the importance of bereavement care, although few reported receiving this care. (U)		
Families of patients who died in the ICU stressed the importance of bereavement care, although few reported receiving this care. (U)	The families need for time and privacy after death	

When their loved one died, they wanted to prolong the moment. (U)		Post-hospital follow-up and bereavement services
When there was only one family member present, he/she experienced a sense of togetherness with the patient and staff. However, these relatives could be assailed by a feeling of abandonment immediately after the death. (U)		
The above family requested to keep their deceased mother in a room for a couple of hours as family members were coming from out of state, but instead she was taken to the morgue as staff said “They needed the bed.” (U)		
As death of his or her loved one became the anticipated outcome, family members emphasized the desire to constantly be with their dying loved ones and other family members. (U)		
Reality of loved ones’ death evolved further as family members entered the hallway and faced staff members who were aware that their loved ones just died. (U)		
Families of patients who died in the ICU stressed the importance of bereavement care, although few reported receiving this care. (U)		
Returning to the ICU for a follow-up conversation was perceived as very positive. (U)		
Some relatives were left on their own once a decision had been made. (U)		
Most family members did not remember the possibility of a follow up meeting. (U)		