A qualitative meta-synthesis investigating the experiences of the patient's family when treatment is withdrawn in the intensive care unit

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End-of-life care in the intensive care unit. A meta-synthesis of qualitative studies investigating the experiences and perceptions of patients' families when treatment is withdrawn.

ABSTRACT

Aim: To synthesise qualitative studies of patients' families' experiences and perceptions of end-of-life care in the intensive care unit, when life-sustaining treatments are withdrawn.

Design: Qualitative meta-synthesis

Data sources: Comprehensive search of 18 electronic databases for qualitative studies published between January 2005 and February 2019.

Review Method: Meta-aggregation.

Results: Thirteen studies met the inclusion criteria. A conceptual 'Model of Preparedness' was developed reflecting the elements of end-of-life care most valued by families: 'End-of-life communication'; 'Valued attributes of patient care'; 'Preparing the family'; 'Supporting the family', and; 'Bereavement care'.

Conclusion: A family-centred approach to end-of-life care that acknowledges the values and preferences of families in the intensive care unit is important. These families have unmet needs related to communication, support and bereavement care. Effective communication and support are central to preparedness and if these care components are in place, families can be better equipped to manage the death, their sadness, loss and grief. The findings suggest that health professionals may benefit from specialist end-of-life care education, in order to support families and guide the establishment of preparedness.

Impact: Understanding the role and characteristics of preparedness during end-of-life care will inform future practice in the intensive care unit and may improve family member satisfaction with care and recovery from loss. Nurses are optimally positioned to address the perceived shortfalls in end-of-life care. These findings have implications for health education, policies and standards for end-of-life care in the intensive care unit.

Key words: ['end-of-life', 'EOLC', 'end of life', 'ICU', 'intensive care', 'famil*', 'withdr*', 'qualitative synthesis', 'preparedness', 'meta-synthesis' 'systematic review']

1. INTRODUCTION

Globally, end-of-life care (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; NHS National End of Life Care Programme, 2010; Office

for National Statistics, 2015; Parliamentary and Health Service Ombudsman, 2015). This is attributable to a lack of clear and consistent guidance for health professionals (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2013). In the intensive care unit (ICU) there is increasing emphasis on improving EOLC, because this is a setting where death often occurs following treatment withdrawal (Bloomer, Tiruvoipati, Tsiripillis, & Botha, 2010; Kentish-Barnes et al., 2016; Lesieur, Leloup, Gonzalez, Mamzer, & Epilat study group, 2015; NHS England, 2014). Accordingly, there is a need for EOLC in the ICU to be informed by a robust evidence base (Coombs, Parker, Ranse, Endacott, & Bloomer, 2016).

1.1 Background

Family-centred care is recognised globally to enhance the quality of EOLC in the ICU, supporting a caring culture of partnering with and providing for the needs of the whole family (ACSQHC, 2015; Coombs et al., 2016; Davidson et al., 2017; Hinkle, Bosslet, & Torke, 2015; Ranse, Bloomer, Coombs, & Endacott, 2016). Family-centred care at the end of life requires an evidence-based approach to preparing families for the dying process, death and bereavement (Department of Health, 2018; Griffiths, 2019; National Palliative and End of Life Care Partnership, 2015). In the ICU 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). The inherent challenges include difficulties in collecting data from patients who are unable to communicate due to severe life-threatening illness and ethical obstacles (Grande & Todd, 2000; Wiegand, Norton, & Baggs, 2008). As a result, current policy, guidelines, position statements and frameworks have been developed without support from evidence relating to ICU patients' needs during EOLC in the ICU. Integrating consumers' perspectives into health policies and practices is reported to enhance the quality of family-centred healthcare and is necessary for comprehensive EOLC (ACSQHC, 2017; Davidson et al., 2017; Hall et al., 2018). During EOLC in the ICU, families are not only required to provide support to patients, but to become "the voice" of patients, thus patients' families have valuable information to offer (Keenan, Mawdsley, Plotkin, Webster, & Priestap, 2000; Mitchell, Chaboyer, Burmeister, & Foster, 2009, p. 544). The *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, articulates that EOLC involves meeting the psychosocial, cultural and spiritual needs of both patients and families (ACSQHC, 2015). Care that does not meet the needs of families at the end of life may increase the risk of adverse psychological conditions (Inoue et

al., 2019; Needham et al., 2012). Current EOLC guidelines provide little direction for health professionals on how to prepare family members for death and their sadness, loss and grief in the ICU (Australian and New Zealand Intensive Care Society [ANZICS], 2014; ACSQHC, 2015; Downar, Delaney, Hawryluck, & Kenny, 2016; National Institute for Health and Care Excellence [NICE], 2015; Sprung et al., 2014). Using a family-centred approach to care, the experiences and perceptions of families are considered as important as those of the patient. A potentially rich source of families' views is qualitative research, which enables an in-depth exploration of participant experiences (Denzin & Lincoln, 2011; Edwards & Titchen, 2003).

While a strong evidence base of the ICU nurse's role in preparing families for treatment withdrawal (Coombs et al., 2016; Noome, Beneken genaamd Kolmer, van Leeuwen, Dijkstra, & Vloet, 2016) and both factors associated with family outcomes and satisfaction with EOLC in the ICU has been published (Chen, Michaels, & Meeker, 2019; Hinkle et al., 2015), to date qualitative studies of family views on the adequacy of EOLC following the withdrawal of life-support in the ICU have not been synthesised. We aimed to conduct a synthesis addressing this topic to provide evidence to inform clinical decision-making, identify research gaps and highlight the value of families' views for informing clinical practice and policies. For the purposes of this review the term 'family' is defined as "those who are closest to the patient…" (Palliative Care Australia [PCA], 2005, p. 11) and may include family, significant others and friends.

2. THE REVIEW

2.1 Aim

To synthesise qualitative studies on the experiences and perceptions of families of adult ICU patients, on the adequacy of EOLC following the withdrawal of life-support.

2.2 Design

A systematic review and meta-synthesis were conducted using meta-aggregation from the Joanna Briggs Institute (JBI) (2014). Meta-aggregation is founded on the principles and assumptions of the philosophic traditions of pragmatism (Hannes & Lockwood, 2011). It involves a three-step process to data synthesis, where findings are identified, categorised on the basis of similarity in meaning, then categories are subjected to meta-synthesis to produce a comprehensive set of synthesised findings (JBI, 2014). Line-by-line coding was used during the extraction and describes the inductive identification of words or phrases that

capture the essence or meaning of each sentence (Thomas & Harden, 2008). Reviewers agreed it was the most effective technique to compare the findings of each study (JBI, 2014). Thematic analysis is "not another qualitative method but a process that can be used with most, if not all, qualitative methods..." (Boyatzis, 1998, p.4). The resultant analysis was comprehensive and transparent, allowing translation into a conceptual model for practice. ENTREQ reporting guidelines were followed in the reporting of this meta-synthesis (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

2.3 Search methods

A comprehensive and systematic search of 18 electronic databases was conducted in June 2012, then rerun in CINAHL and Medline in 2015, 2016, 2018 and 2019. Keywords were identified from an initial limited search of CINAHL and Medline. Bates' Model of Berrypicking was used to expand the synonym base during subsequent searches (Barroso et al., 2003; Bates, 1989). The reference lists of all included studies were scrutinised, and Web of Science was used to locate additional studies. To ensure a high recall and sensitivity of search results, subject and broad-based terms were combined (Flemming & Briggs, 2007). The final search adopted a combination of search terms generated with consideration of the uniqueness of each database (Supplementary Table S1).

Inclusion/exclusion criteria

All primary qualitative research was considered from January 2005, because a focus on current practices is important. Studies were considered that reported the perceptions of families of adult ICU patients' during EOLC, where the decision to withhold or withdraw treatment was explicit. If families' perceptions were not reported separately, the study was excluded. Perceptions of organ donor families were considered for inclusion, as this can be considered care delivered at the end of life in the ICU. Despite there being no language restrictions, we identified no non-English articles. Where studies did not meet the inclusion criteria they were excluded.

2.4 Search outcome

An exhaustive search strategy and sifting process resulted in thirteen studies for meta-synthesis, providing depth and breadth of data to address the review aim. Of the thirteen qualitative studies included in the meta-synthesis, 11 were primary research studies and two were doctoral theses (Table 1). Supplementary Table S2 provides a summary of the 114 excluded studies with justification. A PRISMA flow diagram is provided below to illustrate

the study selection process (Figure 1). No studies were identified that included withholding treatment in the ICU, henceforth, we will only refer to treatment withdrawal.

Figure 1: PRISMA Flow Diagram of Study Selection
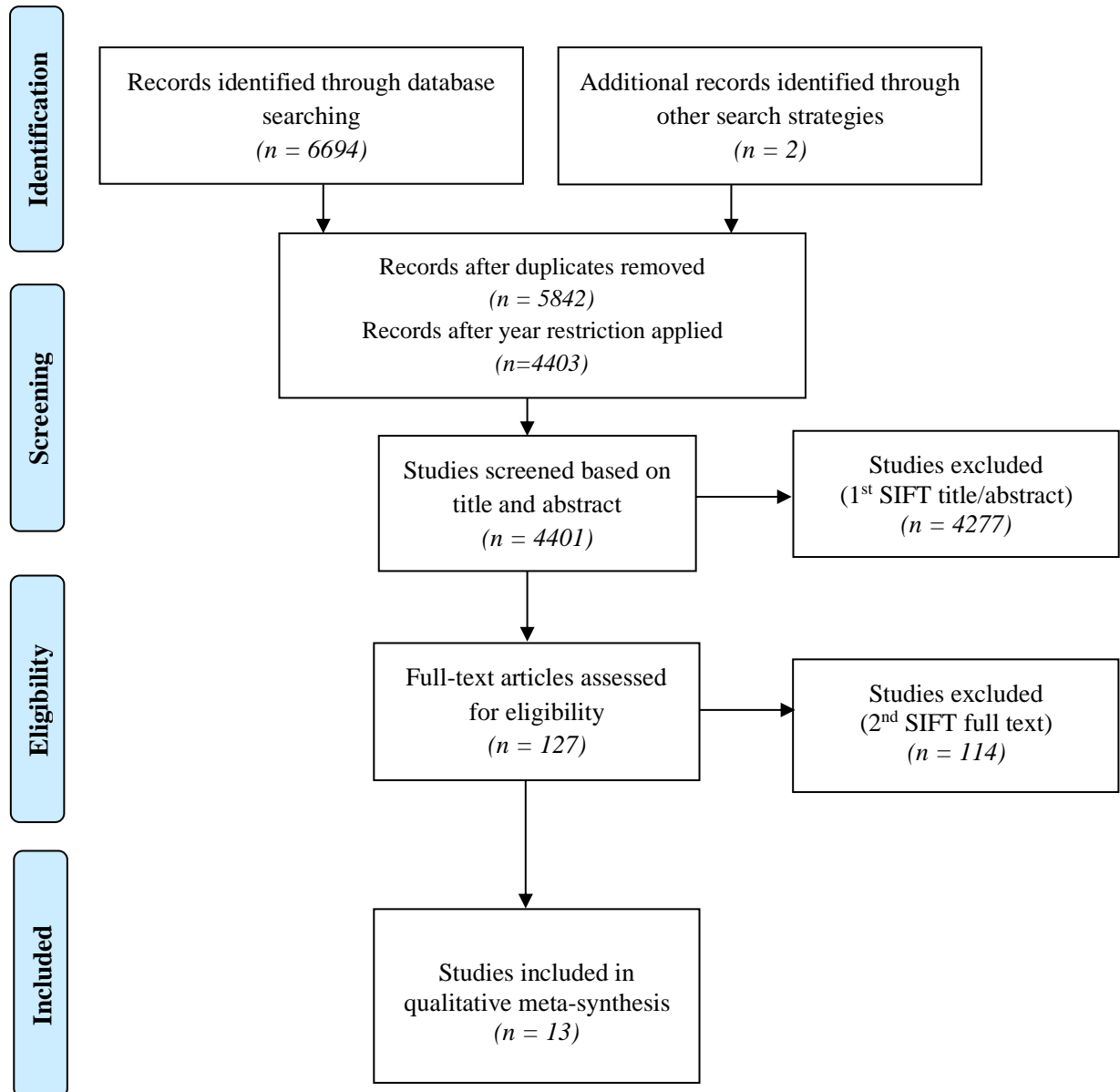
Note. Reproduced from Moher, Liberati, Tetzlaff and Altman, The PRISMA Group (2009)

Table 1: Summary of included studies (*n* = 13)

Included study	Methodology	Study focus	Participants	Analysis method	Key findings
Coombs et al. (2015)	Interpretive qualitative	Bereaved families' experiences of treatment withdrawal in the ICU.	Adult family members (*n* = 21)	Thematic and phenomenological iterative analysis	(1) alleviating further suffering; (2) re-establishing identity; (3) re-connecting with relationships.
Fridh et al. (2009)	Hermeneutic phenomenology	Bereaved relatives' experiences of death in an ICU.	Adult relatives (*n* = 17)	Hermeneutic phenomenology (Lindseth & Norberg, 2004)	(1) the threat of loss; (2) maintaining a vigil; (3) trusting the care; (4) adapting and understanding; (5) facing death; (6) privacy and togetherness; (7) reconciliation.
Kisorio & Langley (2016)	Descriptive exploratory qualitative	Family members' experiences of EOLC in the ICU.	Adult family members (*n* = 17)	Tesch's steps of analysis (Tesch, 1990)	(1) in darkness; (2) emotional support; (3) involvement; (4) family presence; and (5) spiritual support. The findings appear to reflect less than adequate EOLC.
Kociszewski (2005)	Descriptive phenomenology	The families lived experience of ICU bereavement.	Adult family members (*n* = 13)	Descriptive phenomenology (Valle & King, 1978)	Caring and uncaring behaviours profoundly affected a families' ICU bereavement experiences. A theory for compassionate communication is proposed.
Kongsuwan et al. (2011)	Hermeneutic phenomenology	Thai Buddhists' experiences during EOLC in the ICU.	Adult family caregivers (*n* = 9)	Hermeneutic phenomenology (van Manen, 1990)	The participants struggled in the context of changing hope. Feelings of stress and exhaustion were common. Participants' valued empathetic understanding.
Lloyd-Williams et al. (2009)	Unknown qualitative	Needs of relatives of ICU patients who died of brain death.	Adult Relatives (*n* = 29)	Grounded theory (Strauss & Corbin, 1998)	Participants valued the physical care their relatives received; however, communication was poor, privacy was lacking and bereavement follow-up was inconsistent.
Nelson et al. (2010)	Unknown qualitative	Bereaved families asked to define high quality Palliative Care in the ICU.	Adult family members	Qualitative; Grounded theory	A shared definition of high-quality ICU palliative care emerged.

			$(n = 19)^a$		
Noome et al. (2016)	Descriptive phenomenology	Bereaved families experience with nursing during EOLC in ICUs.	Adult family members $(n = 26)$	Inductive thematic analysis (Kvale, 1996)	Families valued communication and nursing care for patients and families. Families reported care was lacking in some areas.
Pattison (2011)	Heideggarian phenomenology	Provision of EOLC for cancer patients in a critical care unit.	Adult family members $(n = 12)^a$	Heideggarian phenomenological (Attride-Stirling, 2001).	A continuum of dying for cancer critical illness is presented with different participants' experiences along that continuum.
Pattison et al. (2013)	Heideggarian phenomenology	Bereaved families define EOLC.	Adult family members $(n = 6)^a$	henomenology (Attride-Stirling, 2001).	Cancer critical illness as part of a continuum towards death. Nurses, in particular, had an important role in determining and enacting EOLC.
Wiegand (2006)	Descriptive phenomenology	Families' experiences of withdrawal of life-support the ICU.	Adult family members $(n = 6)$	Inductive thematic analysis (van Manen, 1990)	The categories that emerged that aid in understanding the families' experiences were issues with health professionals and issues related to the hospital system.
Wiegand (2016)	Hermeneutic phenomenology	Families' experiences of withdrawal of life-support in the ICU.	Adult family members $(n = 22)$	Inductive thematic analysis (van Manen, 1990)	(1) preparing for the dying process; (2) the dying environment; (3) perceptions of patient comfort; (4) the death vigil; (5) essential care; (6) together as a family.
Wiegand et al. (2010)	Unknown qualitative	Families' perceptions of withdrawal of life-support (was it a good death?).	Adult family members $(n = 56)$	Unknown inductive analysis approach	Family members defined a death as good in relation to comfort, duration, awareness, and achieving a sense of peace.

[a]Partial sample of relevance

Supplementary table S3 provides a **detailed summary of included studies**

2.5 Quality appraisal

Methodological quality was independently assessed by two reviewers using the Joanna Briggs Institute critical appraisal tool (Supplementary Table S4) (JBI, 2014). There was considerable variation in quality between the 13 studies, most 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 (Supplementary Table S5) (Fridh, Forsberg, & Bergbom, 2009; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Pattison, 2011).

2.6 Data abstraction and synthesis

Each study was read and re-read by the primary reviewer to ensure familiarity with the data. Following a pilot extraction involving two reviewers, the primary reviewer extracted verbatim findings against a set of pre-determined rules, using participant quotes to illustrate themes (JBI, 2014). During the extraction, data was inductively coded by identifying words and phrases that captured the meaning of each sentence (Thomas & Harden, 2008). The codes informed the development of a comprehensive set of descriptive categories for organising and analysing the data. All coded text was re-examined by the primary reviewer to ensure consistency and to determine if additional coding was required. A second reviewer reviewed the codes and, if needed, discussion took place to resolve any differences.
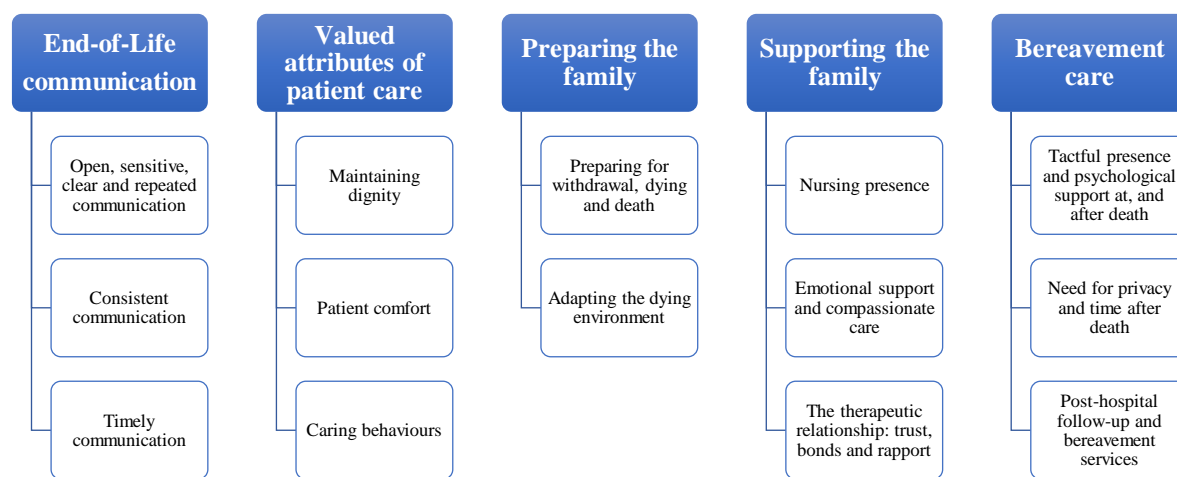
The primary reviewer compared coded data and common themes across studies to establish concepts that encompass more than one study, which can constitute a synthesis. Where necessary, new codes were created by the primary reviewer to capture the meaning of groups of initial codes. The result was a tree structure with several layers used to organise the resultant categories (JBI, 2014). Emerging themes were examined by the review team to develop more refined meanings and new concepts until agreement was reached on the final analytical structure (Walsh & Downe, 2005).

3. RESULTS

3.1 Characteristics of the included studies

This qualitative meta-synthesis included 13 studies from countries with diverse cultures and healthcare models, the UK ($n = 4$), USA ($n = 5$), the Netherlands ($n = 1$), Sweden ($n = 1$), Thailand ($n = 1$) and South Africa ($n = 1$) (Table 1). Findings were synthesised into 14 categories based on similarity of meaning, then aggregated into five synthesised findings that represented families' experiences and perceptions of EOLC delivered in the ICU (Figure 2). Meta-synthesis revealed consistent factors influencing families' perceptions of EOLC across all studies (Supplementary Table S6).

Figure 2: Family-centred EOLC in the ICU: Visual representation of synthesised findings:

End-of-Life communication	Valued attributes of patient care	Preparing the family	Supporting the family	Bereavement care
Open, sensitive, clear and repeated communication	Maintaining dignity	Preparing for withdrawal, dying and death	Nursing presence	Tactful presence and psychological support at, and after death
Consistent communication	Patient comfort	Adapting the dying environment	Emotional support and compassionate care	Need for privacy and time after death
Timely communication	Caring behaviours		The therapeutic relationship: trust, bonds and rapport	Post-hospital follow-up and bereavement services

End-of-life communication

Families described effective communication that was open, sensitive, clear, consistent, timely, and an important element of high-quality EOLC. However, across a diverse cultural sample this did not occur consistently (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Noome, Dijkstra, van Leeuwen, & Vloet, 2016; Wiegand, 2006). Effective communication contributed to feelings of preparedness and had the potential to influence all elements of EOLC.

Communication that provided open and timely conversation about the seriousness of a prognosis supported families to move through their shock, prepare psychologically for the anticipated death and become involved in care (Fridh et al., 2009; Lloyd-Williams, Morton, & Peters, 2009; Nelson et al., 2010). Communication that was not open and clear resulted in families feeling

psychologically unprepared for the possibility of death. Sensitive communication was too often reported as absent (Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010):

> *"It was terrible being told that my son's brain was scrambled."* (Eleanor) (Lloyd-Williams et al., 2009, p. 661).

Timely provision of information by ICU physicians about treatment withdrawal, dying and death was widely regarded as a basic care need (Fridh et al., 2009; Lloyd-Williams et al., 2009; Nelson et al., 2010). Untimely communication shaped families' lasting memories of the dying process 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:

> *"… somebody came and shut down all the monitors… I thought that they switched him off… I didn't understand… it was sickening…I can still see it, I'll never forget it…"* (I: 16) (Fridh et al., 2009, p. 115).

Valued attributes of patient care

The attributes of patient care most valued by families at the end of life included pain management, comfort measures, hygiene care, and maintenance of dignity. Families associated a variety of caring behaviours with dignity, including talking to and touching the dying person to demonstrate compassion (Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Pattison, 2011; Wiegand, 2016) and treating the patient as a person (Nelson et al., 2010). In one study, dignity was perceived with small acts of kindness:

> *"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"* (Wiegand, 2016, p. 163).

As signs of discomfort were distressing for family members to witness, assurances of the dying person's comfort and pain management were important components of care (Coombs, 2015; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). Most families felt that health professionals did everything they

could to manage the dying person's pain (Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010):

> *"... I told [the doctor] I need to know that my husband is not hurting..."* (Widow) (Nelson et al., 2010, p. 7).

Care that was compassionate, respectful, kind, genuine and holistic was valued and associated with family satisfaction (Kociszewski, 2005; Lloyd-Williams et al., 2009; Noome, Dijkstra, et al., 2016; Wiegand, 2016): *"I feel like the people who were there treated her like a family member... she got the best care possible..."* (Family member) (Kociszewski, 2005, p. 114). Dissatisfaction and distress were expressed in the absence of caring behaviours (Kociszewski, 2005; Kongsuwan & Chaipetch, 2011):

> *"I felt unimpressed... They have responsibility to care for patients but why they don't talk to the patients sweetly and softly?... Why?"* (P4) (Kongsuwan & Chaipetch, 2011, p. 332).

Preparing the family

When families knew what to expect during treatment withdrawal and the dying process, and their fundamental needs during this time were met, a peaceful and family-centred death was more likely to be perceived and families felt better prepared for the grieving process and inevitable death (Coombs, 2015; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison, Carr, Turnock, & Dolan, 2013; Wiegand, 2006, 2016; Wiegand & Petri, 2010). Frank conversations with health professionals regarding what might be seen and heard during the dying process was appreciated (Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison et al., 2013; Wiegand, 2006). In the absence of such conversations, families reported finding the unpredictable nature of dying difficult to understand (Coombs, 2015; Kociszewski, 2005; Wiegand, 2006, 2016) and reported painful recollections: *"... his eyes were still open, his mouth was all distorted and it was quite a horrific sight..."* (Case 6) (Coombs, 2015, p. 3).

In some studies, it was evident that perceptions of a peaceful death could be influenced by the physical environment, the presence of family and when nurses assisted those present to build positive memories of the dying person (Fridh et al., 2009; Kociszewski, 2005; Kongsuwan &

Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010). Families of organ donors reported a heightened sense of vulnerability during this period: "...*There weren't any separate rooms...You were aware of others being around so you had to cry really quietly"* (Eunice) (Lloyd-Williams et al., 2009, p. 661). The perception of a family-centred death and dying environment was reported by families who felt they had some level of control during EOLC (Fridh et al., 2009; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Pattison, 2011; Wiegand, 2016; Wiegand & Petri, 2010):

> *"... the 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... It was more family driven"* (Family member) (Kociszewski, 2005, p. 112).

Supporting the family

Support from nurses and physicians was an essential need for families when life-support is withdrawn. Nursing presence as an element of support for families included nurses advocating for their needs and being available when needed (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison, 2011). Nursing support was described by one participant as a *"palpable, reassuring presence"(Wife) (Pattison, 2011, p. 174).*

Families reported that the opportunity to establish a trusting relationship with a particular nurse or medical staff member increased trust from admission, through to the immediate bereavement period (Fridh et al., 2009; Kociszewski, 2005; Noome, Dijkstra, et al., 2016; Pattison et al., 2013; Wiegand, 2016): *"Having the same nurse was really nice, especially the day that he died"* (Family member) (Wiegand, 2016, p. 163).

Participants reported the importance of feeling cared for emotionally and spiritually by nurses at a time of psychological fragility. This feeling of being cared for was facilitated by compassionate and empathic care which was demonstrated by family-centred presence, sincerity and practical support (Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Wiegand, 2016): *"... These women [nurses] were truly amazing – the strength and the fortitude of the personality that they have, the compassion..."* (Family member)

(Kociszewski, 2005, p. 121). Conversely, emotionally detached nursing and medical care was reported and this negatively coloured families' views of care quality (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Nelson et al., 2010; Pattison, 2011): *"… 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 what the family wants, what the family needs…"* (Family member) (Kociszewski, 2005, p. 120).

Bereavement care

There was a perceived lack of bereavement care. When death was imminent, families experienced a strong need to feel close to the dying person (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Nelson et al., 2010; Noome, Dijkstra, et al., 2016; Pattison et al., 2013). A Swedish study labelled this *the bedside vigil* (Fridh et al., 2009). The bedside vigil contributed to perceptions of a family-centred death and when met could help reduce 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, 2011, p. 1450).

During the bedside vigil, families indicated an overwhelming need for unrestricted visiting (Fridh et al., 2009; Kisorio & Langley, 2016; Kociszewski, 2005; Kongsuwan & Chaipetch, 2011; Noome, Dijkstra, et al., 2016; Pattison, 2011; Pattison et al., 2013; Wiegand, 2016). For some, uninterrupted and private time with the dying person was associated with closure and acceptance, a time to reminisce and verbalise grief (Noome, Dijkstra, et al., 2016; Pattison et al., 2013). Reminiscing during the bedside vigil provided an opportunity for some to build positive memories about the dying person and death (Kisorio & Langley, 2016). Those who reported a preference to grieve away from the bedside reported limited access to alternative spaces (Fridh et al., 2009; Lloyd-Williams et al., 2009; Pattison, 2011; Wiegand, 2006).

Families reported intense manifestations of grief and anguish at the actual moment of death and immediately after (Fridh et al., 2009; Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010; Pattison et al., 2013). The ability of the nurse to anticipate imminent dying and provide

timely psychological support during this time was considered a key element of bereavement care:

> *"… she was brilliant… she was obviously aware that 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).

In studies from the USA and UK, families described the challenges of coping without this type of support (Kociszewski, 2005; Lloyd-Williams et al., 2009; Nelson et al., 2010):

> *"While I was in hospital I had loads of care and attention, but at the end I needed someone to take time with me…"* (Irene) (Lloyd-Williams et al., 2009, p. 662).

Immediately after death, few families reported being granted sufficient time and privacy to be alone with the deceased patient. Some reported feeling forced by staff to leave the room before they were ready, leading to a sense of abandonment and heightened distress (Fridh et al., 2009; Nelson et al., 2010). *"...They just came in there and pronounced him dead, and started covering him up and moving him, and pulling out all these things…. So, I just left"* (Daughter B) (Nelson et al., 2010, p. 10).

Many participants reported unmet needs for bereavement follow-up after hospital, such as a follow-up conversation with staff, information about available support services, support groups or chap workers (Fridh et al., 2009; Lloyd-Williams et al., 2009; Nelson et al., 2010; Noome, Dijkstra, et al., 2016). For many, this resulted in long-lasting psychological distress (Lloyd-Williams et al., 2009; Nelson et al., 2010):

> *"… I would have appreciated some follow-up or grief support or social work or anything… I did not cry at all, until 2 months ago… 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…"* (Daughter B) (Nelson et al., 2010, p. 10).

4. DISCUSSION

This review synthesised qualitative evidence of patients' families' experiences and perceptions of EOLC in the ICU, when life-sustaining treatments are withdrawn. The synthesis findings provide new knowledge on what needs to be in place from preparation for dying to bereavement care, to establish a state of *preparedness* in families (Figure 3). Preparedness is well described in palliative care literature, 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). Preparedness has also been defined relative to the caregiver's readiness for a death (Barry, Kasl, & Prigerson, 2002). Our study adds an understanding of preparedness in the setting of intensive care, that is, when families felt prepared, they knew what to expect, felt their needs were being met and felt supported by staff in a trusting family-centred model of care (Figure 3).

Figure 3: An evidence-based 'Model of Preparedness' for the delivery of family-centred EOLC in the ICU
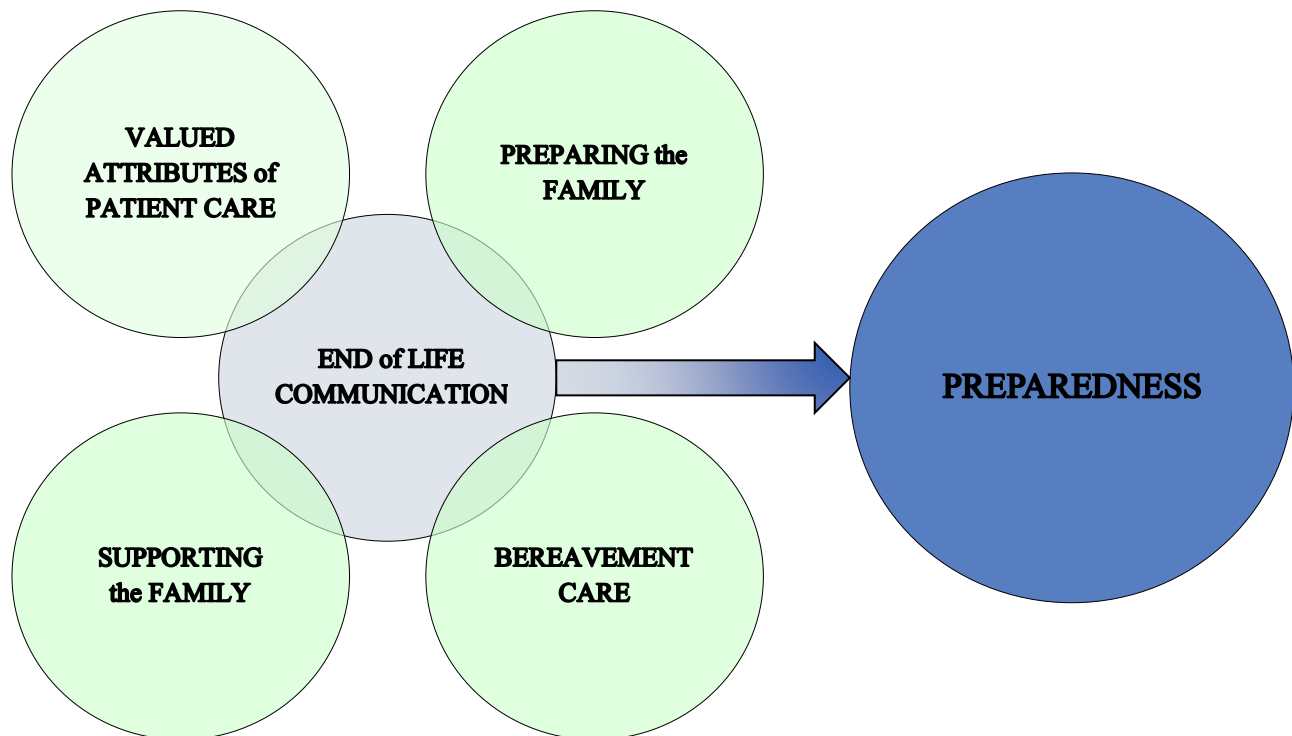
Effective communication underpins preparedness and is integral to the facilitation of family needs during EOLC in the ICU. Our findings confirm an earlier study, which identified effective communication as a strong predictor of families' preparedness for death in non-ICU settings (Hebert, Prigerson, Schulz, & Arnold, 2006). Current ICU guidelines confirm communication as the cornerstone of high-quality EOLC, however guidance on which components of EOLC contribute to a state of preparedness is absent (Australian and New Zealand Intensive Care Society [ANZICS], 2014; Davidson et al., 2017; National Institute for Health and Care Excellence [NICE], 2013, 2015; Sprung et al., 2014).

Our findings show that when communication was open, sensitive, clear, consistent and timely, it assisted families' preparedness for death and the ensuing, sadness, loss and grief. It is widely agreed that outcomes for bereaved families are improved by clear, open communication and support (Coombs et al., 2016; Hinkle et al., 2015; Lautrette, 2007). Effective communication also influenced perceptions of the quality of EOLC and whether a 'good death' was experienced. Previous researchers have shown effective communication can reduce the risk of complicated grief following bereavement in the ICU (Curtis et al., 2016; Kentish-Barnes et al., 2015). Similarly, in a study on bereavement intensity following death in the ICU, being less prepared for death was significantly associated with higher bereavement intensity (Buckley et al., 2015). However, ineffective and absent communication was frequently reported in our synthesis, where families suffered potentially preventable negative outcomes.

In addition to communication, our findings show that assurances of the dying person's comfort contributed to feelings of preparedness. Palliative care research has identified an increase in family satisfaction and well-being and a decrease in anxiety and psychological distress if patient comfort is assured (Funk et al., 2010; Hudson, 2003; Schumacher, Barbara, & Archbold, 2007).

Other unmet needs include the need for proximity, a peaceful dying environment, to experience grief in privacy and to assist in the preparation of the dying environment when death was imminent. Our findings show that the unpredictable nature of the dying process was difficult to witness and that preparing families with information regarding what happens when people are dying helped to ease their distress. A peaceful family-centred dying environment was experienced when nurses supported families to build positive memories at the end of life.

Memory building interventions are demonstrated to counter the "negative visual, auditory and tactile stimuli" of the dying process in the ICU (Cook et al., 2015, p. 277).

A concerning unmet need was that of bereavement care for families. Research has shown that outcomes for bereaved families are improved by access to adequate bereavement care (Coombs et al., 2016; Curtis et al., 2016; Hinkle et al., 2015; Kentish-Barnes et al., 2015). Bereavement support has been identified as a clinical and research priority internationally (Davidson et al., 2017; Department of Health, 2018). Further research is necessary to understand the link between bereavement grief and perceptions of death quality (Wilson et al., 2019).

Despite international guidelines that articulate the need for health professionals to develop specialised knowledge and skills to deliver family-centred EOLC (ACSQHC, 2015; Sprung et al., 2014), our synthesis suggests that ICU health professionals may not have the necessary skills to meet the communication and EOLC needs of families. Given consensus is lacking on educational requisites, our findings recommend guidelines that assist health professionals to assess family preparedness for death and individualised support needs during EOLC (Hudson et al., 2012). Curricular development, education and role support is necessary to assist ICU health professionals to learn and incorporate into practice these important skills.

4.2 Implications for research, policy and practice

Nurses are optimally positioned to facilitate EOLC in the ICU setting. The conceptual 'Model of Preparedness' (Figure 3) can inform the future design of guidelines, practice standards and complex interventions to address families' needs during EOLC in the ICU (Medical Research Council, 2019). This evidence-based model of care for the delivery of family-centred EOLC in the ICU highlights that practice standards should acknowledge the importance of preparedness and support health professionals to: 1) prepare the dying person and their family for treatment withdrawal, the dying process, grief and bereavement, 2) care for the dying patient in a family-centred model of care, 3) promote a peaceful death, 4) communicate effectively and compassionately with the patient and family about end-of-life issues, and 5) assess physical, psychosocial, social, and spiritual needs and provide individualised support and care to the grieving family, including bereavement care.

Practice standards for EOLC should be developed alongside key performance indicators and mandated by registration and governing bodies. To meet international guidelines that articulate the need for health professionals to develop specialised knowledge and skills to deliver family-centred EOLC (ACSQHC, 2015; Sprung et al., 2014), the model could be adapted to support the development of future undergraduate and postgraduate curricula. Evaluation of the effectiveness of EOLC guidelines and their implementation in the ICU is also needed (Chan & Webster, 2016; Luckett, 2017). Healthcare facilities should be appropriately resourced for changes to meet defined standards of care. This qualitative systematic review and meta-synthesis highlights the value of families' views for informing clinical practice, future research and policy development regarding EOLC in the ICU.

4.3 Strengths and limitations of the review

To our knowledge, this is the first qualitative meta-synthesis of the experiences and perceptions of families of adult intensive care patients, on the adequacy of EOLC following treatment withdrawal. A rigorous and transparent approach to systematic review, including quality assessment of included studies and synthesis using meta-aggregation and was employed. The inclusion of thirteen studies from six countries supports the transferability (generalisability) of evolving themes across diverse cultures and healthcare models. Meta-synthesis revealed consistent factors influencing families' perceptions of EOLC across all studies, producing a set of findings that demonstrate dependability and transferability (Boyatzis, 1998; Finfgeld-Connett, 2010). Most authors relied on retrospective recall of events and perceptions. However, the consistency across studies in participant views suggests that these were authentic accounts of experiences. Generalisability was enhanced through maintenance of an audit trail and the use of a range of sampling techniques (Finfgeld-Connett, 2010). Weaknesses in the original design of included papers identified during the quality appraisal guided reviewers to extract some data with caution. In this qualitative synthesis, quality appraisal is not used as basis to exclude, this pragmatic approach was adopted to provide empirical evidence to inform health policy making (Centre for Public Health Excellence, 2009; Downe, 2008; Garside, 2014). ENTREQ guidelines were used to ensure comprehensive reporting (Tong et al., 2012). Limitations include that only the views of family members were reported. It is possible that qualitative studies of health professionals on this topic may have different views.

5. CONCLUSION

Preparedness is key to minimising the distress felt by families and carers in the event families experience EOLC in the ICU. There is consistent evidence from this meta-synthesis that satisfaction with care is experienced when families are adequately prepared for and communicated with about dying and death. Important also to families is to witness compassionate personal care throughout the process and to be present, included and supported. Those who reported feeling unprepared because of perceived shortcomings in communication, support and bereavement care experienced personal distress. To ensure that the needs of families are met during EOLC in the ICU it is suggested that health services and health professionals consider the development of strategies and protocols to support a family-centred approach to preparedness and EOLC.

Acknowledgements

Conflict of Interest statement

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