2017-01-01

An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care

MA Coombs

R Parker

K Ranse

R Endacott *School of Nursing and Midwifery*

MJ Bloomer

An integrative review of how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care

Running title: An integrative review of how families are prepared for withdrawal of life-sustaining treatment in intensive care.

Maureen A COOMBS PhD, MSc, RN
Professor of Clinical Nursing (Critical Care)
Graduate School of Nursing Midwifery and Health, Victoria University of Wellington
Capital and Coast District Health Board, Wellington, New Zealand

Roses PARKER PG Dip Nursing, BSc (Hons), RN
Research Assistant
Graduate School of Nursing Midwifery and Health, Victoria University of Wellington

Kristen RANSE PhD, MN, RN
Assistant Professor in Nursing, Faculty of Health, University of Canberra, Australia

Ruth ENDACOTT PhD, MA, RN
Professor of Critical Care Nursing
Plymouth University, England
School of Nursing and Midwifery, Monash University, Australia

Melissa J BLOOMER PhD, MN (Hons), RN
Formerly Lecturer, School of Nursing and Midwifery, Monash University, Australia
Now Senior Lecturer, School of Nursing and Midwifery, Deakin University, Geelong, Australia

Abstract
Aim. To conduct an integrative review on how nurses prepare families for, and support families during withdrawal of life-sustaining treatments in intensive care.
Background. End-of-life care is widely acknowledged as integral to the practice of intensive care. However, little is known about what happens after the decision to withdraw life-sustaining treatments has been made, and how families are prepared for death and the dying process.
Design. Integrative literature review.
Data sources. MEDLINE, CINAHL Plus, PsychINFO, PUBMED, Scopus, EMBASE and Web of Knowledge were searched for papers published between 2000 and May 2015.
Review methods. A five stage review process, informed by Whittemore and Knafl's methodology, was conducted. All papers were reviewed and quality assessment performed. Data were extracted, organised, and analysed. Convergent qualitative thematic synthesis was used.
Results. From an identified 479 papers, 24 papers were included in this review with a range of research approaches: qualitative (n=15); quantitative (n=4); mixed methods (n=2); case study (n=2); and discourse analysis (n=1). Thematic analysis revealed the nurses: equipped families for end of life through information provision and communication; managed the withdrawal of life-sustaining treatments to meet family need; and continued care to build memories.
Conclusion. Greater understanding is needed of the language that can be used with families to describe death and dying in intensive care. Clearer conceptualisation of the relationship between the medically focussed withdrawal of life-sustaining treatments and patient/family centred end-of-life care is required making the nursing contribution at this time more visible.

Keywords: integrative review, intensive care, end of life, treatment withdrawal, families, nursing role

Summary statement

- **Why is this research or review needed?**
  - The quality of decision making and care delivery at end of life can impact on health outcomes of bereaved families in intensive care
  - Much is known about the preparation of families when discussing the transition from active treatment to end-of-life care
  - Little is currently known about how families are prepared for, and supported during treatment withdrawal of life-sustaining treatments in the intensive care unit
- **What are the key findings?**
  - Families are prepared for the withdrawal of life-sustaining treatment through communication of selected information; active planning and management of the withdrawal of life-sustaining treatments process to meet family need, and continued care of the patient to enable positive memories to be built.
  - Information is shared with families as a result of an assessment about what families know and understand about treatment withdrawal; the selection of relevant information; and the communication of this in a clear and considerate manner
  - The withdrawal of life-sustaining treatments is a complex process that involves the technical process of removal of treatments, the timing and specific order of events and nursing actions of continued care are informed by a nursing assessment of family need.
- **How should the findings be used to influence policy/practice/research/education?**
  - The proposed model provides a framework to guide education and professional development for nurses in treatment withdrawal of life-sustaining treatments in intensive care
  - In describing the important contribution that nurses make at the beside when preparing family members for, and supporting families during withdrawal of life-sustaining treatments in intensive care, the care at end-of-life care has been profiled

Introduction

A substantial number of patients who die in hospital, will die in intensive care (Angus et al., 2004) with the majority dying as a result of withdrawal of life-sustaining treatments (Bloomer et al., 2010; Lesieur et al., 2015). This area of practice has received increasing international attention with research programmes to understand the impact of end-of-life care on patient and family outcomes now well-established in North America, Australasia and Europe. Whilst research has focused on the decision making processes, communication and information required at the point of transition from active intervention to palliation, other areas of end-of-life care have been poorly explored. One such aspect is support given to families in preparation for, and during the process of withdrawing life-sustaining treatment. This is an important omission as care given to families at this time is often shaped by the nurse at the bedside (Long-Sutehall et al., 2011). To inform understanding in this area, an integrative review was undertaken. This paper reports on the findings.

Background

End of life in intensive care provides distinct challenges to families in international intensive care units (Bloomer et al., 2013, Halel et al., 2013, Arbour and Wiegand, 2014). The transition from active treatment to palliation can be rapid (Hoel et al., 2014) requiring re-adjustment and new understanding for all involved. . Furthermore, the withdrawal of life-sustaining treatments prior to death usually results in a dying process that is not natural, but i planned and staged (Harvey, 1997) by the deliberate reduction and eventual removal of treatments such as advanced ventilation, and cardiovascular therapies (Psirides and Sturland, 2009). Removal of these may result in immediate deterioration and rapid death (Wunsch et al., 2005). Families may not be prepared for the death of their family member in such a manner, and in such a setting.

A strong evidence base already exists to guide some aspects of end-of-life practice (Hinkle et al., 2015).The importance of communication with families at the transition from active treatment to end-of-life care and treatment withdrawal has been demonstrated (Scheunemann et al., 2011) and , if not well managed, negative outcomes may result (Azoulay et al., 2005; Davidson, 2009). Once the decision to withdraw treatment has been made, the processes of care, the 'how and when' treatments are withdrawn, and the nature of the support given to the family to prepare for this, is mainly orchestrated by the bedside nurse (Long-Sutehall et al., 2011).

It is widely agreed that outcomes for bereaved families are improved by clear, honest communication and support at this time (Lautrette et al., 2007, Hinkle et al., 2015). It seems logical to suggest that communication and preparation of families for the withdrawal of life-sustaining treatment and subsequent death of their family member may also have some benefit on bereaved family outcomes. This has been less well explored and further guidance is required to inform this area of practice.

For the purposes of this review, the terms 'intensive care' and 'critical care' are used synonymously and the term 'family' is used to encompass 'family, next of kin, significant others and friends'. Treatment withdrawal or withdrawal of treatment is defined as the reduction and cessation of life-sustaining treatments in the intensive care setting.

THE REVIEW

Aim

The question guiding this review was: What is the qualitative and quantitative evidence for how families are prepared for, and supported during withdrawal of life-sustaining treatment in intensive care?

Design

A structured integrative review was conducted of theoretical, empirical and grey literature, based on Whittemore and Knafl's methodology (Whittemore and Knafl, 2005). This enabled empirical work using a broad range of methodologies to be reviewed. Data was extracted and evaluated using a standardised data collection sheet informed by Caldwell et al.'s framework (Caldwell et al., 2011). This framework allows researchers to consider qualitative and quantitative work simultaneously whilst acknowledging differences in the quality measures required. The outcome of this quality analysis is a list of methodological strengths and weaknesses of each study.

Search methods

A broad search strategy was employed across the life span (neonates to adults) and intensive care specialities. Two discrete searches (Table 1) were employed using common Boolean operators.

Table 1: Search strategy

Inclusion and exclusion criteria were developed and agreed (Table 2). Systematic review papers were not included in this review, although reference lists were reviewed for relevant primary research studies. MEDLINE, CINAHL Plus, PsychINFO, PubMed, Scopus, EMBASE and Web of Knowledge databases were searched.

Table 2: Inclusion and exclusion criteria

Search outcome

A five stage screening process was undertaken: removal of duplicates, screening of title, abstract review, full paper review, and reference tracking on the final selected papers. From the original 479 papers, 24 were included in this review (Figure 1). Results from all database searches were exported into Zotero.

Figure 1: PRISMA flow diagram

Quality appraisal

An assessment of quality was conducted using a framework developed by Caldwell et al. (2011) and used by others (e.g. Stelfox et al, 2013). This framework assists in the quality assessment of the papers based on methodological strengths and weaknesses of the studies. The framework uses generic questions, for example on ethical practice in the study, and specific criteria for review of qualitative and quantitative studies. This enables comparison of papers to occur whilst acknowledging different theoretical and paradigmatic positions. Use of this framework addressed a recognised challenge of conducting quality appraisals in integrative reviews (Whittemore and Knafl, 2005). All final papers were read by two researchers (MC and RP), and agreement reached on the quality assessment. Evidence tables were used to provide summary of the studies and quality appraisal.

Data abstraction

All duplicate records were removed and two researchers reviewed the first ten titles of papers identified (MC and RP) to ensure selection and data extraction processes were robust. One researcher (RP) undertook review at each stage of title, abstract and full paper with a second researcher (MC) reviewing all excluded titles, one in ten included abstracts, one in five excluded abstracts and every paper excluded after full review as a quality check. Reference lists of all included papers were also reviewed. f The final list of included papers was reviewed against the inclusion criteria by the full research team (KR, RE, MB).

Data analysis and synthesis

All included papers were read line by line. A convergent thematic synthesis (Pluye and Hong, 2014) was undertaken where findings and results from all studies (qualitative, quantitative and mixed methods) were brought together as themes. Patterns and relationships relevant to the review were identified using an iterative process. Two researchers (MC and RP) discussed similarities and differences in the data with initial codes arising from this. These codes were then grouped into sub-themes and themes, based on connections and variations in the data. Themes were compared and contrasted to ensure logical and rigorous description of patterns were determined. The list of themes and sub-themes along with brief descriptions of each was sent to the research team for verification of accuracy and relevancy. The outcome of the synthesis was presented as a model (see Figure 2).

Results

From an identified 479 papers, 24 papers were included in this review (Table 3). A range of research approaches were used: qualitative (n=15); quantitative (n=4); mixed methods (n=2); case study (n=2); and discourse analysis (n=1). Most studies focussed on withdrawal of life-sustaining treatments as a part of an exploration of end-of-life care. With regards to methodological quality, there was limited use of theoretical frameworks and whilst rationale for studies was clearly given, the hypotheses informing quantitative papers were not always supplied. Detail of methods were well attended to, although detail about study rigour was less clear, for example, two qualitative papers reported on data saturation. Clinical implications were well developed (See supplementary information: Table 1).

Table 3: Papers included in the review.

From the analysis, three themes were developed that described how nurses prepare and support families during withdrawal of life-sustaining treatment in intensive care through: equipping families for end of life through information and communication; managing the withdrawal of life-sustaining treatments; and continuing to care (Figure 2).

EQUIPPING FAMILIES FOR END OF LIFE THROUGH INFORMATION AND COMMUNICATION

The need for nurses to prepare families through use of information for withdrawal of life-sustaining treatment, and for the imminent death of their family member was identified as paramount in many of the papers. Only two papers (McMillen, 2008: Psirides and Sturland, 2009) did not discuss information and communication. The use of information and communication began with nurses assessing families' information needs. This led to the selection of pertinent information and finally to the delivery of this information in a selected way appropriate for the family.

Assessment of families' information needs

Many papers (n=15) discussed how nurses assessed family understanding of the processes of treatment withdrawal. This information was used to inform areas of teaching provided by nurses to family members for example, regarding weaning of ventilation and vasoactive drugs (Arbour and Wiegand, 2014), and to tailoring of the withdrawal of life-sustaining process (Pattison et al., 2013). Nurses had developed skills to assess and address the knowledge needs of families (Long-Sutehall et al., 2011). This included nurses asking questions to assess whether an accurate and realistic understanding was held; results of which then directed further information giving or prompted further actions e.g. discussion with medical staff, support from pastoral care. Recognising that each family was unique acknowledged that there was no 'one size fits all' method during end-of-life care (Heland, 2006).

Selecting information

The type of information nurses offered prior to, and during the treatment withdrawal process was discussed in 21 of the 24 papers. The type of information was informed by the assessment of family need and understanding. Information discussed with families often included: physical changes during the withdrawal of treatment explaining equipment alarms or procedures, such as the removal of an endotracheal tube; or offering information which encouraged interaction with the patient.

There was a strong focus on information about physical changes during treatment withdrawal. In one study, ICU nurses identified 43 descriptors relating to preparing families for withdrawal of mechanical ventilation, 67.5% of which were physical changes (Kirchhoff et al., 2003). Changes frequently mentioned by nurses included colour changes (Kirchhoff et al., 2003, 2008; Epstein, 2008, 2010), and breathing changes (McHaffie et al., 2001; Kirchhoff et al., 2003, 2008; Rocker et al., 2005; Kompanje, 2006; Epstein, 2008, 2010; Yeager et al., 2010). From nurses' perspectives, the difficulty of providing families with accurate information on the likely timeframe between treatment withdrawal and death was highlighted (McHaffie et al., 2001; Epstein, 2003, 2010; Kirchhoff et al., 2003, 2008; Wiegand, 2006).

Understanding how life-sustaining treatments were withdrawn was key to family satisfaction with care (Keenan et al., 2000). Nurses used different strategies to help families, for example, using medical records (Abib El Halal et al., 2013) and talking about how vasoactive medications work and what happens when these are withdrawn (Arbour and Wiegand, 2014). Nurses identified that taking time to explain life-sustaining treatment withdrawal was key (Ranse et al., 2012) with family members being appreciative of this (Pattison et al., 2013). Families spoke of the distress when events happened for which they were unprepared (Rocker et al., 2005; Wiegand, 2006), including changes to monitors and removal of invasive tubes (Kirchhoff et al., 2008).

Nurses also selected information that helped families understand the interaction that they could hold with their critically ill family member. In one study, 42% of nurses said they would provide information encouraging families to talk to their family member (Kirchhoff et al., 2003). Other areas included helping families to understand that stroking the patients' hair (Heland, 2006), being in bed with the patient (Pattison et al., 2013) or participating in providing comfort measures to the patient (Yeager et al., 2010) were possible. In one study that included patients who had been close to death but had survived (Pattison et al., 2013), participants reported that having family present was important in what they thought were their final moments.

Delivery of clear and considerate information

Consideration of how information was delivered was also important. Thirteen studies emphasised that the way in which information was delivered to families was key to optimise family comprehension. Communication was identified by nurses as an essential skill (Zomorodi and Lynn, 2010). Nurses were seen as 'translators' for technical language used by others (Bloomer et al., 2013) and ensuring that they avoided use of jargon and technical terms which could further limit family understanding (Abib El Halal et al., 2013). Nurses perceived relationship building key to the successful communication of information (Epstein, 2008) and intensive care nurses worked to ensure delivery of information was compassionate and respectful (Arbour and Wiegand, 2014).

Figure 2: How families are prepared for withdrawal of life-sustaining treatments in intensive care

MANAGING THE WITHDRAWAL OF LIFE-SUSTAINING TREATMENTS

Nurses managed the complex process of withdrawal of life-sustaining treatments to attend to patient and family needs. This was undertaken through attention to: how individual treatments were withdrawn; how the withdrawal of treatments was commenced (timing); and how symptoms resultant from treatment withdrawal and the dying process were managed. Eleven out of the 24

papers contributed to two or more of the sub-themes. Only three papers (Epstein, 2008; McHaffie et al., 2001; Peden-McAlpine et al., 2015) did not present any data relevant to this particular theme.

Withdrawal of treatments

Nursing interventions to tailor withdrawal of treatment to meet needs of families were described in 11 studies. Nurses described how the withdrawal of treatments was choreographed to mimic gradual decline, often associated with natural death (Long-Sutehall et al., 2011), with nurses and doctors titrating treatment withdrawals, such as the administration of inotropes, to meet the family need and minimise distress (Pattison et al., 2013). Discussion was raised about some practices e.g. extubation at end of life, and whether this would reduce family distress due to the more normal appearance of their relative as a result. The use of passive limb exercises, whilst not usually recognised as a treatment, was also debated by nurses in one study where t the decision to withdraw this was informed by whether seeing this take place gave families comfort or distress (Coombs et al., 2015)

Timing of the withdrawal of life-sustaining treatments

Timing and duration of treatment withdrawal processes was mentioned in 11 studies and seen as of vital importance to families (Arbour and Wiegand, 2014) with a significant reported impact on family satisfaction (Keenan et al., 2000). Nurses emphasised that timing of the process should be individualised (Bloomer et al., 2013). Whilst delays could be distressing to families (Wiegand, 2006), at other times, nurses delayed the treatment withdrawal process, to enable families in conflict to reach resolution, or to enable family members say their goodbyes (Heland, 2006; Bloomer et al., 2013; Pattison et al., 2013). Nurses reported that giving families time to accept what was happening was an important part of the treatment withdrawal process (McMillen, 2008). If managed well, this could help families identify that their relative had a good death (Pattison et al., 2013).

Symptom control during and after the withdrawal of life-sustaining treatments

Ensuring that patients were comfortable and not distressed during treatment withdrawal was important to families with seventeen papers identifying the importance of symptom control and comfort. This was a significant area influencing family satisfaction with the treatment withdrawal process (Keenan et al., 2000) and identified by families as a core tenet to quality end of life care (Pattison et al., 2013). Nurses sought to control pain in patients, so that families did not see their relative suffer (Epstein, 2010). Nurses used sedation to reduce families perception of discomfort in the dying family member (Rocker et al., 2005). One paper also described measures used to control the 'death rattle', a terminal symptom particularly distressing for families (Kompanje, 2006). Nurses' symptom management was often coupled with reassurance given to the family members about patient comfort (Epstein, 2010); achieving good symptom control also contributed to greater job satisfaction for nurses (Arbour and Wiegand, 2014).

CONTINUING TO CARE

Whilst nurses were withdrawing life-sustaining treatment, nurses were not withdrawing care. Nursing care was an area that helped families built positive memories of their family member at end of life. This theme featured heavily in the literature reviewed with over half the papers exploring the sub-themes of preparing the patient, emotional support, adapting the environment, nurse presence with the family and creating memories.

Preparing the patient

Preparing the patient in order to help families remember 'the person' in a favourable way was highlighted in eight papers. Nursing actions involved making the patient look as normal as possible (Arbour and Wiegand, 2014; Peden-McAlpine et al., 2015), and bathing the patient (Epstein, 2008, 2010; Bloomer et al., 2013). Bathing was especially mentioned by nurses in studies regarding

children where parents may find this an important ritual to participate in before saying 'goodbye' (Epstein, 2008). Other examples included nurses covering areas of extensive burns so that the family could not see them (Heland, 2006), organising families to bring bedding from home to create a homely atmosphere, applying the patient's favourite moisturiser and putting the patient in their own night clothes (Pattison et al., 2013).

Providing emotional support for the family

Nurses undertook a key role in providing emotional support to families at this time (Ranse et al., 2012). Indeed, this aspect of the nursing role was referenced in 15 papers. Examples of the words used by nurses to describe the approach offered to families at this time included sensitive (Arbour and Wiegand, 2014), respect (Bloomer et al., 2013), concern, rapport (Coombs et al., 2015), relieving burdens (Epstein, 2010), comfort (Heland, 2006) and expressing emotions (Pattison et al., 2013). Another important aspect of support was offering services such as spiritual support and palliative care (Wiegand, 2006; Yeager et al., 2010). The provision of information is an act of support itself and families were distressed when they were not kept informed perceived its absence (Abib El Halal et al., 2013).

Adapting the environment

Reference to environmental factors was made in 20 of the 24 papers reviewed. Thirty-two percent of nurses in one study said they would modify the environment by removing all unnecessary equipment (Kirchhoff et al., 2003) with this action highly cited in other literature (Rocker et al., 2005; Fridh et al., 2009; Psirides and Sturland, 2009; Epstein, 2010; Zomorodi and Lynn, 2010; Long-Sutehall et al., 2011; Ranse et al., 2012; Pattison et al., 2013; Arbour and Wiegand, 2014; Peden-McAlpine et al., 2015). Adapting the environment was seen by nurses to create a peaceful, 'homely' setting and to de-intensify the clinical environment that could act as a barrier to families interacting with their loved one (Pattison, 2006; Peden-McAlpine et al., 2015). Privacy was another important condition that nurses endeavoured to provide wherever possible (Keenan et al., 2000; Rocker et al., 2005; Heland, 2006; Wiegand, 2006; Fridh et al., 2009; Ranse et al., 2012; Pattison et al., 2013). Indeed, when privacy was lacking, families reported this as a source of dissatisfaction (Abib El Halal et al., 2013). Family privacy enabled private family grieving and prevented families from being exposed to other events e.g. births in one neonatal intensive care unit (McHaffie et al., 2001). When providing privacy was a challenge, for example if limited single rooms, nurses continued to modify the environment as described (Fridh et al., 2009; Bloomer et al., 2013).

Nursing presence with the family

The importance of nursing presence with the family at the bedside was discussed in 12 papers. This often required a judgement to be made balancing the need for nurses to give family privacy for grieving with the requirement for the nurse to be there for the family. However the literature more commonly emphasised the importance of being available to the family whether for questions, information or simply providing presence (McHaffie et al., 2001; Kirchhoff et al., 2003; Long-Sutehall et al., 2011; Ranse et al., 2012; Pattison et al., 2013).

Nurses and physicians reported different perspectives on presence at the bedside during the dying process. Physicians felt that the presence of health care practitioners was intrusive for families, where nurses felt an obligation to be present and available for families (Epstein, 2010). Nurses in one study indicated that even in silence, their presence was important to the family (Peden-McAlpine et al., 2015) and when nurses were asked to describe providing good quality care, a calming presence was one of the characteristics identified (Zomorodi and Lynn, 2010).

Creating positive memories

Although only referenced in five papers, the importance of creating positive memories was a significant contribution to the literature. Conducting end-of-life rituals such as taking photographs, and enabling families to hold the patient were examples of how nurses described creating positive memories for families (Epstein, 2008) with 71% of nurses involved in this study describing such actions. McHaffie et al. (2001) described how these were important ways in which families could be active at this time and interact with the patient (McHaffie et al., 2001). Other papers described the process of creating a "love lock" by removing a lock of hair and putting it into a card for remembrance and making a hand print of the patient and including a poem in the background (Yeager et al., 2010, Ranse et al., 2012)

Discussion

Thematic analysis has allowed identification of a theoretical model that not only identifies how nurses prepare families for, and support families during, withdrawal of life-sustaining treatments in intensive care but also provides information that may be helpful to distinguish between processes involved in withdrawal of treatment and those involved in providing end-of-life care, and indeed where these intersect (see Figure 2). The withdrawal of life-sustaining treatments as part of end-of-life care in intensive care is a complex process that: is prefaced by targeted information given by nurses to families; involves technical procedures of withdrawal, the timing and processes of which are staged to help families understand death and dying in intensive care; combined with specific nursing care strategies to emotionally support families at this time.

At the centre of the developed model is the theme of equipping families for end of life through information and communication. In positioning information and communication centrally within the model, nurses reinforce current understanding about the importance of communication and preparation for families facing death from other diseases (Loke et al., 2013), and when undertaking difficult health care conversations (Nelson et al., 2009). As nurses make assessments about family need at this time and allow this to inform the withdrawal process, a family-centred approach to care is facilitated. Given that very few critically ill patients are able to participate in decision making during life-sustaining treatment withdrawal (Prendergast and Luce, 1997), this is entirely appropriate and consistent with other work in this area (Hinkle et al., 2015).

Withdrawal of life-sustaining treatments, as facilitated by nurses in intensive care, not only focusses the process of treatment withdrawal, it also focusses on practical factors and inter-personal considerations that may affect this. This raises awareness that withdrawal of treatment is not solely guided by physiological factors of the patient, as this process is often described (British Medical Association, 2001). It was notable in the review that there was little detailed discussion as to how the withdrawal of life-sustaining treatments was actually operationalised. Whilst there is some literature in this area (Bell, 2008; El-Khatib and Bou-Khalil, 2008; Kompanje, 2006, 2006), there are few comprehensive guidelines to inform practice. There is a need for further empirical and practice review. In making clear the complex processes undertaken in preparation for, and during treatment withdrawal, together with the nursing care given, the developed model (Figure 2) provides a useful framework to guide practice and may be useful to support for novice (and indeed all) critical care nurses.

In the papers reviewed, no clear distinction was made between treatment withdrawal and end-of-life care. This raises interesting theoretical questions about how terms are used; whether end-of-life care is part of withdrawal of life-sustaining treatments in this context, or vice versa, and whether treatment withdrawal is the medicalisation of end-of-life care in this clinical setting. The emergence

of this theoretical challenge is perhaps, unsurprising given the stronger focus on clinical application and implications, as opposed to theoretical and conceptual critique, within the literature reviewed. Treatment withdrawal, as discussed in the literature, is predominantly an intensive care–centric concept. We would argue that there needs to be clear description of the relationship between withdrawal of life-sustaining treatments and of end-of-life care. Clear articulation of the care given by nurses to the patient and family in intensive care at this time is required, otherwise the nursing contribution by may be rendered invisible.

Strengths and limitations

Strengths of this review have been noted including the innovative area of exploration and the rigorous integrative review process undertaken. Limitations of this study relate to the search strategies undertaken, the heterogeneity of the studies identified, and limitations of the quality framework used. As previously reported by Whittemore and Knalf (2005), inconsistent search terminology and indexing, can lead to search bias and limit the effectiveness of the search (Whittemore and Knafl, 2005). Furthermore, there was potential for language bias (English only) and publishing bias (publications post 2000). The quality appraisal tool was selected due to its applicability to qualitative and quantitative methodologies. However, this tool did not easily allow appraisal of other methodologies encountered in this review e.g. critical discourse analysis, and is a further limitation.

Implications for practice, research and education

Although nurses are key in end-of-life care, there is little evidence to inform practice related to the withdrawal of life-sustaining treatment and its sequelae. Findings from this review highlight the need for further work in this area, especially concerning what information is given to families to prepare for the treatment withdrawal process, and describing what death in intensive care looks like, how nurses make assessment about the information needs of families, and the staging (timing) of withdrawing life-sustaining treatments. There is opportunity to undertake more research in this area to give nurses a vocabulary to describe these events, and an educational and professional development framework to guide care at this time.

There is a need to recognise the nursing role during treatment withdrawal and to extend the current knowledge base of communication at the transition from intervention to palliation into the stage of transition to withdrawal of life-sustaining treatments. Furthermore there is a theoretical and philosophical debate to be had regarding the positioning of withdrawal of life-sustaining treatments and end-of-life care. It could be argued that the intensive care nurse provides end-of-life care; treatment withdrawal is only part of this and solely describes the removal of medical interventions. This is important to understand so that the nursing philosophy of care is seen to continue up to, and beyond the moment of death in an environment that may otherwise be seen as technologically oriented.

Conclusion

There is continued international societal and health care debate on the need for high quality care at end-of-life. This integrative review has made contribution to these discussions through bringing together literature about care delivered in the final hours of a critically ill person's life, and the support given to families at this time. This area has not been well explored to date, and in raising awareness as to events at this time, this review has begun to articulate a model that can inform practice and future research in this area.

Conflict of interest

The authors declare no conflicts of interest.

Funding
This work was part funded by an Australian College of Critical Care Nurses Experienced Researcher Grant.

Author contributions
All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design
- acquisition of data, or analysis and interpretation of data
- drafting the article or revising it critically for important intellectual content.

Impact statement

- Working with families when providing end-of-life care is a key role for the critical care nurse
- Whilst there is understanding about specific aspects of family support e.g. discussing the transition from active treatment to end-of-life care, less is known about the practices during the actual withdrawal of treatment process and how best to support families at this time
- This integrative review critically summarises current knowledge in this area proposing a model of how families are prepared for the withdrawal of life-sustaining treatments.

References

Abib El Halal, G.M.C., Piva, J.P., Lago, P.M., El Halal, M.G.S., Cabral, F.C., Nilson, C., Garcia, P.C.R., 2013. Parents' perspectives on the deaths of their children in two Brazilian paediatric intensive care units. Int. J. Palliat. Nurs. 19, 495–502. doi:10.12968/ijpn.2013.19.10.495

Angus, D.C., Barnato, A.E., Linde-Zwirble, W.T., Weissfeld, L.A., Watson, R.S., Rickert, T., Rubenfeld, G.D., Robert Wood Johnson Foundation ICU End-Of-Life Peer Group, 2004. Use of intensive care at the end of life in the United States: an epidemiologic study. Crit. Care Med. 32, 638–643.

Arbour, R.B., Wiegand, D.L., 2014. Self-described nursing roles experienced during care of dying patients and their families: A phenomenological study. Intensive Crit. Care Nurs. 30, 211–218. doi:http://dx.doi.org/10.1016/j.iccn.2013.12.002

Azoulay, E., Pochard, F., Kentish-Barnes, N., Chevret, S., Aboab, J., Adrie, C., Annane, D., Bleichner, G., Bollaert, P.E., Darmon, M., Fassier, T., Galliot, R., Garrouste-Orgeas, M., Goulenok, C., Goldgran-Toledano, D., Hayon, J., Jourdain, M., Kaidomar, M., Laplace, C., Larché, J., Liotier, J., Papazian, L., Poisson, C., Reignier, J., Saidi, F., Schlemmer, B., 2005. Risk of Post-traumatic Stress Symptoms in Family Members of Intensive Care Unit Patients. Am. J. Respir. Crit. Care Med. 171, 987–994. doi:10.1164/rccm.200409-1295OC

Bell, L., 2008. Preparing ICU Families for Withdrawal of Life Support. Am. J. Crit. Care 17, 123–123.

Bloomer, M.J., Morphet, J., O'Connor, M., Lee, S., Griffiths, D., 2013. Nursing care of the family before and after a death in the ICU—An exploratory pilot study. Aust. Crit. Care 26, 23–28. doi:10.1016/j.aucc.2012.01.001

Bloomer, M.J., Tiruvoipati, R., Tsiripillis, M., Botha, J.A., 2010. End of life management of adult patients in an Australian metropolitan intensive care unit: A retrospective observational study. Aust. Crit. Care 23, 13–19. doi:10.1016/j.aucc.2009.10.002

British Medical Association, 2001. Wiley: Withholding and Withdrawing Life-prolonging Medical Treatment, 3rd Edition - Veronica English [WWW Document]. URL http://au.wiley.com/WileyCDA/WileyTitle/productCd-140515957X.html (accessed 1.29.16).

Caldwell, K., Henshaw, L., Taylor, G., 2011. Developing a framework for critiquing health research: an early evaluation. Nurse Educ. Today 31, e1–7. doi:10.1016/j.nedt.2010.11.025

Coombs, M., Fulbrook, P., Donovan, S., Tester, R., deVries, K., 2015. Certainty and uncertainty about end of life care nursing practices in New Zealand Intensive Care Units: A mixed methods study. Aust. Crit. Care. doi:10.1016/j.aucc.2015.03.002

Davidson, J.E., 2009. Family-Centered Care: Meeting the Needs of Patients' Families and Helping Families Adapt to Critical Illness. Crit. Care Nurse 29, 28–34. doi:10.4037/ccn2009611

El-Khatib, M.F., Bou-Khalil, P., 2008. Clinical review: Liberation from mechanical ventilation. Crit. Care 12, 221. doi:10.1186/cc6959

Epstein, E.G., 2010. Moral obligations of nurses and physicians in neonatal end-of-life care. Nurs. Ethics 17, 577–589. doi:10.1177/0969733010373009

Epstein, E.G., 2008. End-of-life experiences of nurses and physicians in the newborn intensive care unit. J. Perinatol. 28, 771–778. doi:10.1038/jp.2008.96

Fridh, I., Forsberg, A., Bergbom, I., 2009. Doing one's utmost: Nurses' descriptions of caring for dying patients in an intensive care environment. Intensive Crit. Care Nurs. 25, 233–241. doi:10.1016/j.iccn.2009.06.007

Harvey, J., 1997. The Technological Regulation of Death: With Reference to the Technological Regulation of Birth. Sociology 31, 719–735. doi:10.1177/0038038597031004005

Heland, M., 2006. Fruitful or futile: Intensive care nurses' experiences and perceptions of medical futility. Aust. Crit. Care 19, 25–31. doi:10.1016/S1036-7314(06)80020-2

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. Chest 147, 82–93. doi:10.1378/chest.14-1098

Hoel, H., Skjaker, S.A., Haagensen, R., Stavem, K., 2014. Decisions to withhold or withdraw life-sustaining treatment in a Norwegian intensive care unit. Acta Anaesthesiol. Scand. 58, 329–336. doi:10.1111/aas.12246

Keenan, S.P., Mawdsley, C., Plotkin, D., Webster, G.K., Priestap, F., 2000. Withdrawal of life support: How the family feels, and why. J. Palliat. Care 16, S40–4.

Kirchhoff, K.T., Conradt, K.L., Anumandla, P.R., 2003. ICU nurses' preparation of families for death of patients following withdrawal of ventilator support. Appl. Nurs. Res. ANR 16, 85–92.

Kirchhoff, K.T., Palzkill, J., Kowalkowski, J., Mork, A., Gretarsdottir, E., 2008. Preparing families of intensive care patients for withdrawal of life support: A pilot study. Am. J. Crit. Care 17, 113–122.

Kompanje, E.J.O., 2006. "Death rattle" after withdrawal of mechanical ventilation: Practical and ethical considerations. Intensive Crit. Care Nurs. 22, 214–219. doi:10.1016/j.iccn.2005.06.004

Lautrette, A., Darmon, M., Megarbane, B., Joly, L.M., Chevret, S., Adrie, C., Barnoud, D., Bleichner, G., Bruel, C., Choukroun, G., Curtis, J.R., Fieux, F., Galliot, R., Garrouste-Orgeas, M., Georges, H., Goldgran-Toledano, D., Jourdain, M., Loubert, G., Reignier, J., Saidi, F., Souweine, B., Vincent, F., Barnes, N.K., Pochard, F., Schlemmer, B., Azoulay, E., 2007. A Communication Strategy and Brochure for Relatives of Patients Dying in the ICU. N. Engl. J. Med. 356, 469–478. doi:10.1056/NEJMoa063446

Lesieur, O., Leloup, M., Gonzalez, F., Mamzer, M.-F., 2015. Withholding or withdrawal of treatment under French rules: a study performed in 43 intensive care units. Ann. Intensive Care 5. doi:10.1186/s13613-015-0056-x

Loke, A.Y., Li, Q.Mm., Man, L.S.Ms., 2013. Preparing Family Members for the Death of Their Loved One With Cancer: A Review of Literature and Direction for Future Research. J. Hosp. 15. doi:10.1097/NJH.0b013e3182860650

Long-Sutehall, T., Willis, H., Palmer, R., Ugboma, D., Addington-Hall, J., Coombs, M., 2011. Negotiated dying: A grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. Int. J. Nurs. Stud. 48, 1466–1474. doi:10.1016/j.ijnurstu.2011.06.003

McHaffie, H.E., Laing, I.A., Lloyd, D.J., 2001. Follow up care of bereaved parents after treatment withdrawal from newborns. Arch. Dis. Child. 84, F125–F128. doi:10.1136/fn.84.2.F125

McMillen, R.E., 2008. End of life decisions: Nurses perceptions, feelings and experiences. Intensive Crit. Care Nurs. 24, 251–259. doi:10.1016/j.iccn.2007.11.002

Nelson, J.E., Walker, A.S., Luhrs, C.A., Cortez, T.B., Pronovost, P.J., 2009. Family meetings made simpler: a toolkit for the intensive care unit. J. Crit. Care 24, 626.e7–14. doi:10.1016/j.jcrc.2009.02.007

Pattison, N., 2006. A critical discourse analysis of provision of end-of-life care in key UK critical care documents. Nurs. Crit. Care 11, 198–208.

Pattison, N., Carr, S.M., Turnock, C., Dolan, S., 2013. "Viewing in slow motion": patients', families', nurses' and doctors' perspectives on end-of-life care in critical care. J. Clin. Nurs. 22, 1442–1454. doi:10.1111/jocn.12095

Peden-McAlpine, C., Liaschenko, J., Traudt, T., Gilmore-Szott, E., 2015. Constructing the story: How nurses work with families regarding withdrawal of aggressive treatment in ICU - A narrative study. Int. J. Nurs. Stud. doi:10.1016/j.ijnurstu.2015.03.015

Pluye, P., Hong, Q.N., 2014. Combining the power of stories and the power of numbers: mixed methods research and mixed studies reviews. Annu. Rev. Public Health 35, 29–45. doi:10.1146/annurev-publhealth-032013-182440

Prendergast, T.J., Luce, J.M., 1997. Increasing incidence of withholding and withdrawal of life support from the critically ill. Am. J. Respir. Crit. Care Med. 155, 15–20. doi:10.1164/ajrccm.155.1.9001282

Psirides, A.J., Sturland, S., 2009. Withdrawal of active treatment in intensive care: what is stopped - comparison between belief and practice. Crit. Care Resusc. 11, 210–214.

Ranse, K., Yates, P., Coyer, F., 2012. End-of-life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices. Aust. Crit. Care 25, 4–12. doi:10.1016/j.aucc.2011.04.004

Rocker, G.M., Cook, D.J., O'Callaghan, C.J., Pichora, D., Dodek, P.M., Conrad, W., Kutsogiannis, D.J., Heyland, D.K., 2005. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. J. Crit. Care 20, 59–65. doi:10.1016/j.jcrc.2004.10.006

Scheunemann, L.P., McDevitt, M., Carson, S.S., Hanson, L.C., 2011. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. Chest 139, 543–554. doi:10.1378/chest.10-0595

Stelfox, H.T., Perrier, L., Straus, S.E., Ghali, W.A., Zygun, D., Boiteau, P., Zuege, D.J. (2013) Identifying intensive care unit discharge planning tools: protocol for a scoping review. BMJ Open 3:e002653; doi10.1136/bmjopen-2013-002653

Whittemore, R., Knafl, K., 2005. The integrative review: updated methodology. J. Adv. Nurs. 52, 546–553. doi:10.1111/j.1365-2648.2005.03621.x

Wiegand, D., L., Grant, M., S., Jooyoung Cheon, Gergis, M., A., 2013. Family-Centered End-of-Life Care in the ICU. J. Gerontol. Nurs. 39, 60–68. doi:10.3928/00989134-20130530-04

Wiegand, D.L.-M., 2006. Withdrawal of life-sustaining therapy after sudden, unexpected life-threatening illness or injury: Interactions between patients' families, healthcare providers, and the healthcare system. Am. J. Crit. Care 15, 178–187.

Wunsch, H., Harrison, D.A., Harvey, S., Rowan, K., 2005. End-of-life decisions: a cohort study of the withdrawal of all active treatment in intensive care units in the United Kingdom. Intensive Care Med. 31, 823–831. doi:10.1007/s00134-005-2644-y

Yeager, S., Doust, C., Epting, S., Iannantuono, B., Indian, C., Lenhart, B., Manche, D., Morris, M., Newton, B., Ortman, L., Young, K., Thomas, K., 2010. Embrace Hope: An End-of-Life Intervention to Support Neurological Critical Care Patients and Their Families. Crit. Care Nurse 30, 47–58. doi:10.4037/ccn2010235

Zomorodi, M., Lynn, M.R., 2010. Critical Care Nurses' Values and Behaviors With End-of-Life Care Perceptions and Challenges. J. Hosp. Palliat. Nurs. 12, 89–96. doi:10.1097/NJH.0b013e3181cf7cf6

Table 1: Search strategy

First search	Second search
intensive care OR critical care	intensive care OR critical care
nurs*	nurs*
famil* OR bereaved famil*	famil* OR bereaved famil*
withdrawal of treatment OR treatment withdrawal	prepar* for death OR prepar* for dying OR signs of death OR signs of dying

Table 2: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Published between January 2000 and May 2015	Papers relating primarily to non-ICU ward areas
Published in English language	Systematic review, policy or opinion pieces
Theoretical and empirical literature	Papers relating to end of life not including treatment withdrawal e.g. withholding treatment
Papers focusing on adults, children or neonates	

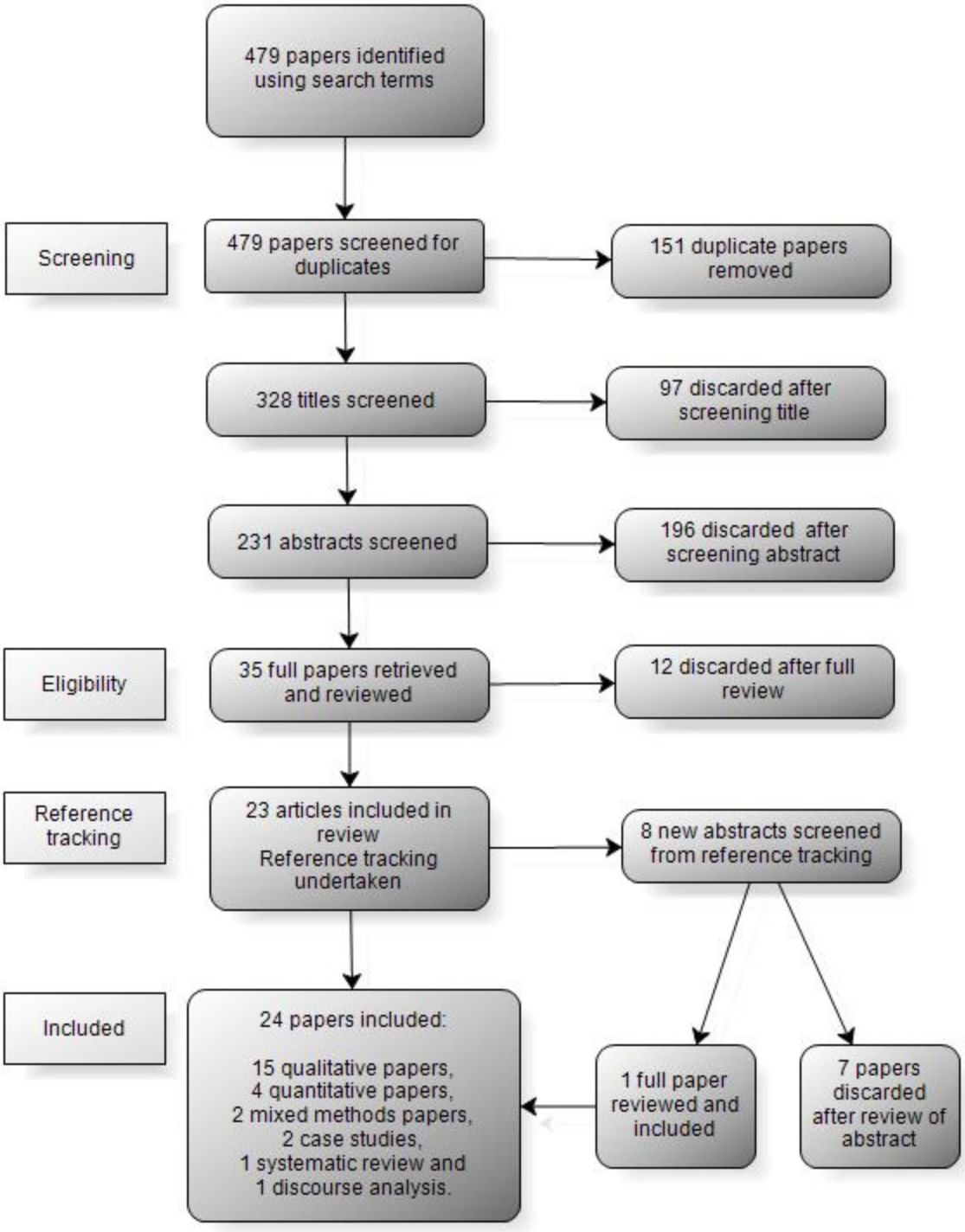

Figure 1: PRISMA flow diagram

NB. No new papers identified from international research centres or grey literature.

Table 3: Papers included in the review. Note TW = treatment withdrawal

Authors, Year, Country, Study design	Purpose / aims	Setting and sample	Measures / data collection methods	Findings
Abib El Halal et al. 2013 Brazil Qualitative	To evaluate the quality of care offered to terminally ill children and their families in the last days of life in two Brazilian PICUs from the parents' perspective.	Two PICUs in two hospitals in one city. Purposive sample: 15 parents of 9 children who died in two PICUs.	Two semi-structured interviews with parents 6-12 months following death of their child in PICU: one interview conducted by assistant physician, one conducted by researcher.	6 categories: communication with the attending physician, quality of care, quality of communication, parental participation in the decision-making process, moments surrounding death, feelings regarding being included in research.
Arbour & Wiegand 2013 USA Qualitative, phenomenological	To understand the experiences of critical care nurses and perceptions of activities and roles while caring for patients and families during the transition to palliative EOL treatment.	Medical and surgical CC unit of a tertiary medical centre. Purposive sample: 19 nurses.	Interview 20-100 minutes, interview guide broad opening question then follow up, observations about nonverbal communication made.	6 categories: Educating the family, Advocating for the patient, Encouraging and supporting family presence, Managing symptoms, Protecting families, Creating positive memories / family support.
Bloomer et al. 2013 Australia Qualitative, descriptive	To describe how nurses in ICU care for family members through patients dying phase and after death, and organisational processes and environmental factors facilitating or limiting care.	2 ICUs, 2 metropolitan multicultural hospitals, May-June 2011. Purposive sample: 12 nurses.	Two focus groups, open-ended questions and guiding concepts, transcribed with field notes related to body language and participation.	4 themes: time, place, presence, culture. Organisational aspects were not helpful. Time spent after death extensive and not recognised.
Coombs et al. 2015 New Zealand Mixed methods: survey and focus group	To investigate NZ intensive care nurses' experiences of and attitudes towards EOL care.	4 tertiary ICUs in New Zealand. Purposive sample: Survey: 203 nurses. Focus groups: 18 nurses.	Replication of (Latour et al., 2009). Survey with relevant cultural adjustments. Focus group guide developed from responses to survey.	78% (n = 159) stated withholding treatment was ethically more acceptable than withdrawing it. Uncertainty in reducing oxygen to air (21%, n = 41). Focus groups detailed supportive, culturally sensitive, collaborative ICU.
Epstein 2010 USA Secondary analysis of Epstein (2008)	To explore the obligations of nurses and physicians in providing EOL care.	Level III NICU in mid-Atlantic teaching hospital serving large rural area. Secondary analysis of previous interviews: see Epstein 2008	Content analysis of participants' responses to the question: What were your obligations to this infant and family?.	Key theme: create the best possible experience. 2 sub themes: Obligations in decision making (talking to parents, timing withdrawal). Obligations in EOL (providing options, preparing parents, being with, advocating for parents, creating peace and normalcy).

Epstein 2008 USA Qualitative	To explore nurses' and physicians EOL experiences in the NICU.	Level III Neonatal ICU in mid-Atlantic teaching hospital serving large rural area, USA. Purposive sample: 19 infants represented by: 21 nurses, 11 physicians	Semi-structured interviews were completed 1 day 6 weeks following an infant's death. Interview explored EOL experience. Analysis of themes (hermeneutic circle) and descriptive statistics were performed.	Overall theme: create the best possible experience. 3 subthemes: building relationships, preparing for the ELO, creating memories.
Fridh et al. 2009 Sweden Qualitative	To explore nurses' experiences and perceptions of caring for dying ICU patients with focus on unaccompanied patients, family members and environmental aspects.	3 ICUs, Sweden (2 general, 1 thoracic-surgical). Purposive sample: 9 nurses	2 open questions provided, some detail on the rest of the interview guide. Evidence of data saturation reported.	Overall theme: doing one's utmost. 4 categories: Ensuring the patients dignity and comfort, caring for the unaccompanied patient, caring for the family, environmental obstacles to doing ones utmost.
Heland 2006 Australia Qualitative	To investigate the perceptions and experiences of nurses practicing in adult ICUs with regard to medical futility.	Different ICUs, no details provided on specific ICUs. Purposive sample: snowball technique 7 nurses.	Semi structured interviews that explored the perceptions and experiences of nurses and medical futility	3 themes: ICU nurses' definition of medical futility, Medical futility and challenges for nurses / engagement in decision making, Medical futility and the ICU nursing role.
Keenan et al. 2000 USA Quantitative	To develop an instrument to assess the satisfaction of family members with withdrawal of life support and to determine which factors are associated with greater levels of satisfaction.	19 bed ICU, single centre, USA. University campus Purposive sample: 29 next of kin of patients who died in 6 month period.	Self-administered quantitative questionnaire developed using informal focus group, computer program language checking and target group checking for content validity.	Strong correlation with greater satisfaction: process of TW well explained (Spearman's 0.696, $P < 0.001$) and TW proceeded as expected (Spearman's rank correlation coefficient 0.658, $P < 0.001$) and patient appeared comfortable (Spearman's 0.584, $P = 0.001$).
Kirchhoff et al. 2003 USA Quantitative	To describe how critical care nurses prepare families for withdrawal from mechanical ventilation that is followed by the death of the patient.	4 ICUs, 1 rural, 2 urban hospitals, Midwest USA Convenience sample. 31 nurses.	Piloting and modification of the 'Preparing Families for Withdrawal' Questionnaire was undertaken before being distributed..	Eight descriptors mentioned by >50% of nurses: Skin colour changes, skin temp changes, varying levels of consciousness, effort with breathing, variable timeframe to death, breathing pattern, sound during breathing, loss of bowel control.
Kirchhoff et al. 2008 USA Intervention	To assess the feasibility of testing 4 tailored messages to prepare families of patients having TW, to assess barriers to	Critical Care Unit of University of Wisconsin Hospital Convenience	Patient information sheet, next of kin demographics collected. Intervention delivered in the form of tailored message. Evaluation of the Experience	Intervention group significantly more satisfied with info (intervention group mean, 9.0; SD 1.25, standard care mean, 7.1; SD 2.28; Mann-Whitney $U = 24.5$, $P = .05$) and understood better

	conducting such a study, and to obtain preliminary data on measurable effects that could be used to compare such preparation with usual care.	sample: Family member, 10 intervention, 10 usual treatment.	of Withdrawal questionnaire and Profile of Mood states-short form administered via phone interview 2-4 weeks later.	(intervention group mean, 9.6; SD 0.52, standard care mean, 8.4; SD 1.35; Mann-Whitney U = 23.00, P =.03). Unsolicited comments suggest info was appreciated.
Kompanje 2005 The Netherlands Case study	unclear - RP: describe practical and ethical considerations for treating the "death rattle" after withdrawal of mechanical ventilation	Neuro ICU Case study: 2 patients	Two cases were used to explore management of the death rattle.	Recommendations: Scopolamine should be administered early for the treatment of 'death rattle' to relieve relatives of patients. This is an ethical obligation.
Long-Sutehall et al. 2011 UK Qualitative	To illustrate how differing dying trajectories impact on decision –making underpinning withdrawal of treatment processes and what nurses do to shape the withdrawal of treatment.	4 critical care units ICU, CICU, NICU, RHC, south of England. Purposive sample: 13 nurses.	Qualitative, modified grounded theory, interviews 50-75 minutes utilising clinical vignettes.	Key findings: decision making the most significant influence on how TW proceeded. 4 key dying trajectories identified.
McHaffie 2001 UK Qualitative	Not explicit. Research questions cited: How willing are they (parents) to take responsibility (for TW decisions)? Is it too burdensome? What do they find helpful?	3 regional NICUs in east of Scotland, Purposive sample: 1st interview: 59 families, 108 individuals. 2nd interview: 50 families, 90 individuals.	In depth interviews using tools (not cited which tools utilised), tape recorded up to 5.25 hours.	9 key elements which parents find helpful: Compassion alongside expertise, evidence of poor prognosis, sensitive timing, according parents a sense of worth and role, full frank information, permission to decide to stop, active involvement in dying process, funeral, follow up.
McMillen 2008 UK Qualitative	To explore the experiences of ICU nurses in caring for patients who have had their TW and to answer 2 research questions: what role do nurses play and how does this affect them?	6 bedded ICU North of England. Purposive sample: 8 nurses.	Semi-structured interviews 40 min - 1 hour. Constructivist grounded theory used to explore the experiences and feelings of ICU nurses. Framework analysis adopted.	2 key themes: Nurses' role (experience counts, not really a nurse's decision, planting the seed, supporting the family, being a patient advocate). Perceptions of TW (getting the timing right, emotional labour).
Pattison 2006 UK Critical Discourse	What contributes to silent / dominant discourses of EOL care provision and decision making? How do powerful groups 'control' discourses	UK 4 key UK critical care documents since 1996.	Critical discourse analysis. Method informed by key critical discourse analysis texts and those applied to health.	Little clear guidance, power dynamics, difficulties encountered, technological environment can be a barrier.
Pattison et al. 2013 UK	To explore the meaning of EOL care for critically ill cancer patients, families, oncologists,	Specialist critical care unit. Purposive sample: Physicians -	Taped interviews undertaken, example questions provided. Analysed	4 main themes: dual prognostication, meaning of decision making, care practices at EOL, choreographing a good death.

Qualitative	palliative care specialists, critical care consultants and nurses.	11, Nurses -7, Bereaved families - 12, Patients who were expected to die but survived - 7.	conducted using Van Manen's phenomenological framework.	4 core tenets for good EOL care: comfort, less visible technology, privacy, dignity.
Peden-McAlpine et al. 2015 USA Qualitative	To describe the specific communication practices experienced ICU nurses comfortable working with dying patients use with families to negotiate consensus on withdrawal of aggressive treatment and / or shift to palliative care at EOL	4 adult ICUs in a 350 bed urban teaching hospital (Neurological, Medical, Cardiovascular, Cardio-thoracic surgical). Purposive sample: 19 nurses.	Unstructured interviews. One question: "Tell me about stories where you were able to negotiate with families and physicians to get everyone on the same page regarding TW".	Overall plot: Constructing the story. 5 subplots: organising and interpreting knowledge from different sources, learning who the patient is as a person and aligning to medical diagnosis, helping families see deterioration status of patient, imagining and acting on moral possibilities for EOL care, facilitating saying goodbye.
Psirides & Sturland 2009 New Zealand Quantitative	To assess methods of withdrawal of active treatment in intensive care patients and compare surveyed practice with beliefs of medical and nursing staff.	One ICU, 14 bed, tertiary-referral, Feb-June 2008, western, city hospital Purposive sample: 56 (11 medical, 45 nursing staff from one ICU).	Questionnaire: indicated which treatment that they think should be withdrawn, what should be started / continued, what should be documented.Retrospective medical record review: 40 consecutive patients who had TW.	20% believed IV fluids should continue. 21% believed ventilation should continue. 40% believed ECG and SpO2 should continue. Audit of records showed 95% had IV fluids continuing. 100% had ventilation withdrawn.
Ranse et al. 2012 Australia Qualitative	To explore the EOL care beliefs and practices of ICU nurses.	14 bed ICU at Australian tertiary teaching hospital. Convenience sample: 5 nurses.	Semi-structured interviews beginning by asking to describe a recent or significant experience of caring for an adult patient at EOL following a decision to withdraw treatment. Follow up questions where required.	3 categories: Beliefs about EOL care (value of participating, complexity), EOL care in ICU context (emotional intensity, organisational support, uncertainty and ambiguity), facilitating EOL care (providing comfort care, modifying the environment, facilitating family experience).
Rocker et al. 2005 Canada Mixed methods: survey and retrospective chart review	To describe the perspectives of RNs and Respiratory therapists (RTs) related to EOL care for critically ill patients.	4 tertiary care hospital ICUs, 4 provinces, 8-24 beds, occupancy 77-98%, during year 2000. Convenience sample: 96 RNs, 73 RTs representing 98 patients.	Research assistant abstracted data for 20/30 patients who died following TW from each unit. Self-administered questionnaire 5-point ordinal scale to assess comfort with 14 items. Open-ended questions.	Most comfortable with withholding CPR and withdrawing life support, ventilation / O2 and sedation. RTs rated less favourably: quality of physician explanation, availability of physician, peacefulness of dying, amount of privacy. Suggestions for improvements made.

Wiegand 2006 USA Qualitative Phenomenological	To describe the interactions between patients' family members, healthcare providers, and the healthcare system during withdrawal of life-sustaining treatment after a sudden, unexpected illness or injury.	3 adult ICUs Purposive sample: 56 family members representing 19 patients 11 of whom died on ICU after having treatment withdrawn.	Hermeneutic descriptive phenomenological approach. Interviews and observations conducted prospectively.	2 categories: Issues with healthcare providers (bonds and consistency with staff, physician presence, information, coordination of care, family meetings, sensitivity to time, preparing for the dying process) Issues with healthcare system (parking, finding privacy, transfers of patients).
Yeager et al. 2010 USA Intervention description and local development	To provide an overview of the specific items that made up the Embrace Hope intervention and use a case study to demonstrate how it was applied.	Riverside Methodist Hospital, Columbus, Ohio Single centred site.	Wide multidisciplinary team involvement using: monthly meetings.	Creation of Embrace Hope tool: signs, staff education, fabric envelope with intervention materials, checklist, symptom brochure, love locks, handprints, grief information, family note, seed packet.
Zomorodi & Lynn 2010 USA Qualitative	To explore nurses' definitions of quality EOL care and to identify the personal, environmental and relational factors that facilitate or inhibit the nurses' ability to provide EOL care to patients and their families.	One hospital south-eastern USA. Burn unit 1, medical ICU 3, surgery / neurosurgery ICU 1, cardiothoracic ICU 2, coronary care unit 2 Convenience sample: 9 nurses.	Flyers, recruitment letters in mailbox. Semi-structured interviews "when you think of optimum EOL care in the ICU what comes to mind?" 45 minutes.	3 categories: Personal factors (moral distress, on the job training), environmental factors, relational factors. 2 strategies: Coaching the physicians, taking a step back.

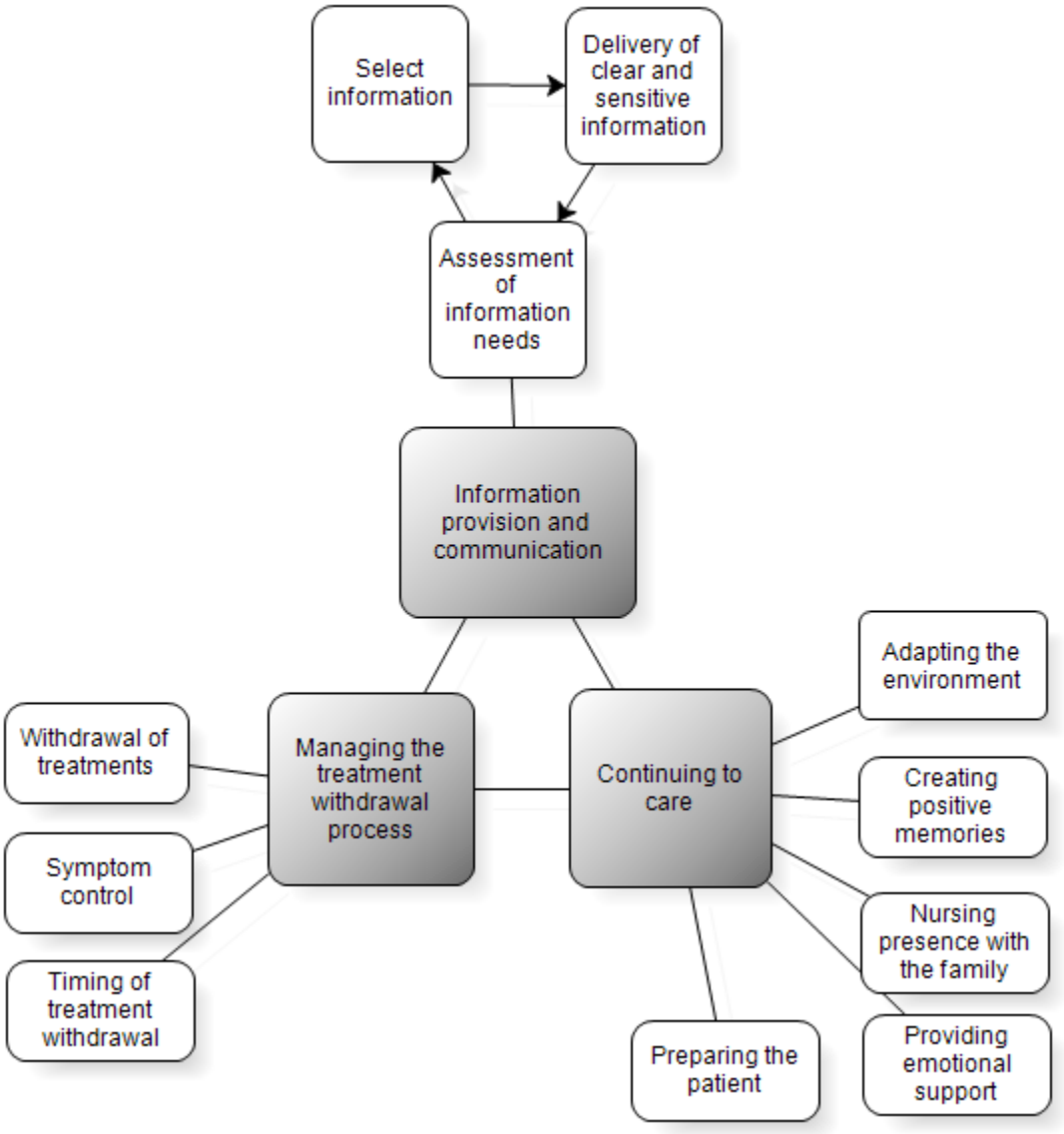

Figure 2: How families are prepared for, and supported during, withdrawal of life-sustaining treatments in intensive care