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

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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.

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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 - 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 bedside 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 & 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 & 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 & Knafl, 2005). This enabled empirical work using a broad range of methodologies to be reviewed. Data were 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.

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.

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.
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 & 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. 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 & 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).

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 & 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 & 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 information was delivered to families was key to optimise family comprehension. Communication was identified by nurses as an essential skill (Zomorodi & 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 & Wiegand 2014).

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 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 & 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 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 & 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 & 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 & Sturland 2009, Epstein 2010, Zomorodi & Lynn 2010, Long-Sutehall et al. 2011, Ranse et al. 2012, Pattison et al. 2013; Arbour & 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 & 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 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 handprint 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 in 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 & 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 & 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, in 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 & Knalf (2005), inconsistent search
terminology and indexing, can lead to search bias and limit the effectiveness of the search
(Whittemore & 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 sequela. 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.

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Author Contributions:
All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE*):
1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
2) drafting the article or revising it critically for important intellectual content.
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Table 1: Search strategy

<table>
<thead>
<tr>
<th>First search</th>
<th>Second search</th>
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<tbody>
<tr>
<td>intensive care OR critical care</td>
<td>intensive care OR critical care</td>
</tr>
<tr>
<td>nurs*</td>
<td>nurs*</td>
</tr>
<tr>
<td>famil* OR bereaved famil*</td>
<td>famil* OR bereaved famil*</td>
</tr>
<tr>
<td>withdrawal of treatment OR treatment</td>
<td>prepar* for death OR prepar* for dying OR</td>
</tr>
<tr>
<td>withdrawal</td>
<td>signs of death OR signs of dying</td>
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</tbody>
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Table 2: Inclusion and exclusion criteria

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

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<tr>
<th>Authors, Year, Country, Study design</th>
<th>Purpose / aim</th>
<th>Setting and sample</th>
<th>Measures / data collection methods</th>
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<tr>
<td>Abboud et al., 2013, USA</td>
<td>To evaluate the quality of care offered to seriously ill children and their families in the last days of life in two Boston PICUs from the parents’ perspective.</td>
<td>Two PICUs in two hospitals in one city.</td>
<td>Two semi-structured interviews with parents 6-12 months following death of their children (PICU); one interview conducted by assistant physician, one conducted by researcher.</td>
<td>All categories: communication with the attending physician, quality of care, quality of communication, parental participation in decision-making processes, mother’s surrounding death. Keep up regarding being included in research.</td>
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<tr>
<td>Arbour &amp; Hoggard, 2013, USA</td>
<td>To understand the experience of critical care nurses and perceptions of activities and roles while caring for patients and families during the transition to palliative ICU treatment.</td>
<td>Medical and surgical ICU in a tertiary medical centre.</td>
<td>Telephone interviews 20-120 minutes, interview guide broad opening question then follow up, observations about nonverbal/communication mode.</td>
<td>6 categories: Educating the family; Advocating for the patient; Encouraging and supporting family presence; Managing symptoms; Protecting families; Creating positive memories / family support.</td>
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<tr>
<td>Bjermer et al., 2013, Sweden</td>
<td>To describe nurses in ICU care for family members through patients’ perspectives.</td>
<td>A ICU in 2 metropolitan teaching hospitals, May-June 2011.</td>
<td>Two focus groups, open-ended questions and guiding concepts transcribed with field notes related to body language and participation.</td>
<td>5 themes: Time, place, presence, culture; Organisational aspects not helpful. Time spent after death assistance and not recognised.</td>
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<tr>
<td>Colombia et al., 2013, New Zealand</td>
<td>To investigate ICU nurses’ experiences of end of life care and attitudes towards EOL care.</td>
<td>7 tertiary ICUs in New Zealand, postgraduate survey, 203 nurses, focus groups: 18 nurses.</td>
<td>Telephone interview with relevant cultural adjustments. Focus group developed from responses to survey.</td>
<td>70% (&lt; 150) stated withholding treatment was ethically more acceptable than withdrawing it. Uncertainty in reducing stages of art (27%), n = 43. Focus group detailed supportive, culturally sensitive, collaborative ICU.</td>
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<td>Cockshott, 2010, USA</td>
<td>To explore the obligations of nurses and physicians in providing EOL care.</td>
<td>A ICU in mid-Atlantic teaching hospital serving large rural area.</td>
<td>Content analysis of participants’ responses to the question: What were your obligations to this patient?</td>
<td>Key themes: create the best possible experience. 2 sub themes: Obligations to decision making (talking to patients, families); Obligations in EOL (providing options, preparing patients, being with, advocating for patients, meeting pain and normality).</td>
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Estonia: 2008, USA Qualitative

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<td>Eesti, 2008, USA Qualitative</td>
<td>To explore nurses’ and physicians’ EOL experiences in the NICU.</td>
<td>Level II Neonatal ICU in mid-Atlantic teaching hospital serving large rural area, USA.</td>
<td>Semi-structured interviews were completed by day 6 weeks following an infant’s death. Interview explored EOL experience.</td>
<td>3 themes: ICUs nurses’ definition of medical futility, Medical futility and challenges for nurses / engagement in decision making, Medical futility and the EOL nursing role.</td>
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<tr>
<td>Frith et al., 2008, Sweden Qualitative</td>
<td>To explore nurses’ experiences and perceptions of caring for dying ICU patients with focus on a unaccompanied patients, family members and environmental aspects.</td>
<td>ICU in Sweden; 2 (unaccompanied) ICU patients, 9 nurses,</td>
<td>2 open questions; provided some detail on the rest of the interview guide.</td>
<td>Overall theme: doing one’s utmost. 6 categories: Ensuring the patient’s dignity and comfort, caring for the unaccompanied patient, providing information, medical futility, family’s support, family’s with withdrawal and comfort.</td>
</tr>
<tr>
<td>Finland, 2008, Australia Qualitative</td>
<td>To investigate the perceptions and experiences of nurses practicing in adult ICUs with regard to medical futility.</td>
<td>Different ICUs with data provided from a specific ICU.</td>
<td>11 interviews, 9 nurses.</td>
<td>Overall theme: create the best possible experience. 3 sub themes: building relationships, preparing for the EOL, creating memories.</td>
</tr>
<tr>
<td>Hakanen et al., 2008, USA Qualitative</td>
<td>To develop an instrument to assess the satisfaction of family members with withdrawal and determine what factors are associated with greater levels of satisfaction.</td>
<td>Self-administered quantitative questionnaire developed using informal focus group, computer program language checking and target group checking the content validity.</td>
<td>Strength correlation with prior satisfaction: process of F/T was well explained (Spearman’s r = 0.698, P = 0.001) and TW was proceded in expected (Spearman’s rank correlation coefficient 0.559, P = 0.001) and patient appeared comfortable (Spearman’s r = 0.544, P = 0.001).</td>
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<tr>
<td>Kirchhoff et al., 2003, USA Qualitative</td>
<td>To describe the critical care nurses prepare families for withdrawal from mechanical ventilation to death.</td>
<td>Critical Care Unit of University of</td>
<td>Eight descriptions mentioned by all nurses: skin color changes, skin temperature changes, varying levels of consciousness, effort with breathing, variable breathing to death,谈恋爱 patient, sitting still (loss of bowel control).</td>
<td>8 categories: communicating with the attending physician, quality of care, quality of communication, parental participation in decision-making processes, mother’s surrounding death. Keep up regarding being included in research.</td>
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<tr>
<td>Kirchhoff et al., 2008, USA Qualitative</td>
<td>To assess the feasibility of text-based messages to Critical Care Unit of University of</td>
<td>Critical Care Unit of University of</td>
<td>Patient information sheet, work on text development, collective intervention.</td>
<td>Intervention group significantly more satisfied with info text intervention group mean. (10, 0.5, 2, 2).</td>
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<td>Wright 2009 USA Qualitative Phenomenological</td>
<td>To describe the interactions between patients, family members, healthcare providers, and the healthcare system during withdrawal of life-sustaining treatment after a sudden, unexpected decline or death.</td>
<td>Phenomenological approach, interviews, and observations conducted prospectively.</td>
<td>3 adult ICU patients, polyvoce sample of 35 family members, interviews of 29 patients, 11 of whom died on ICU after being transferred.</td>
<td>2 categories: issues with healthcare providers (bands and consistency with staff, physician presence, information, communication of care, family members) and issues with withdrawal (anxiety, uncertainty, sense of time, preparing for the dying process, issues with healthcare system (palliative, finding pills, forms of patients).</td>
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<td>Young et al 2010 USA Intervention description and local development</td>
<td>To provide an overview of the specific items that made up the Intensive Hope intervention and use a case study to demonstrate how it was applied.</td>
<td>Riverside Methodist Hospital, Columbus, Ohio Single center site.</td>
<td>While multidisciplinary team involvement using: monthly meetings.</td>
<td>Creating of Intensive Hope tool, signs, Staff education, fabric envelope with internalize materials, checklist, symptom brochure, low levels, handwipes, grief information, family note, seed packet.</td>
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<tr>
<td>Zemanek &amp; Lynn 2010 USA Qualitative</td>
<td>To explore nurses’ definitions of quality ICU care and to identify the personal, environmental and relational factors that facilitate or inhibit the nurse’s ability to provide ICU care to patients and their families.</td>
<td>One hospital southwestern USA, ICU unit 1, medical ICU 1, surgery ICU 1, pediatric ICU 1, cardiac ICU 2, coronary care unit 2 Conference sample: 9 nurses.</td>
<td>Patients;周围的 nurses in meetings. Semi-structured interviews “when you think of optimum ICU care in the ICU, what comes to mind?” 15-35 minutes.</td>
<td>3 categories: Patient factors (mental distress, on the job training), environment factors, relational factors. 2 strategies: Coaching the physicians, taking a step back.</td>
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Figure 2: How families are prepared for, and supported during, withdrawal of life-sustaining treatments in intensive care.