UNIVERSITY OF BIRMINGHAM
University of Birmingham Research at Birmingham

Critical care nurses' experiences of withdrawal of treatment:

Vanderspank-Wright, Brandi; Efstathiou, Nikolaos; Vandyk, Amanda D.

DOI:
10.1016/j.ijnurstu.2017.09.012

License:
Creative Commons: Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)

Document Version
Peer reviewed version

Citation for published version (Harvard):
Vanderspank-Wright, B, Efstathiou, N & Vandyk, AD 2018, 'Critical care nurses' experiences of withdrawal of treatment: A systematic review of qualitative evidence', *International Journal of Nursing Studies*, vol. 77, pp. 15-26. https://doi.org/10.1016/j.ijnurstu.2017.09.012

Link to publication on Research at Birmingham portal

General rights
Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

•Users may freely distribute the URL that is used to identify this publication.
•Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
•User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
•Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy
While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Download date: 27. Apr. 2024

Abstract

Background: Death and dying is reality of the clinical context of the intensive care unit. Death often follows a decision to withdraw life-sustaining treatments. Critical care nurses are the primary care providers to patients and families at the end-of-life in the intensive care unit.

Objective: To synthesize qualitative evidence on the experiences of critical care nurses who have cared for patients and families throughout the process of withdrawal of life-sustaining treatment.

Methods: This was a systematic review and qualitative evidence synthesis modeled on the Joanna Briggs Methodology. Pre-defined keywords were searched for in Medline, CINAHL, PsycInfo, and Web of Sciences to locate studies published in the English, French, and Greek languages in any year. Two reviewers independently screened articles for congruence with eligibility criteria, engaged in data extraction, and assessed quality of the included studies. Meta-aggregation was performed to synthesize the findings. A protocol was developed by two members of the review team prior to initiation of the study.

Results: Thirteen studies were included in the review, 12 qualitative and one mixed-methods. Four key themes were identified from the original research: Navigating Complexity and Conflict; Focusing on the Patient; Working with Families; and Dealing with Emotions Related to Treatment Withdrawal. Critical care nurses provide care to patients and families during the process of withdrawal of life-sustaining treatment which is described as complex and challenging. Despite the inherent challenges, nurses strive towards doing their utmost for patients and families.

What is already known?

- Death and dying is a reality of the critical care environment including intensive care units
- Death in intensive care units often follows a decision to withdraw life sustaining treatments
- Nurses are often the primary providers of end-of-life care to patients and families in context of withdrawal of treatment
- Physical and organizational structures may be perceived to impede good end-of-life care in intensive care units

What does it add?

- Intensive care nurses experience tensions and conflict during the process of withdrawal of life-sustaining treatment due to a lack of clear guidance either from physicians, or the absence of guidelines and protocols.
- Withdrawal of life-sustaining treatment is an emotionally distressing experience for intensive care nurses that requires debriefing to avoid accumulated, long-lasting impact. Exploring peer to peer debriefing is merited as this is frequently used by intensive care nurses.
- Intensive care nurses, as the main enactors of treatment withdrawal, face the challenge of ensuring the comfort of the patient while simultaneously working towards meeting the needs of the patient's family within a highly technological environment.
- This review confirms that nurses identify this aspect of their role as a privilege and that good end-of-life care in intensive care is possible.

Critical care nurses' experiences of withdrawal of treatment:

A systematic review of qualitative evidence

1. Introduction

Adult patients are admitted to critical care units (specifically, intensive care units) for a variety of reasons including respiratory compromise requiring mechanical ventilation, acute cardiac and neurological events and septicemia (Society of Critical Care Medicine, 2017). As a result of complex pathology and hemodynamic instability, patients often experience multi-organ dysfunction and require life-supporting technology. Since its formal inception in the 1950s, critical care has evolved with advancements in diagnostics, hemodynamic monitoring, and other life-sustaining technologies (Fairman and Lynaugh, 1998; Vanderspank-Wright et al., 2015). Yet, many patients continue to succumb to their illnesses and ultimately die in intensive care units. While reported mortality rates vary, studies indicate that approximately 10 to 30 percent of patients will die while in an intensive care unit (Coombs et al., 2012; Heyland et al., 2000; Society of Critical Care Medicine, 2017; Wennberg et al., 2004).

Aside from spontaneous death because of events such as cardiac arrest, the vast majority of deaths in this clinical context occur after a decision is made about withholding or withdrawing life-sustaining treatment (Gerstel et al., 2008; Sprung et al., 2003). Evidence suggests that over one third of all patients who die in the ICU, die as a result of withdrawal of treatment (Prendergast et al. 1998; Sprung et al., 2003). A recent systematic review reported the mean prevalence of withdrawal of life-sustaining treatment for patients who had died in the intensive care at 42.3% and range from 0 - 84.1% (Mark et al., 2015). Decisions made regarding withdrawal of treatment are often collaborative and involve members of the health care team including but not limited to physicians and nurses, patients (where possible) and families.

Withdrawal of life-sustaining treatment is guided by physicians and in some units enacted through the implementation of guidelines and protocols that facilitate processes regarding the removal of life-supporting treatments, however, the process varies across the world (Mark et al., 2015). Despite reported variability, from a nursing perspective, findings reported in the nursing literature suggest that nurses are actively involved in all facets of withdrawal of treatment in the intensive care unit from early discussions through to post-mortem and bereavement care (Birchley, 2013).

Death is a historical, current and future clinical reality for these nurses particularly as it is situated within the context of treatment withdrawal. As de facto agents of treatment withdrawal, critical care nurses are situated as primary carers in situations that are highly emotional, technologically complex, ethically challenging and all occurring within a clinical context that is often considered less than ideal (Curtis and Vincent, 2010; Fridh, 2014; Gerstel et al., 2008).

For over two decades, using both qualitative and quantitative designs, researchers have explored nurses' experiences of death and dying within a critical care context and more specifically, in relation to their experiences of withdrawal of life-sustaining treatment (Jones and FitzGerald, 1998; Peden-McAlpine et al., 2015; Sprung et al., 2003). While quantitative inquiry provides a particular lens to explore this phenomenon, qualitative studies by virtue of their design and philosophical underpinnings, provide richness and depth in the human experience and explore the activities of these nurses who engage with patients, families, and health care teams within a technologically complex and challenging environment (Holms et al., 2014).

While systematic reviews of both research paradigms are merited, this review focuses specifically on qualitative literature that has captured narrated accounts of nursing experience of this phenomenon. Grimshaw (2011) reminds us that "few studies themselves are sufficiently

persuasive to change policy or practice" as such, knowledge synthesis lends itself well in this instance to "identify key messages from global evidence" (p. 3-4). Several qualitative studies on the experiences of critical care nurses caring for patients during withdrawal of life-sustaining treatment exist and yet no attempts have been made to systematically gather, review and synthesize this evidence. At this juncture, a thorough and rigorous review lends itself to not only better understanding what it is like for nurses providing this care and draw out similarities of experiences across countries, time and context but to also critically appraise this body of literature and determine gaps in our understanding and areas for future research and knowledge development with respect to the phenomenon. Therefore, the purpose of this review was to aggregate and synthesize qualitative evidence related to critical care nurses' experiences of providing care to patients and families during the process of withdrawal of life-sustaining treatments. The following review question guided the study: What are the experiences of intensive care nurses who care for patients during the process of withdrawal of life-sustaining treatments?

2. Methods

2.1 Design

This was a systematic review of qualitative studies modeled on the Joanna Briggs Institute (Joanna Briggs Institute; 2014) methodology for Qualitative Systematic Reviews. Joanna Briggs Institute methods were followed to direct the creation of eligibility criteria and search strategies, guide study selection process, and inform data analysis. Syntheses of qualitative research provide a comprehensive view of existing knowledge in a specific area, which may act to underpin and direct evidence-based practice and identify gaps in research (Sandelowski and Barroso, 2007). A protocol was developed by two members of the review

team (BV, NE) prior to initiation of the study. This review adheres to the 21 items reported in the ENTREQ statements (Tong et al., 2012).

2.2. Inclusion and exclusion criteria

Inclusion and exclusion criteria (Table 1) were established a priori and included original research using qualitative or mixed methods studies. Only the qualitative portions of the mixed methods studies were included and this was dependent on presence of a description of the methodology and supporting participant quotes. Although reviews were not included, their references were screened for any relevant studies. Theses, dissertations and abstracts were excluded because peer review processes vary among educational institutes and scientific committees.

Table 1. Inclusion and Exclusion Criteria

Criteria	**Inclusion**	**Exclusion**
Type of Publication and Study Design	Qualitative Mixed methods	Quantitative Reviews of all kinds Grey literature Theses and Dissertations Abstracts
Population	Qualified nurses of all kinds	Other healthcare professionals (eg. physicians, social workers)
Concept	Withdrawal of life-sustaining/supporting treatment	Palliative care generally End-of-life care Withdrawal of any other type of intervention
Context	Adult critical care Adult ICU/ITU Adult intensive care	Neonatal settings Pediatric settings All non-critical care settings
Language	English French Greek	Any other language

Date range	No limit	No limit

2.3. Search strategy

A three step search strategy was devised in consultation with a library scientist. First, we searched the Medline database to identify key articles and define keywords corresponding to three main concepts: 1. Nursing (nurs*); 2. Withdrawal of treatment (withdrawal of treatment, withholding treatment, passive euthanasia); and 3. Intensive care (ICU, ITU, intensive care, critical care). These keywords were searched for throughout the complete citation and article, including title, abstract, text, references, and bibliographic information. Second, we translated the Medline search strategy into the CINAHL, PsycINFO, and Web of Science databases. These databases were chosen because they are most likely to house articles on the topic of interest. The final database search occurred in May, 2016. Third, we conducted a hand search of all included studies or review articles found on the topic. The complete search strategy was not limited to specific dates because there is no precise timeline of when withdrawal of treatment was introduced in most countries.

2.4. Study selection

After removal of duplicate citations, articles were selected for inclusion based on a two-level screening process. First, two reviewers (BV, NE) independently screened all citations by title and abstract for relevance. Citations meeting eligibility criteria or those without sufficient information to determine relevance, based on title and abstract, were retained. Second, full-texts of all articles retained after first-level screening were independently assessed for relevance by two reviewers (BV, NE). A consensus meeting was held to discuss and agree upon the final set of included citations. Following study selection, quality appraisal was completed prior to data extraction.

2.5. Quality appraisal

Quality was assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative studies, which is comprised of 10 questions that consider the results of qualitative research, their validity, and usefulness (CASP, 2013). The tool requires reviewers to systematically check whether a study meets the criteria set in the 10 questions by selecting 'yes', 'no', 'can't tell' for each question. Each of the included papers was appraised independently by two reviewers (NE, BV). Two articles (Efstathiou and Walker, 2014; Vanderspank-Wright et al., 2011) were appraised by a different set of reviewers because they were authored by the reviewers. We felt this posed an ethical concern and wanted to avoid any potential conflict of interest or biased quality appraisal. The appraisals for each paper were brought together in an Excel file and if there were any disagreements/discrepancies in scoring between reviewers, these were resolved through discussion. A score out of 10 was allocated for each paper based on how many questions were answered as 'yes' and we considered a score of seven or more to indicate 'very good' quality. Our aim in conducting quality appraisal was not to exclude studies based on quality, but to engage in a systematic and standardized process to be able to highlight the quality of evidence available on the topic.

2.6. Data extraction

Each study was read a minimum of two times prior to data extraction to ensure a thorough understanding of the content. Using a predetermined Excel data extraction form, two reviewers independently extracted data on study characteristics (bibliographic details, population, setting, aim or purpose of the study, methodology, data collection and analysis methods) and reported findings (primary themes and subthemes, including author description and label, and all supporting illustrative quotes). We held a consensus meeting to compare data

extraction forms and discuss discrepancies. When discrepancy was noted, the two reviewers jointly referred to the original full-text study and agreed upon the correct information.

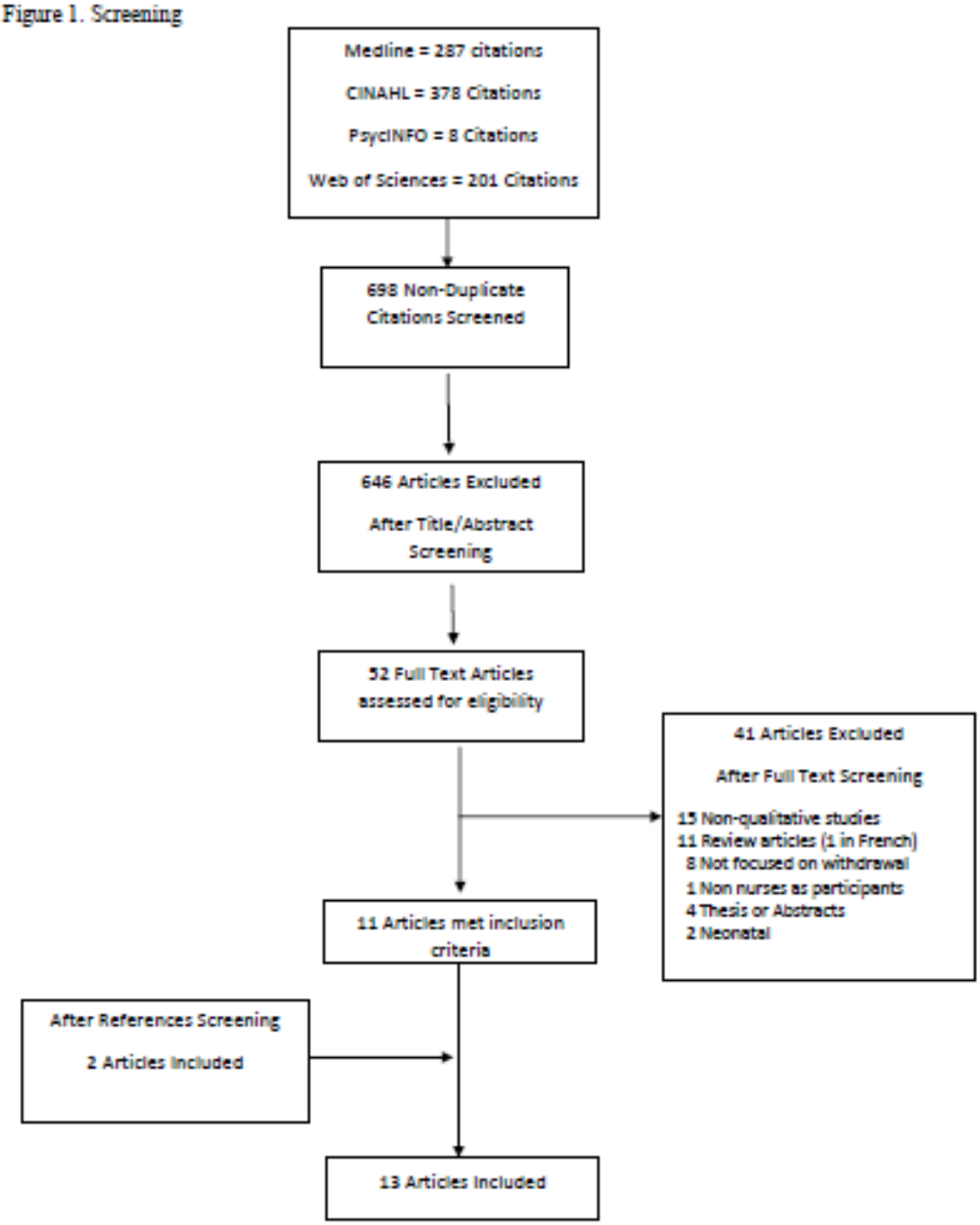
2.7. Data synthesis

Using descriptive statistics, we reported on the study characteristics. Synthesis of the reported findings was done using the meta-aggregative approach, which includes categorising and re-categorising the findings from studies to create a meaningful synthesis (Joanna Briggs Institute, 2014). Specifically, for each extracted finding, we assigned a level of credibility (unequivocal, credible or unsupported) based on the congruency between the finding (using the author's description/interpretation) and supporting illustrative quote (Joanna Briggs Institute, 2014). Following that, we identified similarities and differences between the aggregated findings and illustrative quotes, which helped in creating categories capturing the meaning of the synthesized data. These categories were then re-read to explore inherent variability in the synthesized findings. This process ensured the preservation of the original interpretation and allowed for a better understanding of the concepts related to the topic under investigation. NVivo was used to facilitate the data synthesis process.

3. Results

The search strategy yielded a total of 874 citations, from which we removed 176 duplicates. 646 citations were then removed after first-level screening because their titles and/or abstracts did not match eligibility criteria. 52 full-text articles were subjected to second-level screening from which 11 articles were retained for inclusion in the review. An additional two articles were identified through reference screening (Figure 1) and thus the final set included 13 articles on the experiences of intensive care unit nurses caring for patients during the withdrawal of life-sustaining treatment.

Figure 1. Screening



3.1 Quality Appraisal

Using the CASP tool for qualitative studies, we assessed quality of the included articles (Table 2). The quality of 10 studies was considered very good, with scores equal or higher than seven (out of 10). Three studies scored five or six. In most cases, the authors did not adequately describe the relationship between the researcher and the participants.

Table 2. Quality Appraisal

	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	Scoring
Coombs et al. (2015)	√	√	√	-	-	x	√	-	√	-	5
Donnelly and Psirides (2015)	√	√	-	√	√	-	√	-	-	-	5
Efstahiou and Walker (2014)	√	√	√	√	√	-	√	√	√	√	9
Fridh et al. (2009)	√	√	√	√	√	-	√	√	√	√	9
Hadders (2009)	√	√	x	√	√	√	√	x	√	-	7
Halcomb et al. (2004)	√	√	√	√	√	x	√	√	√	√	9
Jones and FitzGerald (1998)	√	√	√	-	√	x	√	√	√	√	8
Long-Sutehall et al. (2011)	√	√	√	√	√	-	√	√	√	-	8
Pattison et al. (2013)	√	√	√	√	√	√	√	√	√	-	9
Peden-McAlpine et al. (2015)	√	√	√	√	√	-	√	√	√	√	9
Thompson et al. (2011)	√	√	√	-	√	-	√	√	√	√	8
van Rooyen et al. (2005)	√	√	√	-	√	-	√	√	√	√	8
Vanderspank-Wright et al. (2011)	√	√	√	√	√	-	√	√	√	√	9

3.1. Study characteristics

The 13 included studies were published between 1998 and 2015 and conducted in eight countries: three studies from the United Kingdom, two studies each from Canada, Australia, and New Zealand, and one study each from United States, Norway, Sweden, and South Africa. Twelve studies were qualitative and one was mixed methods. Qualitative methodologies included phenomenology, generic qualitative, praxiographic inquiry, grounded theory, modified grounded theory, and interpretive description. Sampling strategies were identified either as convenience (n=2) or purposeful (n=11), although four papers did not clearly report their sampling strategy. Sample sizes ranged from five to 28 participants, and the total number of participants included across all studies was 152. Demographic data reported indicates that most participants were female and the range of experience in intensive care was from 4 months to 35 years. Data were collected through one-to-one interviews (n=12) and focus groups (n=1) and analyzed according to a form of content or thematic analysis (Table 3).

Table 3. Study Characteristics

Author (year) Country	Purpose/ Aim / Research Question	Methodology Data collection Data analysis	Sampling and participants	Main results/ Themes
Coombs et al. (2015) New Zealand	To investigate New Zealand intensive care nurses' experiences of, and attitudes towards End-of-Life care.	Sequential mixed methods Survey and Focus Groups interviews Content analysis (Hsieh & Shannon, 2005)	Convenience n=18	Supportive, culturally sensitive, collaborative environment. Use of intravenous fluids and nutrition; Passive limb exercises; Meeting family as opposed to patient need; Patient comfort.
Donnelly and Psirides (2015) New Zealand	To explore the experience of relatives and staff of patients dying in ICU using qualitative approach.	Grounded theory Interviews Thematic analysis in parallel with interviewing Saturation	Purposive n=10	Empathy; Impact; Continuity of care; Care of the body; Handover.
Efstahiou and Walker (2014) UK	To explore the experiences of intensive care nurses who provided end-of-life care to adult patients and their families after a decision had been taken to withdraw treatment.	Qualitative approach, descriptive and exploratory Interviews Interpretative Phenomenological Analysis (Smith et al., 1999)	Purposive n=13	Caring for the dying patient and their family; Providing and encouraging presence; Reconnecting the patient and family; Dealing with emotions and ambiguity.
Fridh et al. (2009) Sweden	To explore nurses' experiences and perceptions of caring for dying patients in an ICU, focusing on unaccompanied patients, the proximity of family members and environmental aspects.	Qualitative approach (Sandelowski, 2000) Interviews Conventional content analysis; inductive (Elo and Kyngas, 2008)	Purposive n=9	Doing one's utmost; Ensuring the patient's dignity and comfort; Caring for the unaccompanied patient; Caring for the family; Environmental obstacles to doing one's utmost.
Hadders (2009) Norway	To explore various ways health personnel enact death in connection with mechanical ventilation treatment withdrawal in the intensive care unit.	Qualitative Semi-structured interviews; analysis of procedural manuals & 24 hr medical record sheet; field work Praxiographic approach (Mol, 2002)	Purposive n=28	Electronic monitoring and the various enactments of death
Halcomb et al. (2004)	To investigate the experience of	Hermeneutic phenomenology	Convenience	Comfort and care;

Australia	nurses caring for clients in the ICU having treatment withdrawn and withheld.	(Van Manen, 1990) Conversational interviews Thematic analysis (Van Manen, 1990)	n=10	Tension and conflict; Do no harm; Nurse-Family relationships; Invisibility of grief and suffering.
Jones and FitzGerald (1998) Australia	What is it like to be a critical care nurse involved in the process of withdrawing life-support treatment from a patient in the ICU?	Interpretive phenomenology Interviews Interpretive process adapted from Thompson (1990)	Purposive n=7	Being there; Being comfortable and uncomfortable; Being in control and out of control; Being in time; Being able to talk.
Long-Sutehall et al. (2011) UK	To illustrate how differing dying trajectories impact on decision-making underpinning withdrawal of treatment processes, and what nurses do to shape withdrawal of treatment.	Modified grounded theory (Charmaz, 2006) Interviews (facilitated by clinical vignettes) Grounded theory analysis	Purposive n=13	Dying trajectories within ICU shape decision-making related to withdrawal of treatment; The process of decision-making; Assessing patient need—facilitating and coordinating communication with and between patients, family members and medical colleagues; Operationalising withdrawal of treatment processes;
Pattison et al. (2013) UK	To explore the meaning of the issues around end-of-life care, of dying, and those caring for, and witnessing the dying of critically ill cancer patients, as explored through family, practitioner and patient experiences.	Heideggerian phenomenology Interviews Thematic network analysis (van Manen, 1997; Attride-Sterling, 2001)	Purposive n=7	Dual prognostication; The meaning of decision-making; Care practices at end of life: choreographing a good death.
Peden-McAlpine et al. (2015) USA	To document how experienced ICU nurses comfortable with dying patients describe their communication with families to negotiate consensus on withdrawal of aggressive treatment and the shift to palliative care.	Qualitative narrative study Unstructured interviews Narrative approach	Purposive n=19	Constructing the story: Organising and interpreting knowledge of different kinds from different sources; Learning who the patient is as a person and putting the medical diagnosis into the bibliographical life of the patient; Helping families see the deterioration.

Thompson et al. (2011) Canada	To explore the experiences of novice nurses with their first patient death in critical care.	Interpretive description qualitative method Unstructured Interviews Interpretive analysis (Thorne et al., 2004)	Purposive n=5	Anticipating death; Transition from life to death; The moment of death; Being with the family; Carrying on.
van Rooyen et al. (2005) South Africa	To gain insight needed to guide nurses and therefore, enable them to cope more effectively with treatment withdrawal. What is the experience of the RN working in an ICU, of the withdrawal of treatment from a critically ill patient? What guidelines can be developed to support RNs in this situation?	Qualitative, descriptive and exploratory, phenomenology (Haegert, 1997) Phenomenological interviews Coding process by Tesch (in Creswell 1994: 155)	Purposive n=7	Nurses developed relationships with certain individuals related to the process of treatment withdrawal from a critically ill patient in an ICU: Intrapersonal relationships which the nurse develops with him/herself throughout the process of treatment withdrawal from a critically ill patient in an ICU; Interpersonal relationships the nurse develops with other individuals related to the process of treatment withdrawal from a critically ill patient in an ICU. The moral conflict the nurse has within him/herself related to the ethical aspects of withdrawal of treatment: The influence of religion on the nurse's experience of the process of treatment withdrawal from a critically ill patient in an ICU; The role of a living will/advanced directive in the process of treatment withdrawal from a critically ill patient in an ICU; The role of the nurse as a patient advocate; The role of the nurse in accompanying the patient to a dignified death.

Vanderspank-Wright et al. (2011) Canada	To explore the experience of critical care nurses who care for patients during the process of withdrawal of life-sustaining treatment. To explore the nurses' experience and to identify factors that nurses perceived to facilitate them or hinder them in caring for these patients.	Interpretative phenomenology Interviews Content analysis (Colaizzi, 1978)	Purposive n=6	Trying to do the right thing: A journey—creating comfort along the way; Working in professional angst; Providing memories.

3.2. Results of synthesis

Fifty-five findings were identified from the included studies. Almost all the findings from the included papers were assessed by the reviewers as credible or unequivocal. Only one finding was not supported and was excluded from the meta-synthesis because it was not supported by illustrative quotes. The 54 findings were aggregated into 10 categories based on similarities identified from the summary statements and illustrative quotes. Finally, four synthesised findings were developed (Table 4): Navigating complexity and conflict; Focusing on the patient; Working with families; Dealing with emotions related to treatment withdrawal.

Table 4. Synthesised Findings

Synthesised Findings	Categories	Coombs et al. (2015)	Donnelly and Psirides (2015)	Efstahiou & Walker (2014)	Fridh et al. (2009)	Hadders (2009)	Halcomb et al. (2004)	Jones and FitzGerald (1998)	Long-Sutehall et al. (2011)	Pattison et al. (2013)	Peden-McAlpine et al. (2015)	Thompson et al. (2011)	van Rooyen et al. (2005)	Vanderspank-Wright et al. (2011)
Navigating Complexity and Conflict	Interpersonal conflict: The nurse and others						√						√	
	Complexity of critical illness	√		√			√							
	Decision making								√	√	√		√	
	Intrapersonal conflict for the nurse				√			√					√	√
Focusing on the patient	Presence			√	√						√		√	
	Comfort	√	√		√		√		√				√	
Working with families	Focusing on the well-being of the family		√	√		√		√		√	√		√	√
	Information sharing		√		√						√	√		
Dealing with	Debriefing							√				√	√	

emotions related to treatment withdrawal	Emotional impact	√		√		√	√	√

3.2.1. Navigating complexity and conflict

In most studies, the processes of decision making and the actual operationalisation of treatment withdrawal were closely linked and both actions carried high levels of complexity. These multifaceted processes created conflict and tensions on both interpersonal and intrapersonal levels.

Conflict and tension were noted at various times across the trajectory of withdrawal of treatment. However, the period of decision making leading up to treatment withdrawal was identified as the most tenuous for intensive care unit nurses. During this period, time factors needing particular consideration included navigating the complexity of the patient's co-morbidities and prognosis as well as soliciting the wishes of the patient and their family (Pattison et al., 2013). Conflict between physicians and family was reported by nurses with regards to perspectives and/or opinions related to the continuation or discontinuation of active treatment, as well as the use of technology to excess (Pattison et al., 2013; Vanderspank-Wright et al., 2011). Long-Sutehall et al. (2011) described tensions between nurses and physicians. There are some reports of perceived lack of collaboration between doctors and nurses during decision making with physicians described as quite authoritative (Fridh et al., 2009; Halcomb et al., 2004; Jones and FitzGerald, 1998; van Rooyen et al., 2005). Nurses also sometimes disagreed with attempts by physicians to 'over-involve' family members in decision making, considering it unfair (Halcomb et al., 2004; Jones and FitzGerald, 1998; Peden-McAlpine et al., 2015). Jones and FitzGerald (1998) reported that nurses felt comfortable with the decision making but not necessarily comfortable acting on it.

Conflict and tensions were also evident during treatment withdrawal due to perceived lack of clear guidance from physicians about the process (Efstathiou and Walker, 2014; Fridh et

al., 2009; Long-Sutehall et al., 2011), physicians' disengagement following the decision to withdraw treatment and limited communication regarding a clear plan for the withdrawal (Jones and FitzGerald, 1998; Long-Sutehall et al., 2011). Intrapersonal conflict was also experienced by the nurses. The latter was evident in nursing actions including nurses distancing themselves from some difficult situations and the sense of unease created by non-private environments where withdrawal was taking place (Efstathiou and Walker, 2014; Fridh et al., 2009; van Rooyen et al., 2005). Overall, nurses found frequently themselves 'in between' or 'in the middle' trying to juggle questions and navigate through conflict and complexity (Fridh et al., 2009; Long-Sutehall et al., 2011; Vanderspank-Wright et al., 2011). However, despite the challenges, tensions and the difficulties experienced, nurses reported that caring for patients at the end-of-life as well as their families was a privilege (Vanderspank-Wright et al., 2011).

3.2.2 *Focusing on the patient*

Focusing on the patient *through* comfort measures and nursing presence were predominant findings in the reviewed studies. Comfort extended from operationalizing withdrawal of treatment processes with a focus on end-of-life care (Long-Sutehall et al., 2014), to alleviation of pain through symptom management (Fridh et al., 2009), through to post-mortem care which included respect for the body (Donnelly and Psirides, 2015; Thompson et al., 2011). Across the studies, family and nurse presence at the bedside was identified as paramount, and even perhaps suggestive of a moral imperative. It was generally considered both inappropriate and inhumane to allow patients to die alone (Fridh et al., 2009; Peden-McAlpine et al., 2015).

Comfort was a common thread across the experience of providing care to patients and families in the ICU within the context of withdrawal of life-sustaining treatment. Descriptions of

comfort were inclusive of measures put in place to ensure the physical comfort and the provision of a dignified death for patients through both pharmacological and non-pharmacological interventions (Fridh et al., 2009; Halcomb et al., 2004; Long-Sutehall et al., 2014). Non-pharmacological comfort measures were predominantly identified as an important aspect of the nursing role (van Rooyen et al., 2005).

Peden McAlpine et al. (2015) acknowledged that intensive care nurses often learn about who the patient was from the family at the bedside. Knowing who the patient was and what their wishes regarding medical treatment would be, plays a key role in establishing a plan of care. Importantly, Peden McAlpine et al. (2015) also reiterated that in determining treatment goals, family are often reminded by the nurse to focus on "what the patient wanted for end of life care" (p. 1153). Nurses play a role in bringing the family's focus back to what the patient would have wanted.

3.2.3. Working with families

While patients are central to the experience of withdrawal of treatment in the intensive care unit, families and family presence comprised an overwhelming part of intensive care nurses' narratives. In caring for patients during the process of withdrawal of treatment within the intensive care unit, families were described as an integral part of the nursing experience and part of the unit/focus of care. Working with families encompassed several different themes which extended from information sharing and contextualizing the complex aspects of intensive care (Peden-McAlpine, 2015; Thompson, 2011), to focusing on the well-being of family and providing a defined space and place for family presence (Donnelly and Psirides, 2015; Efstathiou and Walker, 2014; Fridh et al., 2009).

In the included studies, nurse participants reflected and emphasized the need to share information with family members. For example, both Fridh et al. (2009) and Peden-McAlpine et al. (2015) described how nurses played a central role in translating the complexities associated with critical care to family members. The latter included providing explanations related to treatments, procedures and prognostic indicators. The nurses also played an active role in working and communicating with family members in order to create, where possible, a shared understanding of the patient's critical condition. In order to facilitate information sharing, nurse participants across studies emphasized that having the time to be with families, and to support and accompany them was important (Fridh et al., 2009; Thompson, 2011). Additionally, it was noted that not only was communication and information sharing important in the moment, but also over time. For instance, intensive care nurses found it difficult to leave families when their shifts were finished and participants reflected on continuity of care and communication during handover rounds and patient transfers as key (Donnelly and Psirides, 2015).

Working with families also included family well-being as paramount. As such, nurses appeared to prioritize relationship building with families (Efstathiou and Walker, 2014). The nursing role encompassed the acknowledgement of the experiences of family members (Donnelly and Psirides, 2015) and the need to be with families throughout the illness trajectory of the patient, from admission to death (Peden-McAlpine et al., 2015). In order to facilitate family presences, the nursing role also included actions that explicitly focused on creating a less technical environment, reducing the distance between the patient and their family as well as providing privacy (Efstathiou and Walker, 2014).

In caring for patients and families throughout the process of withdrawal of treatment, 'time' was also a factor that interested with a focus on care of the family. Time was described as

being both objective and subjective (Jones and FitzGerald, 1998). Objective time was identified as actively beginning the withdrawal process and the moment of death (Jones and FitzGerald; Thompson et al., 2011). Subjective time included watching and waiting, being with patients and families, and the nurses' experiences of reflecting on the process (Thompson et al., 2011). The process concluded with the end of story. In this time related space, the intensive care unit nurses' work encompassed making a space for families to be with their loved ones, which had elements of quality rather than quantity (i.e. providing memories and focusing on meaning making), and processing the experiences through existential reflection (Pattison et al., 2013; Peden-McAlpine et al., 2015; Vanderspank-Wright et al., 2011).

3.2.4. Dealing with emotions related to treatment withdrawal

Findings from the studies reviewed suggest that the experiences of caring for patients and families during withdrawal of treatment can create moral dilemmas and emotional distress. Following the death of the patient nurses reported being left feeling exhausted, drained and grieving (Donnelly and Psirides, 2015; Halcomb et al., 2004). Despite this, nurses felt committed to care for the dying patient and support their family past institutional limits, such as beyond the end of their shift or ICU protocols (Donnelly and Psirides, 2015; Jones and FitzGerald, 1998). It was acknowledged that the emotional effects were less when the nurse knew the patient, the family and their wishes (Vanderspank-Wright et al., 2011; van Rooyen et al., 2005).

Moral dilemmas stemmed from nurses' recognising their attempts to distance themselves from the process to avoid feeling emotionally drained, failure to achieve preservation of life and acting against religious beliefs (Halcomb et al., 2004; Jones and FitzGerald, 1998; van Rooyen et al., 2005). Some nurses felt inefficient when their actions failed to relieve the family's distress

and at the same time found it difficult to support the family while feeling upset themselves (Halcomb et al., 2004; Thompson et al., 2011). All these were coupled by nurses' thought processes about the practicalities of treatment withdrawal such as ensuring adequate sedation and analgesia is provided (Vanderspank-Wright et al., 2011).

Although the process of treatment withdrawal created emotional distress, Thompson et al. (2011) and Halcomb et al. (2004) reported that nurses found it difficult or inappropriate to display their emotions, and as a result suffered alone, while the emotional impact lingered for a considerable time following the death of the patient. Debriefing following the death of a patient was considered beneficial but lack of time due to institutional demands, such as bed filling and paperwork, meant that nurses had to carry on without debriefing and moved on to the care of the next patient quickly after the preceding death (Halcomb et al., 2004; Thompson et al., 2011). It was acknowledged that nurses required support to explore their feelings following withdrawal of treatment and this was done mainly through discussions with peers or close family members and seldom in a formal way (Halcomb et al., 2004; Jones and FitzGerald, 1998; Thompson et al., 2011; Vanderspank-Wright et al., 2011).

4. Discussion

This systematic review of qualitative studies has presented the experiences of intensive care nurses who care for patients during the process of withdrawal of life-sustaining treatments. It was evident from the studies included in this review, that following the decision to withdraw life-sustaining treatments, nurses were doing their 'utmost' to facilitate a dignified death by focusing on the patient's comfort and supporting families, despite the complexities and emotional distress they experienced. Four synthesized findings were identified which could

create lasting effects on intensive care nurses: Navigating complexity and conflict; Focusing on the patient; Working with families; Dealing with emotions related to treatment withdrawal.

The operationalization of treatment withdrawal was identified as a complex task requiring good coordination and communication between nurses, physicians and families to achieve the end point of a dignified death for the patient. Nurses found themselves 'in between', trying to take a withdrawal approach that considered the patients' and the families' wishes, their personal beliefs and organisational demands (Truog et al., 2008). Conflict and/or discordance may be common during the withdrawal process because of procedural, organisational, contextual and relational factors that can affect decisions (Hartog and Bendbenishty, 2015). Unnecessary delays linked with decision making and prolonging treatment withdrawal were among the prominent factors creating conflict between nurses and physicians. While a gradual discontinuation of life support has been supported in the literature to mimic natural occurring death (Seymour, 2001), these delays are not always perceived by intensive care nurses as being beneficial for the patient (Efstathiou and Ives, 2017). In the studies reviewed, conflicts and tension were also related to the lack of clear communication and guidance during treatment withdrawal, either by physicians who were not present during the process or the absence of guidelines. It is imperative that these sources of conflict are investigated further and reduced because they are considered as major obstacles to providing good end-of-life care in intensive care units (Kirchhoff and Beckstrand, 2000).

During withdrawal of life-sustaining measures, nurses in the studies we reviewed, ensured they had a constant presence at the patient's bedside in order to continually assess the process and provide comfort measures so that the patient would die with dignity. Presence and comfort are considered both professional and moral obligations in end-of-life care (Epstein,

2010). Comfort measures included pharmacological adjustments, such as titration of opioids and sedatives, and non-pharmacological interventions such as changing positions or massaging and removing unnecessary monitoring equipment. These interventions are globally congruent with the concept of 'good death' in intensive care (Beckstrand et al., 2006; Cook and Rocker, 2014; da Silva et al., 2015). It was desirable that intensive care nurses knew the patient whose treatment was to be withdrawn and the process was mostly undertaken by a nurse who had cared previously for the patient. Further efforts were made to find more about the patient as a person through consultation and communication with their family. Knowing the patient allows nurses to adjust their care in accordance to what the patient would prefer and provide expert personalised care, congruent with patient wishes (Zolnierek, 2014). However, it was unclear in the studies we reviewed whether 'knowing the patient' was achieved within the timeframe of treatment withdrawal, especially with the lack of opportunities for developing interpersonal relationships during this stage (Jenks, 1993). It remains to explore further what 'knowing the patient' means (Bungaard et al., 2012) and the impact of knowing the patient in the treatment withdrawal context.

Apart from being a source of information about the patient, families needed information about the withdrawal of life-sustaining measures process. The findings of this review suggest that nurses are giving great attention to informing the family about the patient's condition, the process of withdrawal of treatment, and what to expect during the process. Evidence suggests that when family members are well-informed they feel satisfied with end-of-life care in intensive care and they appreciate greatly the efforts by nurses to keep them informed (Henrich et al., 2011; Hinckle et al., 2015).

Feelings of grief were expressed by nurses, related to the patient whose life support was withdrawn, a common finding in the extant literature specific to end-of-life care in intensive care worldwide (Badger, 2005; Shorter and Stayt, 2010). The length and intensity of emotional responses tends to be more profound among newly qualified nurses (Yang and McIlfatrick, 2001; Zheng et al., 2016). Grief and emotional distress had long lasting impact to most of the nurses in the studies we reviewed. This constitutes a major challenge for intensive care nurses and support is required. Findings from this review suggest that one means of support with which nurses engage is informal peer support. This support is readily available and facilitated due to the team work ethic, which has been identified as an essential aspect of critical care nursing (Vanderspank-Wright et al., 2015). However, evidence suggests that more formal mechanisms such as debriefing might be helpful for intensive care nurses (Downar et al., 2016; Keene et al., 2010). Findings of this review suggest that when nurses enact the withdrawal of life-sustaining treatment, despite the challenges and difficulties, they find this experience to be rewarding and highlight the privilege they experience in providing what they perceive as a dignified death.

4.1. Implications for practice

It is important to note that while this review has highlighted some of the more challenging aspects of withdrawal of treatment in intensive care, overwhelmingly it highlights what is done well. The findings have clearly demonstrated that nurses play an integral and central role in working with patients and families along the entire trajectory of withdrawal of treatment - from early discussions through to final moments and bereavement. However, nurses do not necessarily come to intensive care with adequate knowledge around withdrawal of treatment or the confidence to lead this process. Innovative education around withdrawal of life-sustaining measures should be provided for every new nurse in intensive care with frequent

updates to allow the development of skills and confidence for this process - it is inadequate to rely solely on gaining experiential knowledge over time.

Since it is evident that grief and emotional distress are experienced following treatment withdrawal, formal debriefing for all nurses involved in this process should be offered as a standard procedure rather than ad hoc. Already effective debriefing models used in other clinical areas can be adapted and validated for use in intensive care.

Finally, the implementation of guidelines for the withdrawal of life-sustaining treatments could decrease the sources of conflict during treatment withdrawal. Downar et al. (2016) recently published clinical practice guidelines for withdrawing life-sustaining measures, which could be used as a platform to develop unit specific guidelines.

4.2. Implications for research

The findings of this review would suggest that despite the varying approaches to qualitative inquiry that have been used, the experiences of intensive care nurses who care for patients and families during the withdrawal of life-sustaining treatment has been well described within the literature. As such, implications for research can be suggested beyond the lived experience of intensive care nurses to focus on delivery of care that is evidence informed and which builds on the barriers and facilitators that have been identified. For example, nurses' roles in decision-making regarding withdrawal of treatment need to be investigated in greater depth in order to facilitate and clearly explicate what this aspect of the nursing role should be. The latter is particularly important because the period of time leading up to a decision to withdraw treatment is seemingly the most tenuous. Furthermore, a critical evaluation of existing treatment withdrawal protocols and clinical practice guidelines as well as how these guidelines are actualized in intensive care would help to identify and solidify best-practices.

Formal mechanisms of support such as debriefing should also be explored, however, the utilization of such practices need to be grounded in evidence and clearly demonstrate which mechanisms of support are of the most benefit for intensive care nurses. Furthermore, while a body of knowledge exists regarding the integration of specialist palliative care into critical care, clinical competencies need to be explored to ensure that this integration is accomplished in a manner that carefully considers what might constitute comfort care in intensive care that is not consistent with current practices in traditional contexts of death and dying (i.e. in-patient palliative care or hospice palliative care). This would facilitate a better understanding of what type of educational needs intensive care nurses might have in this context.

4.3. Strengths and limitations

There are a number of limitations to consider when interpreting the findings of this study. First, as with all meta-aggregation studies, there is a possibility that we misrepresented the original experiences and/or interpretations. This can occur any time one synthesizes aggregated qualitative data from multiple sources (Sandelowski, et al., 1997; Walsh and Downe, 2005). To minimize this potential error, we followed a rigorous systematic review methodology (Joanna Briggs Institute, 2014), including double citation screening and data extraction and only reported on findings deemed unequivocal or credible. The research team also had expertise in review methods, withdrawal of treatment as well as palliative and end-of-life care in intensive care, and qualitative methodologies. Second, it is possible that our search strategy failed to identify all pertinent literature because we opted to create a narrow search including keywords explicitly relevant to the topic. It is possible that the addition of terms like ‘end-of-life’ might have produced more results including other contexts of death and dying in the intensive care unit,

however, with less specificity related to withdrawal of treatment. Furthermore, we did not include a grey literature search.

The studies we reviewed originated from Australia, Canada, New Zealand, Norway, Sweden, South Africa, United Kingdom and United States, and report very similar findings, however, there were no studies meeting the inclusion criteria on this topic from Asia or South America, limiting the transferability of findings to an Asian or South American healthcare context. In addition, most of the participants were female and the overall experience described in this paper may not represent accurately male nurses' experiences.

5. Conclusion

This systematic review of qualitative studies from various countries provided an aggregated perspective of the experiences of critical care nurses working in adult intensive care units who have cared for patients and families during the process of withdrawal of life-sustaining treatment. The experiences of nurses within this context of care is complex, multifaceted and has similarities across the world where withdrawal of treatment is practised despite evidence of variability of practices. Intensive care nurses are confronted with many challenges, yet they strive towards doing their utmost for patients and families. This review expands our understanding of this experience for nurses in that it provides implications for practice and is suggestive of areas for the development of new knowledge by clearly identifying areas for further research.

Acknowledgements

We would like to acknowledge Susan Stevens, Subject Advisor for Biosciences, Dentistry and Nursing at the University of Birmingham, UK for her assistance in developing the systematic

search strategy. Additionally, we would like to acknowledge Sandra Wong and Dana Forozeiya for their role as research assistants in this project.

References

Attride-Stirling, J., 2001. Thematic networks: an analytic tool for qualitative research. Qualitative Research. 1, 385–405.

Badger, J.M., 2005. A descriptive study of coping strategies used by Medical Intensive Care Unit nurses during transitions from cure- to comfort-oriented care. Heart & Lung. 34 (1), 63-68. doi 10.1016/j.hrtlng.2004.08.005

Beckstrand, R.L., Callister, L.C., Kirchhoff, K.T., 2006. Providing a "good death": Critical care nurses' suggestions for improving end-of-life care. American Journal of Critical Care. 15 (1), 38-45.

Birchley, G. 2013. Doctor? Who? Nurses, patients' best interests and treatment withdrawal: when no doctor is available, should nurses withdraw treatment for patients? Nursing Philosophy, 14, 96-108. doi: 10.1111/j.1466-769X.2012.00553.x

Bungaard, K., Nielsen, K.B., Delmar, C., Sorensen, E.E. 2012. What to know and how to get to know? A fieldwork study outlining the understanding of knowing the patient in facilities for short-term stay. Journal of Advanced Nursing, 68(10), 2280-2288. doi: 10.1111/j.1365-2648.2011.05921.x

CASP, 2013. 10 questions to help you make sense of qualitative research. http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf. Accessed 20/10/2015

Charmaz, K., 2006. Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. London: Sage Publications.

Colaizzi, P., 1978. Psychological research as the phenomenologist views it. In Valle, R., King, M. (Eds.), Existential phenomenological psychology. NY: Oxford University Press, 48-71.

Cook, D., Rocker, G. 2014. Dying with dignity in the intensive care unit. The New England Journal of Medicine, 370, 2506-2514. doi: 10.1056/NEJMra1208795

Coombs, M., Addlington-Hall, J., Long-Sutehall, T., 2012. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. International Journal of Nursing Studies. 49, 519-527. doi: 10.1016/j.ijnurstu.2011.10.019

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. Australian Critical Care. 29, 82-86. doi: 10.1016/j.aucc.2015.03.002

Creswell, J.W., 1994. Research Design. Qualitative and Quantitative Approaches. Thousand Oaks: Sage Publications

Curtis, J.R. & Vincent, JL., 2010. Ethics and end-of-life care for adults in the intensive care unit. Lancet, 375, 1347-1353. doi: 10.1016/S0140-6736(10)60143-2

Da Silva, R.S., Pereira, A., Mussi, F.C., 2015. Comfort for a good death: Perspective nursing staff's of intensive care. Escola Anna Nery, 19(1), 40-46. doi 10.5935/1414-8145.20150006

Donnelly, S.M., Psirides, A. 2015. Relatives' and staff's experiences of patients dying in ICU. QJM: An International Journal of Medicine. 12, 1-8. doi: 10.1093/qjmed/hcv059

Downar, J., Delaney, J.W., Hawryluck, L., Kenny, L., 2016. Guidelines for the withdrawal of life-sustaining measures. Intensive Care Medicine. 42, 1003-1017. doi: 10.1007/s00134-016-4330-7

Efstathiou, N., Ives, J., 2017. Compassionate care during withdrawal of treatment: qualitative secondary analysis of intensive care nurses' experiences. Nursing Ethics. doi: 10.1177/0969733016687159

Efstathiou, N., Walker, W., 2014. Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: a qualitative study. Journal of Clinical Nursing. 23, 3188-3196.

Elo, S., Kyngas, H., 2008. The qualitative content analysis process. Journal of Advanced Nursing. 62, 107—115. doi: 10.1111/j.1365-2648.2007.04569.x

Epstein, E.G., 2010. Moral obligations of nurses and physicians in neonatal end-of-life care. Nursing Ethics. 17, 577-589.

Fairman, J., Lynaugh, J., 1998. *Critical Care Nursing: A History.* Philadelphia: University of Pennsylvania Press.

Fridh, I. 2014. Caring for the dying patient in the ICU – the past, the present and the future. Intensive and Critical Care Nursing. 30(6), 306-311. doi: 10.1016/j.iccn.2014.07.004

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

Gerstel, E., Engelberg, R.A., Koepsell, T., Curtis, R.J. 2008. Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. American Journal of Respiratory and Critical Care Medicine. 178, 798-804. doi: 10.1164/rccm.200711-1617OC

Grimshaw, J., 2011. A guide to knowledge synthesis: a knowledge synthesis chapter. Canadian Institutes of Health Research. Retrieved from http://www.cihr-irsc.gc.ca/e/documents/knowledge_synthesis_chapter_e.pdf (accessed 29.05.2017)

Hadders, H., 2009. Enacting death in the intensive care unit: medical technology and the multiple ontologies of death. health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine. 13(6), 571-587. doi: 10.1177/1363459308341869

Halcomb, E., Daly, J., Jackson, D., Davidson, P., 2004. An insight into Australian nurses' experience of withdrawal/withholding of treatment in the ICU. Intensive and Critical Care Nursing. 20, 214-222. doi: 10.1016/j.iccn.2004.05.010

Hartog, C.S., Benbenishty, J., 2015. Understanding nurse-physician conflicts in the ICU. Intensive Care Medicine. 41, 331-333. doi: 10.1007/s00134-014-3517-z

Henrich, N.J., Dodek, P., Heyland, D., Cook, D., Rocker, G., Kutsogiannis, D., Dale, C., Fowler, R., Ayas, N. 2011. Qualitative analysis of an intensive care unit family satisfaction survey. Critical Care Medicine. 39, 1000–1005. doi: 10.1097/CCM.0b013e31820a92fb

Heyland, D.K., Lavery, J.V., Tranmer, J.E., & Taylor, S.J., 2000. Dying in Canada: Is it an institutionalized, technologically supported experience? Journal of Palliative Medicine. 16 (Supp.), S10-S16.

Hinkle, L.J., Bosslet, G.T., Torke, A.M., 2015. Factors associated with family satisfaction with end-of-life care in the ICU. Chest. 147, 82-93. doi: 10.1378/chest

Hsieh, H.F., Shannon, S.E., 2005. Three approaches to qualitative content analysis. Qualitative Health Research. 15, 1277, http://dx.doi.org/10.1177/1049732305276687 [accessed 05.11.14].

Holms, N., Milligan, S., Kydd A. 2014. A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit. International Journal of Palliative Nursing. 20(11), 549-556. doi: 10.12968/ijpn.2014.20.11.549

Jenks, J.M., 1993. The pattern of personal knowing in nurse clinical decision making. Journal of Nursing Education. 32(9), 399-405.

Joanna Briggs Institute, 2014. Reviewer's Manual

http://joannabriggs.org/assets/docs/sumari/reviewersmanual-2014.pdf (accessed 20.1.2016)

Jones, T., FitzGerald, M., 1998. Withdrawal of life-support treatment: the experience of critical care nurses. Australian Critical Care. 11 (4), 117-121.

Keene, E.A., Hutton, N., Hal, B., Rushton, C., 2010. Bereavement debriefing sessions: An intervention to support health care professionals in managing their grief after the death of a patient. Pediatric Nursing. 36, 185-189.

Kirchhoff, K.T., Beckstrand, R.L., 2000. Critical care nurses' perceptions of obstacles and helpful behaviors in providing end-of-life care to dying patients. American Journal of Critical Care. 9, 96–105.

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 unit. International Journal of Nursing Studies. 48, 1466-1474. doi: 10.1016/j.ijnurstu.2011.06.003

Mark, N.M., Rayner, S.G., Lee, N.J., Curtis, J.R. 2015. Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: a systematic review. Intensive Care Medicine. 41, 1572-1585. doi: 10.1007/s00134-015-3810-5

Mol, A., 2002. The body multiple: Ontology in medical practice. Durham, NC & London: Duke University Press

Pattison, N., Carr, S. N., Turncock, C., Dolan, S., 2013. 'Viewing in slow motion': patients', families', nurses' and doctors' perspectives on end-of-life care in critical care. Journal of Clinical Nursing. 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. International Journal of Nursing Studies. 52, 1146-1156. doi: 10.1016/j.ijnurstu.2015.03.015

Prendergast, T.J., Claessens, M.T., Luce, J.M. 1998. A national survey of end-of-life care for critically ill patients. American Journal of Respiratory and Critical Care Medicine. 158(4), 1163-1167.

Sandelowski, M., 2000. Whatever happened to qualitative description? Research in Nursing & Health. 23, 334-340.

Sandelowski, M., Barroso, J., 2007. Handbook for synthesizing qualitative research. New York: Springer Publishing Company.

Sandelowski, M., Docherty, S., Emden, C., 1997. Focus on Qualitative Methods Qualitative Metasynthesis: Issues and Techniques. Research in Nursing and Health. 20(4), 365-371.

Society of Critical Care Medicine. (no date). Critical care statistics. Retrieved from: http://www.sccm.org/Communications/Pages/CriticalCareStats.aspx (accessed 3.06.2017)

Seymour, J.E., 2001. Critical Moments – Death and Dying in Intensive Care. Buckingham (UK): Open University Press.

Shorter, M., Stayt, L.C., 2010. Critical care nurses' experiences of grief in an adult intensive care unit. Journal of Advanced Nursing. 66(1), 159-167. doi: 10.1111/j.1365-2648.2009.05191.x

Smith, J.A., Jarman, M., Osborn, M., 1999. Doing interpretative phenomenological analysis. In Qualitative Health Psychology: Theories and Methods (Murray, M. & Chamberlain, K. eds). London: Sage Publications, pp. 218–240.

Sprung, C.L., Cohen, S.L., Sjokvist, P., Baras, M., Bulow, H.H., Hovilehto, S., Ledoux D., Lippert, A., Maia, P., Phelan D., Schobersberger, W., Wennberg, E., Woodcock, T. 2003. End of life practices in European intensive care units: the Ethicus Study. JAMA. 290(6), 790–7. doi 10.1001/jama.290.6.790

Thompson, J., 1990. Hermeneutic inquiry. In Moody L.E. ed Advancing Nursing Science through research. Newbury: Sage Publications pp 223-280

Thompson, G., Austin, W., Profetto-McGrath, J., 2011. Novice nurses' first death in critical care. Dynamics. 21(4), 26-26.

Thorne, S., Reimer Kirkham, S., O'Flynn-Magee, K., 2004. The analytic challenge in interpretive description. International Journal of Qualitative Methods, 3(1), Article 1. Retrieved from http://www.ualberta.ca/~iiqm/backissues/3_1/pdf/thorneetal.pdf (accessed 4.06.2017)

Tong, A., Flemming, K., McInnes, E., Oliver, S., Craig, J., 2012. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology, 12(181), n.p.

Truog, R.D., Campbell, M.L., Curtis, J.R., Haas, C.E., Luce, J.M., Rubenfeld, G.D., Rushton, C.H., Kaufman, D.C., 2008. Recommendations for end-of-life care in the intensive care unit: a consensus statement by the American College of Critical Care Medicine. Critical Care Medicine. 36, 953–963. doi: 10.1097/CCM.0B013E3181659096

Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Brajtman, S., Gagnon, P., 2011. Caring for patients and families at end of life: The experiences of nurses during withdrawal of life-sustaining treatment. Dynamics. 22(4), 31-35.

Vanderspank-Wright, B., Bourbonnais, F.F., Toman, C., McPherson, C., 2015. A social construction of the development of ICU nursing in Canada, 160-2002. Canadian Journal of Critical Care Nursing. 26(1), 19-24.

van Manen, M., 1990. Researching Lived Experience: Human Science for an Action Sensitive Pedagogy. New York: New York Press.

van Manen, M. 1997. From meaning to method. Qualitative Health Research, 7, 345-369.

van Rooyen, D., Elfick, M., Strümpher, J., 2005. Registered nurses' experience of the withdrawal of treatment from the critically ill patient in an intensive care unit. Curationis. 42-51.

Walsh, D., Downe, S., 2005. Meta-synthesis method for qualitative research: a literature review. Journal of Advanced Nursing. 50(20), 204-211.

Wennberg, J.E., Fisher, E.S., Stukel, T.A., Skinner, J.S., Sharp, S.M., Bronner, K.K., 2004. Use of hospitals, physician visits, and hospice care during last six months of life among cohorts loyal to highly respected hospitals in the United States. BMJ. 328, 1-5. doi: 10.1136/bmj.328.7440.607

Yang, M., McIlfatrick, S., 2001. Intensive care nurses' experiences of caring for dying patients: a phenomenological study. International Journal of Palliative Nursing. 7(9), 435–441. doi: 10.12968/ijpn.2001.7.9.9302

Zheng, R., Lee, S.F., Bloomer, M.J., 2016. How new graduate nurses experience patient death: A systematic review and qualitative meta-synthesis. International Journal of Nursing Studies, 53, 320-330. doi: 10.1016/j.ijnurstu.2015.09.013

Zolnierek, C.D., 2014. An integrative review of knowing the patient. Journal of Nursing Scholarship. 40(1), 3-10. doi: 10.1111/jnu.12049