International Journal of Nursing Studies 77 (2018) 15–26

Contents lists available at ScienceDirect

International Journal of Nursing Studies

journal homepage: www.elsevier.com/locate/ijns

Critical care nurses' experiences of withdrawal of treatment: A systematic review of qualitative evidence

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ARTICLE INFO

Keywords:
Intensive care units
Critical care
Nursing
Withdrawal of treatment
Qualitative synthesis
Systematic review
Nurses' experiences

ABSTRACT

Background: Death and dying is a 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 Science 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 about the topic?

- 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 the context of withdrawal of treatment.
- Physical and organizational structures may be perceived to impede good end-of-life care in intensive care units.

What this paper adds

- 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.

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

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http://dx.doi.org/10.1016/j.ijnurstu.2017.09.012
Received 30 December 2016; Received in revised form 15 September 2017; Accepted 18 September 2017

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 to 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.

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,

Table 1
Eligibility criteria.

Criteria	Inclusion	Exclusion
Type of Publication and Study Design	Qualitative	Quantitative
	Mixed methods	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