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Review Paper

End-of-life decisions in the Intensive Care Unit (ICU) – Exploring the experiences of ICU nurses and doctors – A critical literature review

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ABSTRACT

Background: End-of-life decision making in the Intensive Care Unit (ICU), can be emotionally challenging and multifaceted. Doctors and nurses are sometimes placed in a precarious position where they are required to make decisions for patients who may be unable to participate in the decision-making process. There is an increasing frequency of the need for such decisions to be made in ICU, with studies reporting that most ICU deaths are heralded by a decision to withdraw or withhold life-sustaining treatment.
Objectives: The purpose of this paper is to critically review the literature related to end-of-life decision making among ICU doctors and nurses and focuses on three areas: (1) Who is involved in end-of-life decisions in the ICU?; (2) What challenges are encountered by ICU doctors and nurses when making decisions?; and (3) Are these decisions a source of moral distress for ICU doctors and nurses?
Review method: This review considered both qualitative and quantitative research conducted from January 2006 to March 2014 that report on the experiences of ICU doctors and nurses in end-of-life decision making. Studies with a focus on paediatrics, family/relatives perspectives, advance care directives and euthanasia were excluded. A total of 12 papers were identified for review.
Results: There were differences reported in the decision making process and collaboration between doctors and nurses (which depended on physician preference or seniority of nurses), with overall accountability assigned to the physician. Role ambiguity, communication issues, indecision on futility of treatment, and the initiation of end-of-life discussions were some of the greatest challenges. The impact of these decisions included decreased job satisfaction, emotional and psychological 'burnout'.
Conclusions: Further research is warranted to address the need for a more comprehensive, standardised approach to support clinicians (medical and nursing) in end-of-life decision making in the ICU.

1. Introduction

End-of-life decisions within acute care hospitals and more specifically Intensive Care Units (ICUs), are likely to increase as the Australian population increases and ages.[1] An estimated 140,000 Australians die each year[2] of which 54% die in acute care hospitals,[3] with most preceded by an end-of-life decision.[4] This resonates with international data which confirms the increased frequency of end-of-life decisions within an ICU setting.[5,6]

While advance care directives have been available as an option for those with a known or deteriorating condition, the uptake has been slow both internationally and within Australia.[7] Due to the unexpected nature and severity of illness on admission, intensive care patients are less likely to have an advance care directive in place.[8] Consequently end-of-life decisions are paramount, particularly in ICUs, where patients in fragile states, often with multiple co-morbidities, are becoming more commonplace.[6]

With advances in medicine and technology, ICUs have the capacity to treat patients who would have previously not been expected to survive, and would therefore not have been managed in ICUs.[9] When an individual is not expected to survive, doctors and nurses face the modern ethical dilemma of death associated with withdrawal of life supporting strategies.[9] It may be taken for granted that ICU doctors and nurses are well equipped to deal with

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end-of-life decisions for these patients.[10] However the literature purports poor communication, doctor and nurses' role ambiguity, and a lack of guidance for making end-of-life decisions, as key factors preventing optimal end-of-life decision making.[10]

End-of-life decisions "include decisions about withholding or withdrawing potentially life-prolonging treatment and about alleviation of pain or other symptoms with a possible life-shortening effect" (p. 2).[11] These decisions place great demand and responsibility on families and ICU staff and are often made without the patient's input, due to their life-threatening condition. This may place significant emotional burden on the family, as well as health professionals involved, to make a critical decision on the patient's behalf, at a time of extreme stress.[12]

Nurses and doctors have revealed that despite knowledge and experience, they often fear that they have failed the patient by abandoning hope prematurely, and frequently cite inadequate preparation on how and when to initiate end-of-life discussions.[12] There is a scarcity of empirical data about end-of-life decisions.[4] With the increasing frequency of these decisions a greater understanding of the experiences of ICU nurses and doctors is required. Insights into these experiences have the potential to inform practice, and the development of educational resources and standards of care, to support a more satisfying approach to end-of-life decisions.

2. Aim

The aim of this review is to investigate the end-of-life decision making process among nurses and doctors in the ICU.

The following three questions guided the literature review:

1. Who is involved in end-of-life decision making in an ICU setting?
2. What challenges are encountered by ICU doctors and nurses in end-of-life decision making?
3. Are these decisions a source of moral distress for ICU doctors and nurses?

3. Search methods

3.1. Inclusion criteria

This review considered peer-reviewed qualitative and quantitative studies that reported the experiences of nurses and/or doctors in making end-of-life decisions in the ICU. All qualitative and quantitative research methodologies were included if they captured, explored or explained the human experience of making end-of-life decisions.

3.2. Exclusion criteria

Studies were limited to the English language from January 2006 to March 2014. Studies excluded were those with a focus on paediatrics and family/relatives perspectives. This was to limit the research to experiences of doctors and nurses, and exclude emotive responses related to paediatric end-of-life issues. Research where end-of-life decisions were not made in ICU, were excluded. Research related to patients with advance care directives was also excluded, due to end-of-life decisions being previously made. International research discussing euthanasia was also excluded, as the practice of euthanasia is illegal within Australia. Finally, literature reviews, editorials, commentaries or conference abstracts were excluded from the review.

3.3. Search strategy

The search strategy aimed to find studies in the English language from January 2006 to March 2014. The year limitation was applied so the review would be representative of current knowledge and research. Search terms, using medical subject headings (MeSH) and key words, were developed and then reviewed by a university librarian. The search terms used were end-of-life, intensive care or critical care, decision making, doctors and nurses. The Boolean operators 'AND' and 'OR' were used for intensive care 'OR' critical care, and doctors 'AND' nurses. Databases searched included Proquest, Cinahl, Cochrane, PubMed, Medline and Google Scholar.

The PRISMA flow diagram (Fig. 1) was used to map this process.[13] 215 records were identified through database searching and an additional 11 that were deemed relevant to the aim of the review were sourced from the bibliographies. 78 duplicates were removed. Of the remaining 148 papers, a further 49 were excluded on screening of abstracts, as they were not relevant to this review. The remaining 99 papers were manually reviewed in full text versions, allowing further exclusion of 87 papers, when measured against the exclusion criteria. 12 papers were identified for this literature review, and each critically appraised using the CASP[14] tool (Table 1). Through thematic review, end-of-life decisions were identified as the core theme, with subsequent reference to the three topic questions (Who is involved?; What are the challenges?; and Are decisions a source of moral distress?). These issues are critically examined below.

4. Who is involved in end-of-life decision making?

ICU doctors and nurses agree that the attending physician (doctor in charge of ICU for that day), holds overall responsibility for the patients' treatment, and is the most appropriate person to initiate end-of-life decisions.[15] Nurses spend the most time with the patient, and are therefore in a unique position as the family and/or patient often discuss their end-of-life wishes with them.[16] The Australian and New Zealand Intensive Care Society (ANZICS) state that although the Intensivist (physician) leads the decision making process, it should always remain a shared decision making process.[17] Thus, unilateral medical decisions are inappropriate, and should always incorporate all key stakeholders, such as nurses and family members.[17] In most cases, due to critical illness, the patient is unable to participate in the decision making process. It is therefore considered best end-of-life practice, for the attending physician and nurse to guide the family in the decision making process.[18] Despite this, the literature indicates that nurses are not integral in the end-of-life decision making process, and at times are excluded from the decision making process.[18] Heland[19] in an Australian qualitative study, identify that in some ICUs, end-of-life decisions are made unilaterally by physicians. Latour, Fulbrook and Albarran[20] identify that the inconsistent inclusion of nurses in end-of-life discussions leads to lack of uniformity and role ambiguity for nurses. With 68% of the 162 nurses surveyed indicating they wanted to be more involved in end-of-life decisions, there is evidence that nurses are frequently not included.[20]

In a US qualitative study conducted in a 51 bed ICU, 19 registered nurses were interviewed about end-of-life decisions. All agreed that the attending physician was the appropriate person to make end-of-life decisions, as the person in charge of the patient's care, however nurses were considered as being most likely to recognise the point where patient treatment becomes futile.[21] This resonates with another study by Jensen, Armmentorp, Johannessen and Ording[22] who surveyed 11 nurses and 10 physicians across two Danish ICUs. They found both doctors and nurses agreed that nurses recognised the point at which treatment was futile. Similarly,