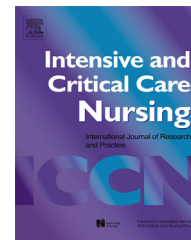




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ORIGINAL ARTICLE

Factors affecting stress experienced by surrogate decision makers for critically ill patients: *Implications for nursing practice*



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Accepted 30 August 2013

KEYWORDS

Surrogate decision maker;
Critical illness;
Provider-SDM communication,
Qualitative data collection;
Social science research

Summary

Objectives: This study explores surrogate decision-makers' (SDMs) challenges making decisions related to the care of patients in critical care, to (1) characterise the SDM stress, (2) identify personal, social, care-related factors influencing stress and (3) consider implications of findings to improving critical care practice.

Methodology: Semi-structured interviews were conducted with SDMs of critically ill patients receiving care in two tertiary care institutions. Transcripts were analysed using a grounded theory approach. Domains explored were: stress characteristics, stress mitigators, coping strategies, social networks, SDM decision-making role, decision-making concordance, knowledge of patient's preferences, experience with provider team, SDM-provider communication, patient outcome certainty.

Main outcomes: We interviewed 34 SDMs. Most were female and described long-term relationships with patients. SDMs described the strain of uncertain outcomes and decision-making without clear, consistent information from providers. Decision-making anxiety was buffered by SDMs' active engagement of social networks, faith and access to clear communication from providers.

Conclusion: Stress is a very real factor influencing SDMs confidence and comfort making decisions. These findings suggest that stress can be minimised by improving communication between SDMs and medical providers. Nurses' central role in the ICU makes them uniquely poised to spearhead interventions to improve provider-SDM communication and reduce SDM decision-making anxiety.

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Implications for clinical practice

- Stress is natural, ubiquitous and unavoidable caring for critically ill or injured patients and can compromise SDMs' confidence and comfort partnering with providers to make decisions on patients' behalf.
- A primary source of stress exacerbation is SDM's perception that information and communication with providers is unclear, uncoordinated, and inconsistent.
- SDMs' personal and social assets – such as an extended social networks sharing decision-making responsibilities, religious faith and faith communities – can significantly buffer the stress of making decisions.
- A family-centered approach to critical care must be designed to assess SDM needs, sources of stress and support and offer clear, consistent communication throughout the critical care experience.
- Critical care nurses are uniquely positioned to play a pivotal role leading interventions to improve SDMs comfort and confidence, assessing and addressing SDM needs and becoming the nexus of information and support.

Introduction

There is a growing body of research examining the stress of caring for and making decisions on behalf of patients in a variety of clinical settings (Goddard, 2011; Van Rosendaal et al., 1999; Wendler and Rid, 2011). Few clinical environments present more challenges to thoughtful and timely decision-making related to patient treatment than critical care. It is often the case that families of patients in intensive care units (ICU) are thrust into the role of decision-maker as a result of conditions that are precipitous, life-threatening and that render patients incapable of making their own care decisions (Luce et al., 2004). Compounding the emotional stress of uncertain outcome, these surrogate decision-makers (SDMs) are called upon to render judgments within a limited amount of time about treatment which is often complex and may be highly technological. These stresses not only impede thoughtful and timely decision-making, but have been found to take a significant psychological toll on SDMs, even when patients survive (Kentish-Barnes et al., 2009). Anxiety, depression and posttraumatic stress disorder (PTSD) are increasingly being linked to families' experiences with critically ill or injured loved ones (Corrigan et al., 2007; Jones et al., 2004; Kross et al., 2011). Female SDMs appear most vulnerable to these psychological sequelae (Paparrigopoulos et al., 2006).

Investigators have identified individual, provider-related, environmental and patient factors that appear to compound stress inherent to the critical care experience. These factors include SDMs' poor comprehension of patients' condition and treatment (Kentish-Barnes et al., 2009) perceptions of insufficiently supportive staff, poor communication with providers (Bowman, 2010; Mitchell et al., 2003; Nelson et al., 2010) and providers' lack of responsiveness to family needs and stresses (Buckley and Andrews, 2011; Gay et al., 2009; Pryzby, 2005). In addition, SDMs appear to experience greater emotional trauma when they perceive that providers are not clear or transparent in discussing prognosis or when they appear to avoid prognostication altogether (Apatira et al., 2008; Evans et al., 2009). Structural factors and policies have been found to contribute to stress and family discomfort, such as limited space to visit, restricted visiting hours, limitations on number and age of visitors, and inadequate waiting areas (Bazuin and Cardon, 2011; Jastremski, 2000; Vandijck et al., 2010).

Many of these studies rely on recall and are conducted after the episode of critical illness has concluded. Few studies have been conducted while SDMs remain actively engaged in the ICU experience. Additionally, while frameworks have emerged helping us understand the broad individual-, provider- and patient-related constructs likely to influence stress in the ICU (Vig et al., 2007), few have examined factors that may exacerbate stress or buffer its impact. Findings reported here are based on individual, in-depth interviews (IDIs) conducted with SDMs of adult ICU patients which explore the challenges of decision-making related to the care of their loved ones. The aims of this analysis were to (1) identify and characterise the stressors SDMs confront, (2) identify personal, social, provider-related and structural factors that appear to ease or exacerbate these stresses and (3) consider the implication of these findings for critical care practice.

Methods

Findings reported here are based on individual, in-depth interviews with a sub-sample of 34 SDMs randomly selected from the larger study sample of 78 SDMs recruited to participate in focus groups to understand attitudes regarding critical illness research (reported previously) (Iverson et al., 2012, 2013). The focus groups provided insight into SDM perceptions of several hypothetical scenarios in which they might be asked to provide consent to participate in research on behalf of their loved one currently in critical care. To better understand the emotional and structural context in which SDMs might be asked to make such decisions, the study team designed individual interviews to elicit SDMs' accounts of their experience making decisions for their loved one currently in the ICU and explore the impact of stress caring for a patient in the ICU on their experience and comfort making decisions.

Setting

Data collection took place from February 2008 to July 2009 in the intensive care units (ICUs) of two tertiary care, urban, university-based hospitals: Barnes Jewish Hospital (BJH), St. Louis, MO, and Parkland Hospital (PH), Dallas, TX. Both institutions provide care to ethnically and socio-economically diverse patient populations.

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