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#### Clinical research article

# A qualitative study of factors that influence active family involvement with patient care in the ICU: Survey of critical care nurses

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#### ABSTRACT

*Objective*: Family caregiver involvement may improve patient and family outcomes in the intensive care unit. This study describes critical care nurses' approaches to involving family caregivers in direct patient care.

Research Methodology/Design: This is a qualitative content analysis of text captured through an electronic survey.

Setting: A convenience sample of 374 critical care nurses in the United States who were subscribers to one of the American Association of Critical Care Nurses social media sites or electronic newsletters. *Main outcome measure:* Critical care nurses' responses to five open-ended questions about their approaches to family involvement in direct patient care.

Findings: Nurse, patient, and family caregiver factors intersected in the context of the professional practice environment and the available resources for family care. Two main themes were identified: "Involving family caregivers in patient care in the intensive care unit requires careful ssessment" and "There are barriers and facilitators to caregiver involvement in patient care in the intensive care unit."

*Conclusion:* Patient care demands, the professional practice environment and a lack of resources for families hindered nursing family caregiver involvement. Greater attention to these barriers as they relate to family caregiver involvement and clinical outcomes should be a priority in future research.

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#### Implications for clinical practice

- Family caregiver involvement can improve family experiences in the intensive care unit; however, nurses use varying approaches to incorporate family caregivers into the direct care of critically ill patients.
- Nurses' decisions about involving family caregivers is based on assessment of factors related to the professional practice environment, family and patient characteristics, and the overall intensive care unit culture.
- Nurses have concerns regarding potential negative effects of family caregiver involvement, including overburdening family caregivers and exacerbating stress and anxiety for the involved family members. They also identified risks to patient and caregiver safety.
- Nurses are more likely to endorse family caregiver involvement when there is a strong patient and family engagement culture, available family resources and a healthy professional practice environment.

#### Introduction

Each year, 5.7 million Americans are admitted to an intensive care unit (ICU) (Society of Critical Care Medicine, 2017). Critical illness is physically and psychologically distressing for patients and their families. Family members of critically ill patients are rou-

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tinely expected to assume caregiving roles, often without adequate preparation, which can negatively affect their health and wellbeing (Cameron et al., 2006, 2016; Choi et al., 2011; Douglas and Daly, 2003; Fry and Warren, 2007; Hickman and Douglas, 2010; Johnson et al., 2001; Van Pelt et al., 2007). In fact, half of family members of patients receiving care in the ICU report symptoms of depression, anxiety and post-traumatic stress disorder (PTSD) (Anderson et al., 2008). The intense negative psychological impact of a patient's critical illness may be further exacerbated when family members are not involved as a component of care or if they do not receive sufficient emotional support, information, or communication from critical care providers (Anderson et al., 2008; Tyrie and Mosenthal, 2012).

#### Background

Recent policies and practice guidelines supported by clinical research recommend care delivery guided by a patient and family engagement (PFE) model of care (Brown et al., 2015). The PFE model of care constitutes an active partnership between healthcare providers, patients and families (Brown et al., 2015). PFE has been successfully incorporated in the ICU through passive care interventions such as open visitation, family presence during cardiopulmonary resuscitation and invasive procedures and shared decision making between caregivers and healthcare staff (Brown et al., 2015; Davidson et al., 2007, 2017; Olding et al., 2015). However, implementation of PFE by involving family caregivers in direct patient care has the potential to enhance the patient and family experience with critical illness as well as improve safety, quality and delivery of care (Brown et al., 2015; Davidson et al., 2007, 2017; Mitchell et al., 2009; Olding et al., 2015). Active family involvement in patient care in the critical care setting has received little attention in research and policy, possibly due to opposing ideologies about family involvement in the ICU and a small body of literature examining the practice (Al-Mutair et al., 2013a,b; El-Masri and Fox-Wasylyshyn, 2007; Garrouste-Orgeas et al., 2010; Hammond, 1995; Olding et al., 2015).

Critical care nurses have an opportunity to establish meaningful relationships with patients and their families and are well positioned to promote active family involvement. In one study, as nurses' comfort level with family care increased, familyfocused nursing interventions increased as well (El-Masri and Fox-Wasylyshyn, 2007). This finding indicates an opportunity to enhance PFE through nurse engagement and training. Yet, some evidence suggests that critical care nurses have varying opinions about the family's role in the ICU, particularly when involving family in direct patient care (El-Masri and Fox-Wasylyshyn, 2007; Garrouste-Orgeas et al., 2010; Hetland et al., 2017; Institute for Patient- and Family-Centered Care, 2016; McConnell and Moroney, 2015). A significant correlation between the barriers related to the delivery of family-centred care and nurse attitudes was reported in a prior study (Ganz and Yoffe, 2012) and ambiguity among nurses about enabling family involvement with patient care has been documented in recent reviews (Liput et al., 2016; Olding et al., 2015). Potential threats to patient and family safety is a theme across the limited body of literature addressing family involvement in care (Hammond, 1995; Liput et al., 2016; McConnell and Moroney, 2015). Thus, without nurse support of the PFE practice model, it is difficult to further explore and test the benefits of this approach to

Although there are many documented family benefits to family involvement in exploratory studies, such as: 1) a greater sense of family-centred care (Mitchell et al., 2009); 2) feeling connected to the goal of improving the health of the critically ill family member (Hammond, 1995); 3) a reduction of anxiety (Al-Mutair et al.,

2013a) and 4) higher satisfaction for family members (Al-Mutair et al., 2013a), there is a paucity of research examining the impact of family involvement on patient and family outcomes (Al-Mutair et al., 2013b; Brown et al., 2015; Hammond, 1995; Liput et al., 2016; McConnell and Moroney, 2015; Olding et al., 2015). In the 2017 Guidelines for Family-Centred Care in the ICU (Davidson et al., 2017), the recommendation to teach family members about how to assist in care is only directed at the neonatal population, as the majority of interventional studies have been conducted in this setting. Although some studies have examined outcomes of family involvement in care (Liput et al., 2016; Mitchell et al., 2009, 2016), the majority of the literature is descriptive and focused on attitudes of nurses regarding the practice of family involvement (Al-Mutair et al., 2013b; Garrouste-Orgeas et al., 2010; Hammond, 1995). There is a gap in the literature addressing how critical care nurses currently practice PFE and the ways they perform this component of patient and family care in the ICU environment.

A comprehensive analysis of critical care nurses' approaches to family involvement in patient care will help critical care nurse leaders understand how to build collaborative partnerships between patients, families and critical care nurses (Hetland et al., 2017). Understanding how nurses involve families in direct patient care can guide future studies that aim to test PFE interventions. Therefore, the purpose of this study was to explore nurses' approaches to incorporating family caregivers into patient care in the ICU and identify opportunities to enhance active family involvement in the critical care environment.

#### Methods

Design

This study is a qualitative content analysis of text obtained from a mixed-methods survey (Hetland et al., 2017) that explored critical care nurses' approaches to family involvement in the care of a critically ill patient. The mixed-methods survey consisted of a 15-item quantitative measure titled, "Questionnaire on Factors that Influence Family Engagement (QFIFE)" and five open-ended qualitative questions. This paper reports only the qualitative data from the five open-ended questions.

#### Sample

A convenience sampling methodology was used to recruit critical care nurses who were subscribers to one of the American Association of Critical-Care Nurses (AACN) social media sites or electronic newsletters. At the time of participant recruitment, AACN's total membership was 108,422. Participants were critical care nurses who were responsible for the direct delivery of nursing care to patients and their families for at least 20 hours per week.

#### Materials and measures

An electronic survey was used to capture both quantitative and qualitative data. Specific to this qualitative content analysis, the electronic survey consisted of five open-ended questions to identify the approaches used to facilitate family involvement in the care of critically ill patients. Participants were asked to provide responses for the following questions:

- 1) How do you determine to what extent families should be involved in ICU care?
- 2) How do you determine which family caregivers should be involved in care?

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