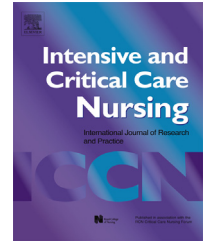




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ORIGINAL ARTICLE

Family members' experiences of being cared for by nurses and physicians in Norwegian intensive care units: A phenomenological hermeneutical study



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Summary

Objectives: When patients are admitted to intensive care units, families are affected. This study aimed to illuminate the meaning of being taken care of by nurses and physicians for relatives in Norwegian intensive care units.

Research methodology/design: Thirteen relatives of critically ill patients treated in intensive care units in southern Norway were interviewed in autumn 2013. Interview data were analysed using a phenomenological hermeneutical method inspired by the philosopher Paul Ricoeur.

Results: Two main themes emerged: *being in a receiving role* and *being in a participating role*. The receiving role implies experiences of informational and supportive care from nurses and physicians. The participating role implies relatives' experiences of feeling included and being able to participate in caring activities and decision-making processes.

Conclusion: The meaning of being a relative in ICU is experienced as being in a receiving role, and at the same time as being in a participating role. Quality in relations is described as crucial when relatives share their experiences of care by nurses and physicians in the ICU. Those who experienced informational and supportive care, and who had the ability to participate, expressed feelings of gratitude and confidence in the healthcare system. In contrast, those who did not experience such care, especially in terms of informational care expressed feelings of frustration, confusion and loss of confidence. However, patient treatment and care outweighed relatives' own feelings.

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Implications for clinical practice

- Many families are well cared for in Norwegian ICUs. The significance of caring practices should be reflected on and discussed based on evaluation and research.
- Family care is skilled nursing invention that need to be integrated in the total care for the critically ill patient in ICU. The ICU staff should take relatives' experiences into account when planning and organising for the future. This means that the family as a whole should be cared for, not just the patient and will require increased staff resources.
- Relatives still experience a lack of information and support from nurses and physicians. Among other educational challenges is the need for some healthcare professionals to improve their skills concerning family crisis, inclusion of relatives and communication.
- Better family care also implies physical arrangements so that families can be with the patient without interrupting the healthcare professionals in their daily routines.

Introduction

The role of family members in intensive care units (ICUs) has been highlighted in both research and practice in recent years (Bailey et al., 2010; Eggenberger and Nelms, 2007). In Norway, there are no guidelines for family care, similar to American 'family-centred care' (Davidson et al., 2007). However, family members' vital involvement with critically ill individuals has resulted in virtually unlimited visiting hours in Norwegian ICUs (Lind et al., 2012). These families are exposed to highly technological environments and life-threatening symptoms or potential death of loved ones. Relatives also often represent the patient in decision-making processes (Azoulay and Sprung, 2004; Moselli et al., 2006; Myhren et al., 2011). The 'taken for granted' quality of family members' lives, as described in the phenomenological perspective, is at stake when experiencing critical illness (Engström and Söderberg, 2007; Toombs, 1993).

Different emotional reactions, such as confusion, frustration, anxiety and guilt, can result from the shock and stress experienced by family members (Hughes et al., 2005). There has been an increasing focus on ICU patients' family members' vulnerability to 'post intensive care syndrome-family' (Baumhover and May, 2013). In addition to psychological symptoms, there are physical symptoms and social changes after ICU experiences (Samuelson and Corrigan, 2009).

Caring for relatives during the ICU stay is important for their coping with unexpected events and with challenges after the patient's return home (Cypress, 2011; Davidson et al., 2012). According to Auerbach et al. (2005), quality relationships with healthcare staff are highly valued by relatives. Good communication between healthcare staff and the family is important for preventing long-term psychological burdens on family members (Myhren et al., 2011; Schmidt and Azoulay, 2012).

It is important to investigate family satisfaction in order to improve care for families in ICUs (Wall et al., 2007) and there has been some recent research on this topic (Heyland et al., 2002, 2009; Khalaila, 2013; Schwarzkopf et al., 2013; Shaw et al., 2014). Most studies are quantitative and typically performed during the ICU stay. We have insufficient knowledge of helpful solutions to ICU care needs defined specifically by relatives (Johannessen et al., 2011).

In this study, this knowledge is gained through describing and interpreting the family members' lived experiences as they remember them after having returned home for a

period of time. There has not been much previous research on relatives' experiences in Norwegian ICUs, although they have included family members for several years. Therefore, this study illuminated the meaning of nurses' and physicians' care for close relatives in Norwegian intensive care units.

Methods

A phenomenological hermeneutical method with individual interviews was used. This method, developed for interpreting qualitative research (Lindseth and Norberg, 2004), was inspired by the philosopher Paul Ricoeur. Consistent with Husserl's (1982) description of the phenomenological attitude, we dispense with our 'taken for granted' attitude, and strive to allow the meaning of the phenomenon to appear to the mind in its meaning structure. With this subjective experience as a beginning, we look for essential characteristics of experiences to generalise. Interview narratives could be a natural and suitable method for relatives to express their care experiences, and interpretation by distancing is needed to make the meaning public (Ricoeur, 1976).

Participants and setting

Thirteen close relatives of critically ill patients treated in university, regional or local level ICUs in southern Norway, who had participated in a former survey study, were interviewed (see Table 1). Closest relatives of ICU patients, a total of 261 people, were identified from hospital electronic records systems during the spring of 2013. They received a questionnaire: autumn 2013, including an invitation to participate in a follow-up interview study. The survey study, not yet published, showed variations in satisfaction among relatives that required deeper qualitative examination. Thirty relatives responded positively to this request, the participants were chosen from this group by the researchers. Data saturation guided decisions regarding the exact number of participants included in the interview study (Kvale et al., 2009). Data collection ended when the data were rich and varied enough to illuminate the phenomenon, and no new themes emerged. None of the participants refused to participate during or after the interview period.

The inclusion criteria were that patients must have experienced at least a 24-hour ICU stay with 2–12 months since ICU discharge. This interval was chosen because we wanted

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