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ORIGINAL ARTICLE

A trajectory towards partnership in care — Patient experiences of autonomy in intensive care: A qualitative study

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Summary
Objective: The aim of this study was to describe and elucidate patient experiences of autonomy in an intensive care context from a caring perspective.
Background: Patients in intensive care units (ICUs) are critically ill and in a dependent and vulnerable position. There is thus a risk of staff taking command not only of the patients' vital functions but also of their decision-making.
Methods: A qualitative design was selected. Individual interviews were conducted with 11 adult patients with an intensive care episode of two days or more at six Swedish ICUs. The data were analysed using Inductive Content Analysis.
Findings: Patient autonomy in intensive care was shown to be 'A trajectory towards partnership in care depending on state of health and mutual understanding'. It was experienced through acknowledged dependence, being recognised as a person, invited participation and becoming a co-partner in care.
Conclusion: Patients in need of intensive care wanted to be involved in making decisions about their care as this creates a trusting and healthy care environment. Greater awareness is required about the ICU patient not only being a passive care recipient but also an active agent and where involvement in decision-making and participation in care are crucial.

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Implications for Clinical Practice

- Patients in the ICU could be highly dependent and at the same time independent and it is therefore important to handle each nursing care activity in an adjusted way to ensure the patient feels included.
- Staff continuity is essential to ensure a tacit understanding that creates a good care relationship as the communicative skills of patients in the ICU are often impaired and they rely on a continuous stream of information in order to feel they are involved in their own care.
- Patients in need of intensive care want to be coached and pushed into activities in relation to their state of health as this reinforces their confidence in their own ability.
- Creating an ICU environment where the staff attitude is supportive and inclusive is of great importance to the patients' potential to influence their care and recovery as they want to play an active role relative to their capacity.

Introduction

Patients in intensive care units (ICUs) are critically ill, are often receiving life-sustaining treatment and in most cases their admission is unexpected, unplanned and traumatic. They become highly dependent on staff and technical equipment as their ability to perform self-care is reduced (Lykkegaard and Delmar, 2013), thus putting them at risk of having their autonomy challenged. Increased vulnerability has been identified as the antecedent of patient autonomy in a caring context (Lindberg et al., 2014), i.e. a preceding phenomenon that through a changed interdependence and/or a need of care support challenges the potential for a person to manage autonomy. ICU staff must be sensitive to this vulnerability. They must be alert and develop a 'clinical eye', watching over the whole of the patient's body and not just focusing on parameters and technical equipment (Gjengedal et al., 2013). The forced dependence on equipment has been shown to make the patient feel passive and shut in, preventing them from performing simple actions, such as getting out of bed or going to the toilet (Almerud et al., 2007). This often creates a distance between the patient and the carer as a result of technical monitoring where the focus is on the biological body. There is therefore a risk that ICU staff not only take command of the patient's vital functions but also their decision-making, leaving the patients without control of their own body and mind.

The democratisation process in many western societies has included a change in discourse related to the power balance between staff and patient, with a shift in favour of the patient (Hewitt-Taylor, 2004). This is not always regarded as positive for the patient as decision-making can be stressful and confusing and could create a sense of unease (Pierce and Hicks, 2001). There is a risk that healthcare professionals develop irrelevant conceptions of a patient's ability to be active and self-managing if they regard autonomy to be an overarching goal of healthcare (Delmar et al., 2011). This may leave too much in the hands of the patients and have a possible disadvantageous effect on their dignity.

Due to medication, or for disease- or treatment-related reasons, patients do not always have the metacognitive capacity to make decisions about their own care (Levinsson, 2008). This dependence requires the care staff to be ''standing by'', attentive to the patient at all times and to have the courage, willpower and knowledge to support the patients in their attempts to achieve independence and a sense of control (Karlsson et al., 2012). Consequently, the caring and technological aspects of ICU care should not be seen as separate entities, or viewed in relation to a specific health profession, but as parts of 'the crafting process', balancing the many skills that are intrinsic to patient care in a high-tech environment and working in the patients' best interests (Price, 2013, p. 284).

There is a lack of research in the field of patient autonomy related to ICU care that involves the patient's own experiences. Patients in need of intensive care are critically ill, the mortality rate is high and their recollection of the time spent in the ICU is often affected (Bergbom-Engberg et al., 1988; Capuzzo et al., 2001), all of which impede involvement in research or the ability to reflect on care provision (Lykkegaard and Delmar, 2013). Other concepts, such as empowerment, have been investigated and the results reveal that 'nursing maternalism' could be an obstacle to restoring patient control (Christensen and Hewitt-Taylor, 2007, p. 160) and that 'strengthening and stimulating the patient's inherent joy of life and will to fight' could be a prerequisite for restoring patient control (Wåhlin et al., 2006, p. 375). Nevertheless, it has been shown that it is not self-evident for intensive care RNs to regard the patient as an active subject, since patient self-determination is not a specific goal for nursing care in this high-tech environment (Meijers and Gustafsson, 2008) even though Western healthcare is oriented more and more towards person-centred care (Ekman et al., 2011; McCormack and McCance, 2010). If patient autonomy is to be considered an issue in future intensive care, where the patient is thought of as an active agent, there is a need to address the patient's perspective.

Aim

The aim of this study was to describe and elucidate patient experiences of autonomy in an intensive care context from a caring perspective.

Ethical considerations

This study was conducted in line with the ethical principles for research outlined in the Declaration of Helsinki (World Medical Association, 2013), and was approved by the Regional Ethical Review Board in Lund (No. 2012:343), Sweden. The patients were given oral and written information about the study and their right to discontinue