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Original article

Patient participation in the intensive care unit

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ABSTRACT

Objective: Patient participation in healthcare is important for optimizing treatment outcomes and for ensuring satisfaction with care. The purpose of the study wasto explore critical care nurses' perceptions of patient participation for critically ill patients.
Design and settings: Qualitative data were collected in four separate focus group interviews with 17 nurses from two hospitals. The interviews were analyzed using qualitative content analysis.
Findings: Initially, the nurses stated that patient participation in the intensive care unit (ICU) was dependent on the patient's health condition and consciousness. However, during the interviews three descriptive categories emerged from their experience, that is: passive patient participation, one-way communication and nurse/patient interaction.
Conclusion: In the ICU, the possibilities for patient participation in nursing care are not only dependent on the patient's health condition but also on the nurse's ability to include patients in various care actions despite physical and/or mental limitations. When the patient is not able to participate, nurses strive to achieve participation through relatives' knowledge and/or other external sources of information.
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Implications for clinical practice

- The possibility for patient participation in intensive care nursing care is dependent on the patient's health condition.
- When patients have limited ability to express their needs, relatives' knowledge and/or external sources of information can be used to achieve the patient's participation.
- Communication strategies can be used to promote patient participation.

Introduction

In many European countries, patients' right to participate in healthcare have been established in laws and formal regulations (Organization, 2013). In practice though, patients have often perceived difficulties in taking an active position in their care and have sometimes been met by a paternalistic attitude by healthcare professionals (Vincent, 1998). Until relatively recently, it was not unusual that the healthcare system did not allow active patient participation or that caregivers opposed of patients being involved in their process of care (Suominen, 1992; Charles et al., 1997; Sahlsten et al., 2005a; Chewning and Sleath, 1996). However, since patient participation has been shown to be an important factor in increasing motivation for treatment adherence, inducing higher satisfaction with care and optimizing treatment outcomes (Williams et al., 1998; Sainio et al., 2001), practice is slowly changing. Most patients want to be involved in major decisions regarding their care, such as whether to undergo an operation or not, but are less concerned about minor decisions (Mansell et al., 2000). Patients state that they expect to receive competent care, but want to have knowledge about their condition and possible treatments and wish to be respectfully met by the healthcare personnel (Eldh et al., 2008, 2010; Larsson et al., 2007). Information has been con-

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sidered to be the key to patient participation, but often patients lack the most basic information (Organization, 2013; Sainio et al., 2001; Sahlsten et al., 2005b; Tutton, 2005). Patients are highly dependent on the caregiver to provide adequate and sufficient information to be able to give informed consent to care and treatment (Larsson et al., 2007).

Critically ill patients treated in an intensive care unit (ICU) are completely dependent on the ICU personnel. Many patients are comatose, sedated or in other ways affected by life-threating illnesses. Compared to in general health care, active participation in care and treatment may be difficult to achieve. In most countries today, the majority of patients survives the acute phase of critical illness (Vincent et al., 2014) and recovers cognitively enough to be able to participate in their process of care. Despite this, ICU patients rarely participate in decisions regarding their own care (Lautrette et al., 2008; Ferrand et al., 2001). When ICU patients were asked, they expected caregivers to make expert decisions for them, but as soon as they had recovered consciousness and vital parameters were stabilized, they wanted to participate in the process of care as much as they possibly could (Lindberg et al., 2015). Even though many factors influence the level of patient participation, there is an urgent need for ICUS to implement and practice a more person-centered care (McBrien, 2009). Today, little is known about the possibility for patient participation in the ICU (Olding et al., 2016). Therefore, this study explores critical care nurses' perceptions of patient participation.

Method

Objective

The purpose of the study was to explore critical care nurses' perceptions of patient participation for critically ill patients.

Settings and participants

The present study used a qualitative research design that involved four focus group interviews. The study was conducted in two intensive care units, with 8 beds per unit, at two county hospitals in Stockholm, Sweden. Swedish-speaking critical care nurses who worked at the two ICUs were included in the study by using convenience sampling. The head nurse in each ICU introduced the project and a facilitator from each unit scheduled the focus group interviews.

A total of 17 critical care nurses (14 female and three male) agreed to participate in the focus group (FG) interviews; with five nurses in FG1, four nurses in FG2, three nurses in FG3, and five nurses in FG4. Participation was voluntary and therefore the size of the focus groups varied. The nurses' ICU working experience was between four weeks to 18 years.

Ethical considerations

The study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2015/1404-31/5) and agrees with the principles described in the Declaration of Helsinki (Rickham, 1964). Each individual gave informed consent to participate in the study. During the time for data collection, none of the interviewers worked or was in training in the ICUs.

Data collection

Focus group interviews were used to collect data in this study. Focus group interviews are especially useful when researchers aim to explore how and why the respondents think as they do (Kitzinger, 1995). The interviews were conducted by two nurses per interview occasion. The nurses were under specialist training to become critical care nurses. The first two interviews were conducted by the first pair of nurses and took place during one month in 2015. The second two interviews were conducted by the second pair and were performed during one month in 2016 (Vannefors and Pettersson, 2015; Westring and Malmqvist, 2016). To maximize participation, the interviews took place at the nurses' workplaces. The interviews were arranged in quiet and secluded rooms. One interviewer guided the discussion and helped the nurses to reflect upon their experiences. The other person took notes and ensured that all nurses participated in the discussions. They posed questions, listened and made sure that all respondents contributed to the discussion. During the focus group discussion, the interviewers began the interview with the question "In your intensive care unit, what is patient participation?" There were follow-up questions such as: "How do you mean?", "In what way?", and "Can you elaborate on that?" All interviews were digitally audio-recorded and lasted approximately one hour. The interviews were transcribed verbatim.

Table 1
An example of the analysis process.

"I found documentation that said that the patient was a Jehova's witness"	Documentation	Passive patient participation
"the clinical objective values"	Bodily expressions	
"the relatives know what the patient wants"	Relatives	

Data analysis

The transcribed text from the focus group interviews was analyzed by two of the authors using qualitative content analysis based on a description made by Graneheim and Lundman (Graneheim and Lundman, 2004). The transcribed interviews were read through completely, line by line. First, meaning units were identified. The meaning units were shortened, condensed and abstracted through a coding process. The codes were then sorted according to similarities and differences. The sorting process resulted in subcategories. According to Graneheim and Lundman (Graneheim and Lundman, 2004) subcategories refer to a descriptive level of content, thus, the categories describe the content of the text. Next, the subcategories were reflected on and sorted into categories. In order to achieve credibility of the findings, agreement was sought through dialogue among all the members of the research team. During the last stages of the analysis, all the researchers jointly reflected on, discussed and revised meaning units, codes and evolving subcategories until agreement about the descriptions was reached (Table 1).

The final analysis rendered three categories, where each category included three subcategories (Fig. 1).

Findings

In the ICU context, patient participation was initially described as being conditional to patients' health condition and consciousness. During the life-threatening phase of critical illness, patient participation was explained as passive involvement in care. Once the life-threatening phase was over and the patients' vital parameters were stabilized, a more active patient participation could gradually be incorporated in nursing care. However, the nurses found it to be challenging to know when to start allowing patients to participate in care, since *"we have told them not to move or do anything and all of a sudden we ask them to participate"* FG1A. The nurses' experience of patient participation can be described in three descriptive categories: passive patient participation, one-way communication and nurse/patient interaction.

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