

Research Article

Barriers in achieving patient participation in the critical care unit

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ABSTRACT

Objectives: Patient participation in healthcare is important for optimizing treatment outcomes and for ensuring satisfaction with care. Therefore, this study aims to identify barriers to patient participation in the critical care unit, as identified by critical care nurses.

Design and settings: Qualitative data were collected in four focus group interviews with 17 nurses from two separate hospitals. The interviews were analyzed using qualitative content analysis.

Findings: The results show three main categories: nurse's attitude toward caring, the organization of the critical care unit and the patient's health condition.

Conclusion: Barriers for patient participation in the ICU were found and this lead to a power imbalance between patient and nurse. In contrast to other care settings, this imbalance could be a consequence of the critical care organization and its degree of highly specialized care. The clinical application of our results is that these barriers should be considered when implementing patient participation in such a highly technological care situation as a critical care unit.

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Implications for clinical practice

- Introducing patient participation as a concept during basic and continued education in order to enable patient participation in clinical practise.
- Daily reflections on patient participation during practise among the health care team is needed to make patient participation possible.
- Cultural changes in both critical care organisations and nursing personnels attitude needs to be addressed if more patient participation is targeted.

Introduction

Patient participation is today an established concept in public welfare, both nationally and internationally and has been strengthened through laws and regulations (WHO, 2018; SFS, 1982; SOC, 2011) to promote patient safety.

The concept of patient participation can be defined as “patients’ rights and opportunities to influence and engage in the decision making about his/her care through dialogue attuned to the person’s preferences, potential and a combination of his experiential

and the professional expert knowledge” (Castro et al., 2016). As stated by Alligood (2014), patients are experts on their own bodies, symptoms and situations and their participation is recognised as being crucial for improvement of the quality of care (Alligood, 2014). At the same time, when patients are cared for in critical care units they are critically ill and fighting with existential questions and not always have knowledge concerning their critical illness or different treatment methods (Egerod et al., 2015).

The benefits of patient participation have been shown in reports of improved patient safety with less adverse events (Longtin et al., 2010; Pinto et al., 2013; Grol, 2001), increased patient satisfaction and increased patient empowerment to improve adherence to treatment recommendations.

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However, to achieve patient participation in medical wards, results has shown that several obstacles must be overcome from both patients and caregivers' point of view. From the patient's perspective obstacles such as: the paternalistic model of health care, patients' own capabilities due to illness and functional ability and their willingness to participate was found.

The obstacles for patient participation from the caregivers' point of view were reported as the patient's attitude, health status and age (Tobiano et al., 2015a,b).

For critically ill patients, who may be comatose, sedated or in other ways affected by life-threatening illnesses while being cared for in the intensive care unit (ICU), such circumstances can hinder patient participation. However, sedation practises in the critical care units have evolved from deep sedation toward lighter sedation (Ström and Toft, 2014) and this may enable early rehabilitation and optimise weaning from mechanical ventilators (Roberts et al., 2012). In a previous study, nurses stated that patient participation was possible to obtain in critical care, not only on an active level, but also through relatives or by using other means (Schandl et al., 2017). Also, some research results show that patients cared for in critical care units stated that they trusted the caregivers to make expert decisions for them, but as soon as they were capable, they wanted to be involved in their own care (Lindberg et al., 2015). Still, patient participation is not easy to understand according to the literature (Lautrette et al., 2008). As a result, patient participation is frequently used concept in laws and regulations; however, reports of non-patient participation still exist from the patient's perspective. Therefore, our knowledge of what hinders patient participation in critical care units is lacking from the nurses' point of view (Olding et al., 2016). More knowledge is needed to ensure that nursing practise is based on knowledge from both patients and nurse's perspective to reflect a high-quality caring relation. Therefore, this study aims to identify barriers to patient participation in the critical care units identified by critical care nurses.

Method

This qualitative study was based on four focus group interviews (Kitzinger, 1995). The study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2015/1404-31/5). Each individual respondent gave informed consent to participate in the study. During the period of data collection, none of the interviewers worked or was in training in the specific critical care unit.

Settings and participants

By using convenience sampling, 17 Swedish-speaking critical care nurses working in the critical care unit were recruited from two regional hospitals in Stockholm, Sweden. A total of four focus groups was performed to enhance variability in nurses work-experience and age to get a maximum variety of experience-based data (Kitzinger, 1995).

Focus groups 1 and 2 consisted of nine nurses from an eight-bed medical critical care unit and focus group 3 and 4 included eight nurses from an eight-bed general critical care unit. Fourteen nurses were women and three were men. Their critical care working experience varied from between four weeks to 18 years.

Data collection

Data collection was carried out through interviews in four focus groups. Each interview was led by a nurse who was undergoing critical care nurse specialist training. A fellow critical care nurse specialist student took notes, recorded the interviews and

observed the interview situation. Focus groups 1 and 2 were conducted by one pair of nurses and were performed in 2015, while focus groups 3 and 4 were performed by another pair of nurses and took place in 2016 (Vannefors and Pettersson, 2015; Westring and Malmqvist, 2016). One interviewer guided the discussion and helped the nurses to reflect upon their experiences of patient participation. The other person took notes and ensured that all nurses participated in the discussions with posed questions. During the focus group discussion, the interviewers began the interview with one 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 took place close to the ward where the nurses worked. Each interview lasted for approximately one hour, was digitally audio-recorded and was transcribed verbatim.

Data analysis

The transcribed text from the focus group interviews was analysed by two of the authors (ACF & CF) using qualitative content analysis based on a description given by Graneheim and Lundman (2004). The transcribed interviews were read through completely, line by line and meaning units were identified. The meaning units were then individually shortened, condensed and abstracted through a coding process. During the analysis each focus group members statement was marked with the focus group number (Fg1–4) and a personal number (a–d) to ensure that the analysis was including statements from all focus groups and several focus groups members, in the result. After this step, the two authors sorted the codes according to similarities and differences. The sorting process resulted in subcategories. Subcategories refer to a manifest level of content. The subcategories were reflected on and then sorted into categories. The analysis involved a constant moving back and forward between the entire data set. During the last stages of the analysis, all the researchers jointly reflected on, discussed and revised meaning units, evolving subcategories and categories until agreement was reached. The final analysis rendered three categories, where each category included two subcategories.

Findings

The main categories regarding barriers for patient participation during critical care was described as the nurse's attitude toward caring, the critical care unit organisation, and the patient's health condition (See Fig. 1).

Nurse's attitude toward caring

The category includes two subcategories: to be *nurses as experts* and *risks concerning patient safety issues*. The nurses express an attitude of acting as an expert, being the one who knows best about the patient's needs, knowing what needs to be done and should be done is based on knowledge of the professional role as a nurse. Since the nurses describe a position of acting as an expert in caring situations, they show an unwillingness to respond to the wishes of the patient. "How can we let the patient decide? It is we (the nurses) who know what is best for them (the patient)" (Fg2c).

The description of being an expert and deciding if the patient should be allowed to take life-determining decisions because of the perceived insecurity about the patient's ability to determine his or her situation. Patients and close relatives were described as laymen who lack the skills in intensive care and medicine that are required to be able to participate, "Decisions are hard to make when you, as a layman, do not have any medical knowledge" (Fg2c).

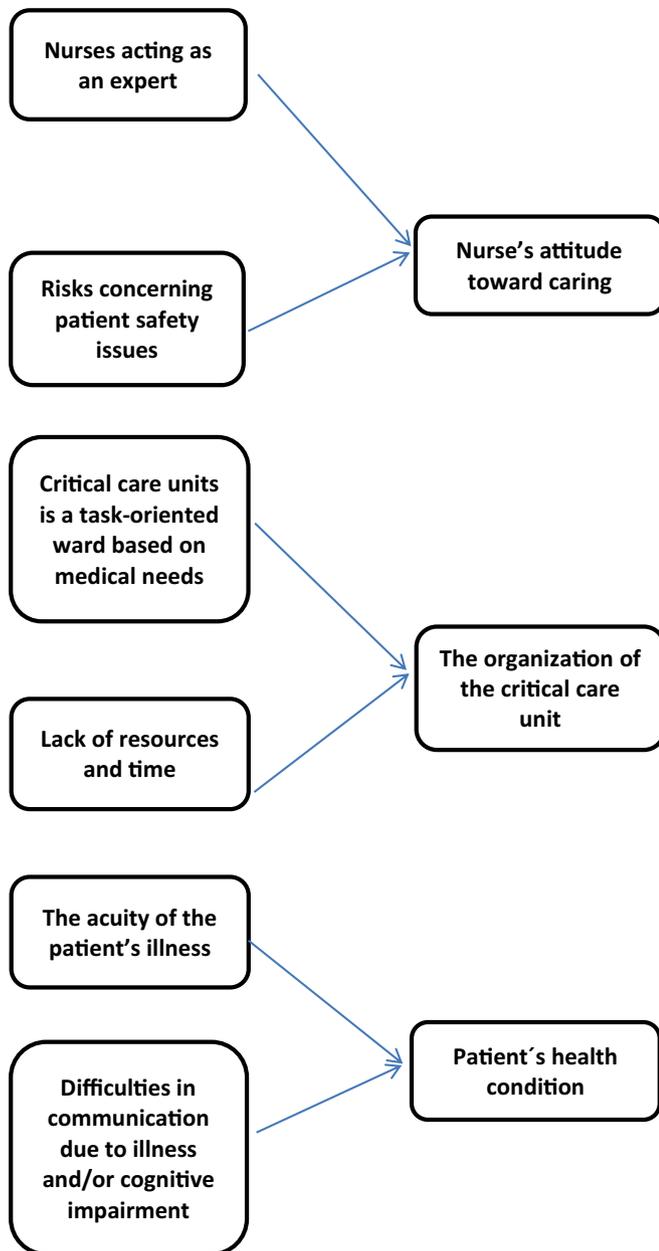


Fig. 1. Overview of categories and subcategories describing the barriers towards patient participation in the critical care unit.

The respondents also describe an unwillingness to allow patient participation when patients' lives were perceived to be at risk or when patients had unreasonable demands concerning care, "If the patient or others are at risk then you cannot let them participate" (Fg1d). This is described in situations when nurses perceive that patients have unreasonable wishes in relation to certain types of rehabilitation, "No, I don't want to sit at the bedside; no I do not want to do that, it is not feasible for the recovery" (Fg2c).

This leads to a conflict regarding what is possible based on the nurse's attitudes and results in a disagreement between patient and nurse, "The nurses are the experts and have the knowledge about critical care rehabilitation, so the patients are not able to make their own decisions" (Fg2d).

In situations when staff and patients do not share the same basic values about what patient participation may mean, the nurses sometimes choose to avoid contact or to try to understand what the patient is expressing, "When the patient's wishes

concerning care are not in agreement with...my moral thoughts and also with what kind of care we perform at this ward" (Fg1a).

The organisation of the critical care unit

The category is formalised of following subcategories; *Critical care units is a task-oriented ward based on medical needs and the lack of resources and time.*

The possibility for patient participation is affected if there are pre-defined priorities in the critical care unit and regarding how resources are allocated.

The analysis shows that the mission of an ICU is to save lives, and therefore medical tasks and measures are prioritised prior to communicating with the intensive care patient. As a result of this, prioritisation time for data collection/and administration of medication related to saving lives comes first for the nurses, "The nursing care is not organised based on the patients' needs; instead, it's planned from a task-oriented medical point of view" (Fg4a).

Lack of time as part of healthcare priorities is described by the nurses. For example,

when they are responsible for more than one patient at the same time is considered a barrier to patient participation, "An awake patient on ventilator support requires more time and when I am responsible for two more patients there is just not time for patient participation because I cannot stand there all the time" (Fg1b).

This means that the nurse can be occupied with a patient for a long time with no time for the other patient, "Today, when the patients were not sedated and I asked the patient questions, it took such a long time to determine an answer, and I had to be incredibly patient just to stand there and hold the whiteboard when the patient wrote long sentences" (Fg2d).

The availability of staff varies, which means that it is considered a challenge to allow the patient to participate in, for example, the choice of time for care such as mobilisation, "I hear what you (the patient) are saying but I don't have time right now: it might be possible in 20 min or tomorrow" (Fg1b).

At the same time, it appears that the nurse is uncertain as to what the patient should be participating in based on available resources in the intensive care unit, "I mean there is actually a limit to the resources. So, when it comes to participation, there is a limit on how much you can let the patients participate" (Fg2d).

Patient's health condition

The patient's health condition in the critical care unit is perceived as a barrier. The subcategories was found to be *the acuity of the patient's illness, difficulties in communication due to illness and/or cognitive impairment.*

Patients treated in the critical care unit is usually acute critically ill and may have an altered consciousness, "it might be right that we (health care staff) during the acute phase take command over the patients" (Fg2b).

This means that the critical health condition may require mechanical assistance, for example with breathing, which affects the ability to communicate. The barrier is perceived both in the physical constraints, such as patients being connected to a ventilator and monitoring equipment, and the fact that patients are cognitive affected by illness and/or drugs, "And if the patients are sedated, they cannot give their consent to care" (Fg1b).

Another barrier as perceived by nurses is the physical limitations as the patients have difficulty in communicating with the body because they have limited physical space. There is also the barrier in the critical care situation as the nurses perceive that the patients insufficiently understand the extent to which physical limitations affect the ability to actively participate in rehabilitation as they wish, "When patients (have unreasonable demand or) just do

not realise their own limitations, such as that they are not able to use a cycle for exercise" (Fg2b).

Patients' cognitive ability is also perceived as a barrier and there is uncertainty about how patients understand and can participate in care situations as the patients' cognition are affected by drugs to varying degrees. "Even when our patients are lightly sedated they are still affected by drugs, so you have to ask yourself; are they able to make decisions?" (Fg3c).

Lack of or difficulties in communication is also seen as a barrier. There are mechanical barriers to communication such as patients being intubated, which can complicate communication. Even when patients use different tools for communication such as pen and paper or whiteboard, there can be difficulties in understanding what the patient is trying to express in speech as well as writing, depending on the patient's cognitive capacity "Even if the patient can use a paper and pen, it does not show any coherence and is not understandable" (Fg4c).

Discussion

In this study, we identified barriers to patient participation in the critical care units as reported by critical care nurses.

The nurses perceive themselves as experts with the power of knowing what is best for patients in ICU care situations. This result corresponds to the result shown by Hickey and Kipping (1998) in mental care and Henderson (2003) in acute medical and surgical care. This implies that the nurses do not expect to ask the patient for any opinion concerning if, how and when care should be performed, and this suggests that nurses and patients do not meet under the same terms due to the discrepancy in medical knowledge. Patient participation requires a partnership between the health care personnel and the patient. Controlling manners from nurses as in present result are identified as hindering patient participation (Tobiano et al., 2015a,b). As a pre-condition for patient participation nurses need to surrender some power (Frank et al., 2008; Sahlsten et al., 2008). Power imbalance can reduce the effectiveness of rehabilitation by devaluing what patients can contribute (Hartford-Kvaal et al., 2018). When patients experience some power in this cooperative atmosphere it's possible for patients to use their own power to actively influence their situation (Hartford-Kvaal et al., 2018; Rundqvist, 2004). Present result about nursing expert attitude leads to power imbalance and this become a barrier for patients to actively take response for their own health condition. The question on how to overcome the barriers for patient participation due to organisation and management in several care contexts is yet to be answered.

The imbalance in power between nurses and patients should be investigated to really elaborate the true meaning of participation in different health care settings.

In critical care, medical advances with high technology and high competencies among all health care personnel have resulted in a short length of stay (mean 2.7 days) for patients treated in Swedish critical care units. This short length of stay could imply that care focuses on advanced medical care and not the patient as a person. Further research should focus on the nurse's attitudes of patient participation and interventions to promote change.

However, this can result in a feeling of loneliness, as reported by Egerod et al. (2015) especially for voiceless patients (Tembo et al., 2015). The patients also express a loss of independence and ability to communicate, which in our results is shown as the nurses being a proxy for the patients' needs and taking all responsibility for performed care. Research has also shown that patients have trust in the health care staff to make the appropriate medical decisions during the critical care. Research shows that there is a fine line between feeling loneliness and safe at the same time when life is at stake.

According to our results, organisational factors are perceived as barriers, and Burns et al. (2018) has identified similar barriers to patient participation in the ICU. Because the participants described care as prioritised to handle life and death situations as well as medical treatments and care, the patients' ability to participate is limited due to cognitive impairment. This result is in line with the findings on the patient's experience of intensive care as reported by Egerod et al. (2015) who suggest that patients descend into a liminal state, when they face the choice between life or death. Further research should focus on patient's experience of their participation in the ICU to understand patient participation during severe illness.

There is also the fact that care is provided with medical aspects in focus and that communication is time-consuming in a setting which lack resources. The nurses describe no thoughts/obstacles to not being in charge or not having an impact on the planning of resources or the prioritising of the work load in the ICU.

Previous studies have shown that, independent of context, patient participation is not easily achieved (Tobiano et al., 2015a) However, compared to general wards, the ICU is unique in that most patients cannot express their own will or perceptions verbally (Kvangarsnes et al., 2013).

Our results show that the patient's health situation when suffering critical illness results in a decreased possibility for communication as well as altered cognitive capacity.

A well-known consequence of both acute critical illness and lack of communication is that adverse events increase in both clinical management and complications with diagnosis or other adverse events (Bartlett et al., 2008; Burns et al., 2018).

Another barrier identified in the ICU by Burns et al. (2018) is the lack of willingness to develop personally meaningful relations between the nurses and patients and family, which is in line with our results when resources were limited, the nurses avoided eye contact and pretended not to understand the patients' wishes. Critical care nurses have an important role in enabling patient participation, since they are close to the patient and can understand and judge their current capabilities (Tobiano et al., 2015b).

Our results should be used to deepen the understanding of barriers to patient participation during critical illness. However, as reported in a previous study (Schandl et al., 2017), nurses have identified several ways to make participation possible, despite these reported barriers.

Limitations

The findings of the study should be interpreted in the light of some limitations. The interviews were conducted by two different sets of interviewers with limited experience of interviewing, which may have influenced the results. However, all interviews were analysed by two researchers. In a qualitative study, the researchers should be aware of and bridle their pre-understanding (one researcher had vast ICU experience and the other had more experience of patient participation in general). Therefore, discussions between the researchers were conducted throughout the process to prevent pre-understanding influencing the process (Dahlberg et al., 2008). There was a constant dialogue during the analysis and the findings were discussed with the third author until consensus was reached. Individual interviews could have been another option for collecting data. Still, we wanted to use the group dynamics to help the nurses explore experience about the phenomenon during discussions. However, questions regarding barriers for patient participation at ICU had not been asked. Though, nurses related reflections concerning situations where they described barriers for patient participation.

Trustworthiness in qualitative research studies entails a rich and thorough description of the phenomenon and a carefully

detailed description of the research setting and process. We have attempted to describe the research process carefully to make it possible for others to follow the process to achieve trustworthiness according to Graneheim et al. (2017). Another aspect of trustworthiness is whether the results can be transferred to other settings. The findings of this study are transferable between critical care nurses where care and treatments follow a similar pattern. However, the relation between patients and healthcare staff may vary more across different countries and cultures. Therefore, similar studies in different cultures are warranted.

Conclusion

Barriers for patient participation in the ICU were found to be the nurse's attitude toward caring, the critical care unit organisation, and the patient's health condition. Similar to other care settings, a power imbalance between patient and nurse, in favour of the latter could be found. In contrast to other care settings, this imbalance could be a consequence of the critical care organisation and its degree of highly specialised care. The clinical application of our results is that these barriers should be considered when implementing patient participation in such a highly technological care situation as a critical care unit. A broader discussion of the aim of working with critical care including caring from patient perspective as well as to save lives.

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Conflict of interest

No conflict of interest.

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