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Published in:
Nursing in Critical Care

DOI:
10.1111/nicc.12815

Publication date:
2022

Document version:
Final published version

Document license:
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Citation for pulished version (APA):
Egelund Hansen, A., Lehmkuhl, L., & Højager Nielsen, A. (2022). Critical care nurses' perception of patient involvement in care: A qualitative focus group. *Nursing in Critical Care*. https://doi.org/10.1111/nicc.12815

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Download date: 04. Jun. 2023

Check for updates

Received: 29 December 2021 | Revised: 15 May 2022 | Accepted: 8 June 2022

DOI: 10.1111/nicc.12815

RESEARCH ARTICLE

Critical care nurses' perception of patient involvement in care: A qualitative focus group

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Abstract

Background: Patient involvement in care in the intensive care unit (ICU) is complex. Knowledge about the nature and extent of patient involvement in the Intensive care unit is scarce.

Aim: The aim of the study was to explore the critical care nursing staff's perception of patient involvement in their care in the ICU.

Design: A phenomenological, hermeneutic research study was carried out using qualitative data. Data were collected in two focus group interviews analysed using Ricoeur's theory of interpretation. The study was conducted in a level 2 medical-surgical 8-bed ICU in a regional hospital in Southern Denmark.

Results: Critical care nurses found it important to maintain involvement in intensive care. Depending on the patient's ability to partake in care, approaches for patient involvement ranged from (1) continually adjusting care activities according to the patient's bodily responses, (2) formation of a relationship with the patient to enable personalized care and (3) making room for self-determined care progressing with the patient's recovery.

Conclusion: Critical care nurses' perception of patient involvement depended on the patient's level of consciousness. When unconscious, patient involvement was possible but took a physical approach. However, the power inequality in the nurse–patient relationship must be expressed if patient involvement in the ICU is to take place.

Relevance to Clinical Practice: Results suggest that nurses' perception of patient involvement in the ICU depends on the patient's level of consciousness. Patient involvement may be possible even when the patient is unconscious but it takes a more physical approach. It is essential that the power inequality in the nurse–patient relationship must be expressed if patient involvement in the ICU is to take place.

KEYWORDS
critical care, focus group interview, patient involvement, patient participation, qualitative

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1 | INTRODUCTION

In the intensive care unit (ICU), the ideal of involving patients in their own care may be difficult to achieve as patients may have difficulties expressing their needs because of mechanical ventilation, sedation, and the effects of critical illness. In such cases, informed consent to treatment may be sought from next of kin if the patient is not able to provide it. Besides honouring patients' legal rights to self-determination, smaller-scale patient involvement may provide patients with a sense of control in a very difficult situation. Consequently, to understand the possibilities and potentially expand the concept of patient involvement in care in the ICU (hereafter patient involvement), this study explored how Critical care nurses (hereafter nurses) perceive involving critically ill patients in their own care.

2 | BACKGROUND

Improving self-management of chronic diseases and promoting equity and self-determination through the involvement of patients has become a globally accepted standard.[1] Both nationally and internationally, the involvement of patients has been strengthened through laws and regulations, to promote patient safety and patient rights.[1–3] In clinical practice and in research, different terms have been used to describe this ideal: Patient participation, patient centring, patient involvement, patient empowerment[4] and shared decision-making.[5–7] For daily practice, Snyder and Engström define patient involvement as a deliberate activation of patients in their own care.[8] Patient involvement depends on the patient's need for health care, personal characteristics, and the professional relationship with the health care professional,[9] but the level of involvement should be defined by what the patient feels most comfortable with.[10] The patient's demands for involvement may be reduced if the patient has no former experience with the illness, or if the illness is acute and serious,[9] which is often the case for patients in the ICU. In addition, patient involvement in the ICU may be challenged by ventilator treatment and the use of sedation, which may render patients unable to express their needs. In the last decade, however, a new paradigm of non-sedation has emerged in the critical care setting.[11–14] Previous studies of non-sedated, critically ill patients reflect that the patients felt vulnerable and helpless when unable to speak and that they sought to alleviate their suffering through communication, companionship with the nurse and by participating in activities.[15–19] However, lack of resources and team collaboration may negatively affect the provision of care centred on the patient.[20,21] In addition, knowledge about the nature and extent of patient involvement in the ICU is scarce and needs further exploration to understand how patient involvement may be achieved in intensive care.[20,22]

3 | AIM

The purpose of the study was to explore the nursing staff's perception of patient involvement in their care in the ICU.

What is known about this topic

- Patient involvement in critical care is complex.
- Knowledge about the nature and extent of patient involvement in the Intensive care unit is scarce.

What this paper adds

- The nurses' perception of patient involvement depended on the patient's level of consciousness.
- Unconscious patients can be involved but take a physical approach.
- Power inequality in the nurse–patient relationship must be expressed, if patient involvement in the ICU is to take place.

3.1 | Research design

The study was a hermeneutic-phenomenological study using Ricoeur's theory of interpretation[23] to analyse data generated in focus group interviews. Bradbury-Jones et al.[24] argue that focus group interviews may open up to new perspectives and allow the researched phenomenon to come alive within the group. As such, focus groups are compatible with interpretive phenomenology and may advance health care research.[24] Moreover, Ricoeur's theory of interpretation allowed us to go beyond what was actually said in the group interviews to what participants talked about and thereby identify the most probable interpretation among competing interpretations in a systematic and transparent analysis.[23]

3.2 | Setting

The study was conducted in a level 2 medical-surgical 8-bed ICU in a regional hospital in Southern Denmark. Approximately 90% of the nurses had ICU certification, and the nurse–patient ratio was 1:1. The department had no former initiatives regarding patient involvement.

3.3 | Participants

From the unit 15 nursing staff members, who appeared to be valuable sources of information, were sampled for the study using intensity sampling.[25] They all received a written invitation to participate in the study. All invited participants who provided direct patient care had a minimum of two years of ICU experience and represented different levels of experience.[26] Five declined participation. One participant was prevented from participating because of sick leave, and therefore a total of nine participants; eight registered nurses and one assistant

TABLE 1 Participant's characteristics

Focus group interview (Nr#)	Participant (P#)	Sex (Male/Female)	Nursing experience (years)	ICU experience (years)	ICU certification[a]
1	P1	F	13	2	No
1	P2	M	10	10	Yes
1	P3	F	4½	4	No
1	P4	F	4½	2½	No
1	P5	F	21	20	Yes
2	P6	F	18	13	Yes
2	P7	F	18	13	Yes
2	P8	F	18	13	Yes
2	P9	F	28	18	No

[a]Equivalent to 2 years of education on top of primary nursing school/bachelor's degree.

nurse were interviewed (Table 1). Assistant nurses have a three-year education focused on basic care. Thus, the Assistant nurses have a big task in involving the patients and we, therefore, found the assistant nurses particularly relevant, and with the right perspective to participate in the interviews although they do not work autonomously.

3.4 | Data collection

Focus group interviews were conducted to produce group-level data on the interpretation, interaction, and norms of patient involvement in the ICU. Focus group interviews give the participants the opportunity to comment on each other's experiences and understandings and therefore produce more complex data, a well-known methodological strength.[26] Therefore, two focus group interviews with four and five participants respectively were conducted at the hospital in June 2019.

Prior to the interviews, nurses from the unit took photographs of patient–nurse interactions they perceived as patient involvement. All patients were conscious and gave written informed consent to use the photographs for interviews with the health care professionals. The dual purpose of the photographs was to serve as an icebreaker[26] and stimulate the participants to narrate and explain, rather than give direct answers and thereby facilitate inductive data collection.[27] Photo interviews were used as a frame for the interviews,[26,27] which gave participants the opportunity to tell their own stories[24] combined with an interview guide.[28]

The interview guide was pilot-tested on a different group of ICU nurses; the data from this interview were not included. A few adjustments to the interview guide were made. At the beginning of the interviews, participants were introduced to the focus group interview and asked to select one of 12 displayed photographs they felt best-reflected patient involvement and from that talk about their understanding of patient involvement. Participants were prompted to elaborate on their responses.[28] The semi-structured interviews focused on three main themes: (a) experience with patient involvement, (b) experience with their professional role and possibilities for patient involvement in the ICU, and (c) A commitment to change the culture within the ICU to increase patient-involvement.

The moderator led the discussion, while the more experienced assistant moderator paid attention to a potential power imbalance and supplemented it with elaborating questions during the interviews. The interviews lasted approximately one hour and were digitally audio-recorded and transcribed verbatim by the first author. The citations were translated by XX who has a university qualification in the English language.

3.5 | Research team and reflexivity

Investigator triangulation was used during the data acquisition and analysis.[29] Authors AEH, LL, and AHN were all certified critical care nurses and females. LL and AHN were experienced qualitative researchers. AEH and LL were, more or less acquainted with the participants, AEH was employed in the clinic and LL was employed at a research department associated with the clinic. AEH moderated the interviews and LL was an assistant moderator AEH conducted the initial analysis, and this was discussed with LL and AHN and refined through continuous discussions and contributions. The trustworthiness of the study was strengthened by using direct quotations from the participants.

3.6 | Data analysis

Data were analysed based on Ricoeur's theory of interpretation. The analysis was divided into three steps: a naïve reading, a structural analysis, and a critical interpretation.[23] In the naïve reading, the interviews were read several times to achieve an overall understanding of the text. According to Ricoeur, this initial reading should be based on an open approach allowing the text to make an impression. The structural analysis is an explanatory procedure and represents mediation between two stages of understanding: the naïve reading and the critical interpretation.[23] In the structural analysis, we identified units of meaning across the data set and explained them by asking, "What is said" and "what does the text talk about", thereby following the movement from sense to reference.[23] Ricoeur describes this as a process of dynamic interpretive reading on units of significance and their internal relationships.[23] Finally, the most

probable interpretation among competing interpretations was identified and formulated as three final themes.[23]

3.7 | Ethical considerations

The study was conducted in accordance with the Declaration of Helsinki,[30] but not registered with an ethics committee, as Danish law does not require this. All patients gave written informed consent to photographs being used in the study. Likewise, all participants did participate in the focus groups. All data were anonymised to protect participant confidentiality and the participants were encouraged not to share experiences from the focus group interviews outside the group.

4 | FINDINGS

Nurses found it important to maintain the involvement of critically ill patients in intensive care and although challenging, they saw possibilities for patient involvement even in very frail patients and patients with impaired consciousness. Depending on the patient's ability to partake in care, approaches for patient involvement ranged from (1) continually adjusting care activities according to the patient's bodily responses, (2) formation of a relationship with the patient to enable personalized care and (3) making room for self-determined care progressing with the patient's recovery

4.1 | Continually adjusting care activities according to patients' bodily responses

Involvement of the patient was adapted to the patient's ability to communicate. When the patients were unable to communicate because of critical illness or lack of consciousness, the nurses had a physical approach to patient involvement. Using nonverbal communication to stimulate the patient's bodily memory during a bed bath or when brushing the patient's teeth were ways to involve the unconscious patient like touching the chin to notify the patient that something near the mouth would occur shortly and letting the toothbrush touch the mouth before brushing or placing the patient's hand into the washbasin with warm water before bathing the patient. This kind of involvement would not necessarily involve talking to the patient as it would if the patient was conscious. During their interaction with the patient, the nurses would closely monitor the patient's bodily responses, for example, the variation in blood pressure, pulse rate and facial expression of comfort or discomfort to interpret the patient's preferences and talk to the patient if she found that it made the patient calm.

> I figure, that is also a way to support the physical memory, and if the patient is not fully aware of, 'what is coming?' then the body and its physical memory will make the patient aware: 'this is what is going to happen – I am part of this – this is my life'. And in my mind that is involvement. (Particpant1, interview 1)

The nurses would change the level of involvement and combine the physical approach with information and more verbal communication when the patients over time regained consciousness and were able to communicate with the nurse, despite their voicelessness caused by the endotracheal tube. The physical approach would then focus on supporting the patient's natural pattern of movement, for example, helping the patient to brush his teeth himself by supporting his arm.

> [In] some patients, a little goes a long way whereas others can take a lot. Take tooth brushing, some patients just needs the things put in front of them but others… You have to take their hand and literally give them a helping hand. Al in al it really depends on the patient and his abilities. (Participant 6, interview 2)

4.2 | Personalized care enabled by creating a relationship with the patient

Engaging with the patient and knowing his or her preferences and interests contributed to the development of a nurse–patient relationship with the patient. The nurses described the importance of creating a relationship with the patient, which was a key to enable patient involvement. The patients should feel that they were treated with respect by the nurse. One nurse said:

> When I involve the patient, I do it because I want him to feel that he is being both heard and seen (noticed). To me that is important, because so many other things are going on all around the patient – so I think it must be nice to feel noticed. (Participant 1, interview 1)

This statement described an approach to intensive care nursing, and furthermore the foundation upon which relationships was built. The nurses described how knowing the patient's personal preferences and their family made it possible to develop a relationship in which the patient felt safe. Engaging in conversation with the patient's relatives was an important source of information and helped the nurse to get to know the patient. This enabled the nurse to create a relationship with the patient and the relatives. Other sources of information included the patients' medical records and last not least conversations with the patient. The relationship with the patient also depended on continuity in the sense of a small, dedicated team of nurses, which enabled recognition and thereby promoted a feeling of trust and confidentiality in the patients. Furthermore, the nurses stated that the relationship depended on the nurse being willing to invest in the relationship with the patient as well. This included noticing and remembering what the patient found meaningful, for example, being a grandparent, having a certain hobby or a job. Nurses found establishing a relationship with the patient pivotal to patient involvement.

> It is also important - as a minimum -to establish a relationship with the patient, and then continuity, to know the patient and his preferences: 'Oh yes! You prefer the taste of strawberry' etc. – 'Should we try something else today?' That is a good thing. (Participant 3, interview 1)

This shows how attention to the patient's preferences and personal history enabled nurses to personalize care and involve the patient in a meaningful way.

4.3 | Self-determined care aimed at progressing the patient's recovery

The nurses emphasized the importance of giving the patient a chance to choose between different options in the care given, for example, to shower or to be bed bathed. The nurses described different ways to make room for patient involvement in the nursing care, depending on an assessment of the patients' personality and attitude to their own rehabilitation. All nurses had experienced that sometimes the choices given to the patient were neither pleasant nor attractive. Moreover, critically ill patients may feel overwhelmed and decline participation in nursing interventions because of lack of energy: interventions with the purpose to facilitate the recovery of the patients. This could be mobilization, a bed bath or as little as brushing the patient's teeth.

> So we aim to clarify the patient's daily routines and try to emulate this as much as possible. We might have to start out with limited options to simplify the task. (Participant 7, Interview 2)

Nurses described how the patient sometimes would be offered a "reward" if he took part in his own treatment and nursing care. This reward could be a nap before mobilization or a foot massage. Another way of handling the patient's lack of initiative and resources was setting a goal for the intervention, for example, time spent in a chair or walking a fixed distance. A nurse referred to it as a caring nudge in the right direction.

> Sometimes you're conflicted between empathy and knowledge, because we know professionally what is right and, in the patient's, best interest and what will help further the patient's progress, as a nurse we have an insight the patient doesn't have. (Participant 8, interview 2)

This excerpt illustrates the dilemma between acting according to a professional assessment of the patients' needs and at the same time acknowledging the patient's right to self-determination. The solution was therefore to engage the patient to participate by offering a limited range of predefined choices or offering the patient a reward when an unpleasant activity was well done.

5 | DISCUSSION

This study showed that nurses saw possibilities for patient involvement in critically ill patients as a process of continuously adjusting care activities according to the patient's bodily responses when patients suffered from impaired consciousness and progressing towards more self-determined care on the way to recovery. Nurses sought to establish a relationship with the patient and used their knowledge of the patient to enable personalized care in line with the patient's preferences.

Taxonomy for patient involvement, developed by Thompson[9] distinguishes between patient-determined, co-determined and professional-determined participation. The highest levels of participation relegate decision-making power to the patient, whereas the lowest levels include merely giving information to the patient or excluding the patient from the decision-making processes altogether.[9] Our findings, however, indicate that there may be room for involving patients with impaired consciousness, who are unable to receive information and thereby partake in a more traditional patient involving activities such as shared decision-making. We found that continuously adjusting care activities to the patient's bodily responses did not necessarily involve verbal communication but relied primarily on touch and observation of the patient's physical responses to care. This approach bears similarity to the Basic Stimulation approach,[31] which was developed in Germany by Fröhlich[31] and adapted for ICU nursing in the 1990's by Nydahl and Bartoszek.[31,32] The concept of Basic Stimulation uses touch and sensory stimulation to encourage those with compromised attention to communicate through bodily signs and thereby facilitate interaction with the surrounding environment.[31] Although not mentioned by the participants in present study, it is conceivable that the bodily approach to patient involvement found in present study is inspired or influenced by Basic Stimulation as many Danish ICUs have implemented at least some of the Basic Stimulation principles in practice.[16]

A qualitative study by Schandl[33] exploring nurses' perception of patient participation in the ICU classified participation as passive or indirect when patients were unconscious or had impaired attention, although nurses did interpret patients' bodily reactions to determine the patients' preferences.[33] This suggests that employing Basic Stimulation in critical care nursing may have advanced an understanding of active patient participation as possible despite patients' inability to stay alert and communicate verbally.

In the present study, getting to know the patient's personal preferences and their family was necessary for providing personalized care according to nurses. Schandl,[33] who found that knowledge about the patient was necessary to interpret the patient's preferences, supports this. In addition to knowing the patient's preferences, we found that building a relationship with the patient was a way to promote patient involvement. Other studies have suggested that building a relationship with the patient may support caring for the patient and mediate negative consequences of the highly technological environment,[34,35] although challenging to nurses[36] and dependant on available resources.[37]

Our findings show that nurses were very aware of the power they possessed regarding patient involvement, as they described how they guided the patient towards self-determination. In terms of Thompson's taxonomy for patient involvement, this could be described as professional-determined participation.[9] Christensen and Hewitt-Taylor[4] discussed the empowerment of patients in the ICU and argued that there is an inherent inequality of power in the relationship between patient and nurse and that patient involvement of the sedated, mechanically ventilated patient in decision-making may be difficult if not unwise. They emphasize, however, that patient dignity and respect for humanity should be used to create an empowering environment as the patient progresses towards recovery[4] or towards a patient-determined participation.[9] However, in the present study, all nurses had experienced that sometimes the choices given to the patient were neither pleasant nor attractive, but they described the choice between different options as a caring nudge. Similarly, a study by Stayt[35] exploring patients' experiences of technology in the ICU found that tracheal suctioning was called "a necessary evil" by patients but was followed by a feeling of comfort in being able to breathe freely.

Schandl[33] and Karlsen[38] also found that nurses and patients entered into negotiations about care. Karlsen et al.[38] explored the degree of patient involvement in the numerous small-scale decisions made at the bedside every day in relation to care and therapy and found that in many cases decisions were merely proposed by staff and patient consent only assumed. However, Karlsen[38] also found real self-determined decisions by patients and decisions made in agreement by patient and staff. In the present study, the nurses emphasized the importance of giving the patient an option for exercising self-determination in care, for example, choosing between a shower or a bed bath. It could, however, be questioned whether such small-scale decisions are actual patient involvement but according to Christensen and Hewitt-Taylor,[4] the key to patient involvement in the ICU is to articulate the power inequality in the nurse–patient relationship. Barriers to patient involvement in the ICU is, according to Falk[21] and Olding,[22] that nurses might be unwilling to respond to patients' wishes because they believe themselves the experts of caring needs. Other barriers to patient involvement in the ICU include lack of resources and time.[21] Thus, the power inequality between patient and nurses and the difficulties of involving the patient with impaired consciousness and fragile constitution illustrates that patient involvement in the ICU is no easy task but is highly dependent on articulating power inequality between nurses and patients, maintaining favourable attitudes of nurses towards patient participation, as well as organizational resources.

6 | LIMITATIONS

Limitations of this study include sampling participants from one Danish ICU only. The sample was relatively small and from an ICU devoted to caring for conscious intubated patients, which might affect the transferability of the findings of the study. Nonetheless, we found that patient involvement was possible even in patients with impaired consciousness and our findings are therefore not limited to the unsedated ICU population.

The study was embedded in a cultural understanding of patient involvement and respect for patients' individual rights as desirable while at the same time, nurses had strong views of themselves as experts on intensive care nursing and the patients' needs. It seems reasonable that the findings of the study are transferable in similar settings, but more studies in different cultural settings may be warranted.

7 | IMPLICATIONS FOR CLINICAL PRACTICE

Patient involvement in critical care is complex; however, this study has shown that involvement can be implemented even in patients with decreased consciousness. This requires nurses to be guided by the patient's non-verbal communication. Moreover, ICU nurses should be aware of the power inequality in the relationship with the patient and strive to make room for real self-determination as the patient's condition improves.

8 | CONCLUSION

Nurses' perception of patient involvement depends on the patient's level of consciousness. When unconscious, patient involvement was possible, but took a physical approach—creating a nurse–patient relationship to enable patient involvement, depended on the patient's ability, mentally and/or physically. Furthermore, the relation between the patient's relatives and the nurse was important in the enablement of the patient. The nurses also recognized that making room for guided self-determination was important in patient involvement. However, the power inequality in the nurse–patient relationship must be expressed if patient involvement in the ICU is to take place.

ACKNOWLEDGEMENTS

We wish to thank the patients for their participation in the photographs while they were hospitalized. We also wish to thank the nurses for their participation in the focus group interviews. Finally, we wish to thank Carina Egelund for her language supervision.

FUNDING INFORMATION

Department of Anaesthesiology and Intensive Care Medicine, OUH, Svendborg Hospital supported the study.

DATA AVAILABILITY STATEMENT

The authors state that data are available on request. Patient consent statements have been given to authors and saved at an encrypted site. All sources used in this article are available for public use.

ETHICS STATEMENT

The study was conducted in accordance with the Declaration of Helsinki (Association, 2018), but not registered with an ethics committee, as Danish law does not require this. All patients gave written

informed consent to photographs being used in the study. All participants gave written informed consent to participate in the focus groups. All data were anonymised to protect participant confidentiality and the participants were encouraged not to share experiences from the focus group interviews outside the group.

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How to cite this article: Egelund Hansen A, Lehmkuhl L, Højager Nielsen A. Critical care nurses' perception of patient involvement in care: A qualitative focus group. *Nurs Crit Care*. 2022;1-7. doi:10.1111/nicc.12815