Research Article

The core of patient-participation in the Intensive Care Unit: The patient's views

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Abstract

Objectives: Patient participation is an established concept in public welfare. However, reports of the phenomenon of patient participation during intensive care from the patient’s point of view are scarce. Therefore, the aim of this study was to explore the meaning of patient participation in the intensive care unit from the patient’s perspective.

Research design: A qualitative design was used for the purpose of the study with a purposive convenient sample of nine adult patients with memories from their intensive care stay.

Method: Data was collected through individual interviews and analysed using a phenomenological hermeneutical method.

Findings: The results of our study show a variety of meanings and degrees of participation that continuously move on a sliding scale from acting as a captain to feelings of being on an isolated island. Patient participation varied due to individual cognitive abilities and individual preferences, and the caregiver’s attention alternated between the body and the person through the continuum of care.

Conclusion: Patient participation during ICU care is more than participation in decision-making processes or direct patient care decisions. An understanding of the concept participation from the individual patient is necessary to support person centred care and the patient’s relatives play an important role in during the entire care process.

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Implications for clinical practice

- Patient participation is more than participation in decision-making processes or direct patient care decisions, it is based on individual preferences.
- Relatives play an important role to support patient participation and should be invited to act as fellow passengers to ensure both high quality care and improved patient safety.
- Intensive care units should organise a structure for dialogue with patients and/or relatives on a daily basis to support person-centred care.
- It is necessary to develop a common understanding of the concept of patient participation that requires a relationship among health care providers working in the intensive care unit.

Introduction

Patient participation is today an established concept in public welfare, both nationally and internationally, and has been strengthened through laws and regulations in Sweden [1].

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Ministry of social affairs, 2017; The National board of welfare, 2011; WHO, 2020. According to Entwistle and Watt (2006), participation is a concept that is both dynamic and complex and includes not only visible activities but also thoughts and feelings and the significance of a relationship between health care professionals and the patient (Angel and Frederiksen, 2015). Furthermore, patient participation as a concept been researched in several studies in non-intensive care contexts (Henderson, 2003; Larsson et al., 2007; Nilsson et al., 2019; Oxelmark et al., 2018; Ringdal et al., 2017; Tobiano et al., 2015b). Today, patient participation is mostly described as a cornerstone of person-centred care with its key concepts: initiating the narrative, shared decision-making and documentation (Elman et al., 2011) and is a requirement in health care to improve patient safety with less adverse events (Grol, 2001; Longtin et al., 2010; Pinto et al., 2013) and increase patient satisfaction and empowerment, leading to improved adherence to treatment recommendations (Castro et al., 2016; Grol, 2001).

The intensive care environment in combination with the patient’s severe illness which itself can lead to existential questions, is challenging when it comes to patient participation (Egerod et al., 2013; Egerod et al., 2015; Jakopovic et al., 2015). For seriously 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 (Falk et al., 2019; Kvangarsnes et al., 2013). Research has shown that patients cared for in the ICU trust health care providers to make expert decisions for them, but as soon as they are capable, they want to be involved in their own care (Egeröd et al., 2015; Lindberg et al., 2015). However, research from general wards on patient participation has shown that several obstacles must be overcome such as: the paternalistic model of health care and patients’ lack of capability and/or unwillingness to participate due to illness (Tobiano et al., 2015a; Tobiano et al., 2015b).

Previous research has shown that patient participation is possible to obtain in the ICU, in both active and passive ways, but also through relatives (Mackie et al., 2019; Schandl et al., 2017; Stayt et al., 2016). However, reports of the phenomenon of patient participation during intensive care from the patient’s point of view are scarce. Therefore, this study is based on a phenomenological hermeneutical method (Lindseth and Norberg, 2004) with a focus on describing and interpreting the lived experience of the phenomenon of patient participation in the ICU context. More knowledge is needed to guarantee that the patient’s perspective on patient participation is heard, to ensure high quality care, and to increase patient safety as well as patient satisfaction.

Methods

A qualitative study design with a phenomenological hermeneutical method (Lindseth and Norberg, 2004), inspired by the theory of interpretation presented by Ricoeur (1976), was used for this study. According to this, lived experience as a speech event, gets transcribed into text, which is then interpreted to reveal the meaning of the phenomenon studied, here patient participation. The phenomenological hermeneutic method is grounded in the tradition of both phenomenology and hermeneutic which represent a text interpretation of lived experience using preunderstanding in the process of analysis (Lindseth and Norberg, 2004). Interpreting the text means entering the hermeneutical circle described by Ricoeur (1976) using the three steps from Lindseth and Norberg's method, naïve understanding, structural analysis, and comprehensive understanding (see detailed description in the method section) (Lindseth and Norberg, 2004). This study was conducted and the results reported adhering to the consolidated criteria for reporting qualitative research guidelines (COREQ) (Tong et al., 2007).

Research question

This study aims to explore the meaning of patient participation in the ICU from the patient’s perspective.

Setting

By using purposive convenience sampling, nine native-speaking patients were recruited from one general ICU at a university hospital. The patients were recruited at the post intensive care follow-up unit, which is a part of the ICU clinic. The follow-up unit invited patients cared for in the ICU to assess for physical and psychological risks for long-term consequences (Schandl et al., 2014). A patient with a more than 50% risk for physical and/or psychological consequences were offered a follow-up visit.

Participants

The patients were invited to the follow-up appointment approximately three months after their ICU care. During the period of inclusion, November 2017 until June 2018, 33 patients visited the follow-up clinic. Eligible respondents were identified by one of the researchers (AS) who acted as a facilitator. The inclusion criterion was that patients had memories from the ICU period. Out of the 33 eligible patients, 11 initially agreed to participate. Out of these 11 patients, two later declined to participate, therefore nine patients, four women and five men, aged between 26 and 65 years old (mean 47 years) which represented the distribution of the ICU population at our university hospital, were interviewed. As for transparently we described the respondents’ gender and age as they represent the ICU population in Sweden (Morse, 2015).

Data collection

Data collection was carried out through individual interviews, with openness to the phenomenon of patient participation. The patients were interviewed approximately four to six months after their stay in the ICU. The interviews were performed face to face and started with the question: Can you tell me about how you experienced participation when you were cared for in the ICU. All interviews were conducted by one researcher, at a separate time from the inclusion occasion, at a time and place that was suitable for the respondents. Each interview lasted approximately one hour, was digitally audio-recorded, and was transcribed verbatim to ensure that the patient’s own words were captured (Tong et al., 2007). The open-ended research question was discussed among the researchers throughout the inclusion period and during the analysis to ensure openness to the data, to guarantee dependability and confirmability, and to ensure all researchers had the same understanding of the phenomenon (Morse, 2015).

Data analysis

The analysis, based on a phenomenological hermeneutical method according to Lindseth and Norberg (2004), included three phases: naïve understanding, structural analysis, and comprehensive understanding. The transcribed text from all the interviews was analysed by all authors together. The text was repeatedly read in its entirety to grasp its overall meaning and a naïve understanding was formulated in Swedish. In the structural analysis the text was divided into meaning units relevant to the purpose of the study. Those meaning units were discussed repeatedly by all authors, reflected over, and condensed into the essential meaning.
of each meaning unit. All condensed meanings units that were similar were further condensed and abstracted to form subthemes that were assembled into themes i.e. the meaning of patient participation in the ICU (for example see Table 1). In this step a dialectic movement between the naïve understanding and the structural analysis took place to validate the meaning of the phenomenon. Finally, a comprehensive understanding was formulated using the authors’ pre-understanding to contextualise the themes and the essential meanings and to see a new mode of being in the world (Lindseth and Norberg, 2004; Singsuriya, 2015). The entire analysis was conducted in Swedish to ensure a shared understanding of the phenomenon among the authors. The entire text from the different stages of the analysis were then translated from Swedish into English by one of the authors (A-C.F). The translation and wording were then reflected over by all authors to ensure that the interpretation and meaning of patient participation was retained during the translation process. The entire text was then reviewed by a native English-speaking language reviewer. The suggested wording was then read and discussed among all authors until consensus were reached (Regmi et al., 2010).

To assess credibility (Morse, 2015), all researchers pre-understanding, with different experience of the ICU environment and theoretical and practical knowledge were used during the analysis to explore the phenomenon patient participation (Lindseth and Norberg, 2004). All authors continuously discussed the analysis process to strengthen the credibility and trustworthiness of the interpretations and descriptions of patient participation in the ICU (Morse, 2015).

Ethical approval

The study was approved by the Regional Ethical Review Board in Stockholm, Sweden (Dnr: 2015/1404-31/5) and conforms to the principles described in the Declaration of Helsinki. Each individual gave informed consent to participate in the study. None of the researchers had cared for the included respondents during their ICU period in order to ensure that the respondents could speak openly during the interviews.

Findings

Naive understanding

Meanings of participation varied among patients during their stay at the ICU. In the light of their memories the understanding of participation depended on the critical condition and was expressed in a variety of thoughts, feelings and stories. The patients described how participation played an important role during the critical care period in different ways. Provided that the patient was invited by a caregiver, participation was a relational dialogue about needs and wishes. Patients felt included in a context with the caregiver through, among other things, the caregiver listening, talking and using humour to create a relationship and affinity. Participation was also described by the patients as handing over their body to the health care providers, the submission was perceived as safe and trusting, in an acceptance of routines and nursing care. In the absence of a relationship with a health care provider, the body is handed over as an object to routine activities. Vulnerability was also described, including a feeling of lack of control. Patients reflected upon the fact that health care providers objectified the body, which resulted in an experience of feeling not respected as a human being, ignored and not being listened to, all of which, in turn, created a feeling of isolation. Participation can also be experienced through family and relatives. When family are included in an information exchange with the health care provider and patient, they can interpret and convey information in both directions. Stories also showed that patients who are cared for in the ICU environment adjust to the actual situation by not causing a disturbance or being difficult, trying not to be a burden in the health care providers working situation.

Structural analysis

The structural analysis identified three themes: acting as the captain, being a fellow passenger and being on an isolated island.

Acting as the captain

Patients experienced participation when they acted as a captain during the course of the ICU stay. The active captain was responsible for personal boundaries during care processes and participated in different care decisions.

They experienced themselves as equal among the multidisciplinary team by taking their own initiatives in different care situations based on their own needs. Even when relatives acted in the patient’s interest, the patients experienced participation. Relatives had an active influence on care when they acted on behalf of the patient.

“When I felt that different activities were not synchronized and I did not have the strength to exercise, I said: No, you have to come back at another time” (Participant 2)

Patients acted as a captain and took active initiative, for example, by holding the endotracheal tube themselves to control the situation.

“.........I was in control by holding the endotracheal tube the whole time......I was a good patient because they (the health care professionals) were never worried that I would extubate myself.........” (Participant 8)

Table 1

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Condensation</th>
<th>Subtheme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I still had to decide if and for how long it would be .... how I would blow in the mask” (Participant 9)</td>
<td>I decided, when and how interventions were done</td>
<td>Setting own boundaries</td>
<td>Acting as the captain</td>
</tr>
<tr>
<td>“Everyone told me what they were going to do and I just: but do what you want” (Participant 8)</td>
<td>They informed and I let them do it</td>
<td>Invited in a one-way communication</td>
<td>Being a fellow passenger</td>
</tr>
<tr>
<td>“Someone rattled around with the central line catheter, pulled it and injected a lot of things without you knowing” (Participant 2)</td>
<td>Someone rattled around with the central line catheter .... without information</td>
<td>Not being included</td>
<td>Being on an isolated island</td>
</tr>
</tbody>
</table>
Patients could also initiate care actions as they called for attention by physically creating sound.

In conversations with the health care providers, patients experienced that they were listened to and were taken seriously in a dialogue and thus were able to actively participate in different situations.

**Being a fellow passenger**

Patients experienced themselves as fellow passengers, which meant that they felt invited to different activities by the health care providers. Invitations for participation were often a one-way communication and were experienced by the patients as being seen as a person with unique needs.

“...I was treated as an individual. ...and it was like I was part of the team” (Participant 6)

When health care providers informed about different care activities and/or treatments the patients felt like they were invited to participate in different activities. When patients understood what was going to happen and why, they felt relaxed and went along with the course of events in a passive way.

“...I trusted them (the health care professionals) and I just accepted what was happening. . . . . . ” (Participant 5)

Even if patients received information concerning things that they could not influence, either treatment and/or the time of different interventions that affected their condition, this was also perceived as being treated like a fellow passenger and they went along with the course of events.

When health care providers verbally used "we" in communication with patients, the patients felt invited and experienced themselves to be included in the team.

As a fellow passenger the patients expressed a need to be accommodating by not disturbing or bothering with questions or other demands in a hectic world.

“...you as a patient do not have the competence or knowledge so you should not strive against. ...what is happening” (Participant 1)

Not only the individual treatment from the health care providers towards the patient but also how the relatives were treated made the patients experience a sense of participation. When the patient was too passive to intervene, they observed that their relatives were verbally invited as fellow passengers, which created a feeling of togetherness.

“...But I felt that my family felt relaxed when they were there and they did not feel in the way, they were always welcome, and then it felt like they were happy with my care, and then I could be too” (Participant 8)

**Being on an isolated island**

Patients experienced a feeling of being on an isolated island in relation to how they were treated in the caring context. This meant that as a patient, they were not mentally included in the team. In these situations, the patients experienced that the health care providers regarded them as objects, when the treatment focused on the body and not the person.

Patients experienced that they were ignored, which created a feeling of not being seen or respected as a human being.

“I did not experience it as questions. I experienced it more as statements like this “now let’s do this. Not “is it ok if we . . .”? or I had not said no anyway but it would have been nice with a question like “would you like to brush your teeth?” (Participant 2)

On one hand, there was the experience that people came and went without introducing themselves or their reason for being there; on the other hand, there was sometimes a feeling of being excluded from the common ‘we’ when the health care providers adhered to their routines and ran their own race.

Experiences of the feeling of being just another body that needed to be addressed in various ways through interventions, or that the patient was seen as an interesting case rather than as a person, were also described. Measures were often taken over the head of patients without giving them prior information about what would happen, or when it would happen.

“...everything just happened (to my body) automatically” (Participant 7)

The experience of people talking over one’s head and not being included created a wish to be able to object to such treatment, which in some cases was not possible. The experience of not being listened to, or not being asked about things, was expressed, among other things, through stories about when the health care providers simply moved something away, such as a glass of water, without asking the patient first.

**Comprehensive understanding**

The patient’s experience of participation manifests itself as a phenomenon that varies, related to varying degrees of severe illness as well as the ability and opportunity for participation. The sliding scale starts from an experience of being an active integrated whole where the subject and object (the body) are integrated into a caring ‘we’. When the patient’s ability and opportunity fail, the patient moves to a more passive participation of the object (body), which is given space to act when the subject is being addressed but is included in care without space for active participation.

Relatives can function as an extended self for the patient’s opportunity for participation, through their relatives’ interaction with the health care providers. The quest for being a good patient includes a wish for acceptance, as a person, i.e., to be included in a relationship with health care providers.

Finally, an experience of isolation was present when the patient felt that the body was taken care of as an object without him/her as a subject being addressed. In this situation the critical illness was prioritised which resulted in a lack of feeling of togetherness. Participation can thus have different meanings depending on the severity of illness during the same course of care. This can be accepted by the patients but can also mean frustration and a feeling of being abandoned in a difficult situation when participation is lacking.

**Discussion**

The results of our study show a variety of meanings of the phenomenon of patient participation, where the meaning and degree of participation continuously move on a sliding scale of illness during the ICU care period.

As for participation in different contexts, most of the existing literature from the ICU describes participation from the perspective of the health care personnel or the family (Burns et al., 2018). One reason for the lack of literature focusing on patients' views on participation in the ICU could be related to the dominant view of involvement being a decision-making process with information sharing that requires a relationship (Angel and Frederiksen 2015) which depends on the ability to communicate, which could be compromised by severe illness, sedation or delirium (Burns et al., 2018; Olding et al., 2016). Patient cared for in
the Emergency departments (ED) have the ability to communicate and participation is described as when patients struggling for involvement, acting aggressive and demanding against health care personnel (Frank et al. 2009) which is contrary to our result where the patients described how they wanted to be a good patient in the ICU context.

Our patients cared for in the ICU described participation as acting as a captain in different care situations throughout the care process.

Acting as a captain could be seen in the light of person-centred care (Ekman et al., 2011) and were described in our study in different situations such as managing medical procedures or safety measures in the ICU. Despite this, no patient in our study described participation as part of a decision-making process for treatment decisions which is contrary to the result by Frank et al. (2009) and Ringdal et al. (2017) who found that patients cared for in the ED and in medical wards wanted to be part in decision-making discussions concerning their condition because they were the experts of their condition. Our result could be related to the fact that the patients felt safe and relied on the caregiver’s medical knowledge in situations where the health care providers focused on the body with severe illness that was unknown to the patient.

To be able to understand the patient’s perception of illness and to support the person’s self-care capacity even in the acute care phase, the patient and/or family must share their story with all health care providers so that a joint understanding is achieved. Routines, a time and space for the collection of the patient’s narratives, and to document the patient preferences are necessary to establish person-centred care in a health care context (Swedish institute for standards, 2020). Whether or not this is actually done in acute care is not known.

Our results show that the body was in focus when the patients experienced being an isolated island, and during medical care some objectification of the body might not always have been avoided in critical situations (Dahlberg, 2019). However, the patients felt an understanding of the situation during the period of severe illness. Therefore, it might be time to put aside the dichotomous understanding of the human as divided into subjective and objective parts, and instead see the whole person, also described by Dahlberg (2019). This could mean identifying individual preferences for participation in different situations in the ICU context, where sometimes this means relying on someone else to survive as a fellow passenger. In our results, patients describe themselves as acting like a captain during different phases of the illness while during the acute phase they surrender the control which is supported by the results of Lindberg et al. (2015) who showed that patients during ICU care could act as a passive recipient of care but also an active agent during care. However, in many non-acute care situations, patients highlighted that they felt like an object when health care providers talked over their heads or moved things out of reach. These situations give an impression of health care providers not fully accepting their ethical responsibility (Lögstrup, 1992).

Research has shown that health care providers working in ICUs mostly inform patients about biomedical problems and focus more on technical assignments, rather as in a dialogue to understand the patients’ needs and to create a relationship with the patients (Slatore et al., 2012; Olding et al., 2016; Happ, 2001). One explanation for this could be the rapid development of highly technological equipment, which has caused the focus to develop and maintaining technical skills rather than non-technical skills in the ICU environment, as suggested by Kvangarsnes et al. (2013). Another explanation could be, as suggested by Slatore et al. (2012), that communication needs a more interdisciplinary focus to really put the focus on person-centred care. However, our respondents described how they found creative solutions to communicate even when the ICU care did not support oral communication and patient participation, for example by writing on a piece of paper or knocking on the side of the bed. Maybe it is time to abandon the idea that the seriously ill patient has communication problems and instead find ways to improve health care providers’ ability to hear both patients’ and relatives’ voices in acute care? Both the result from the ED (Frank et al., 2009) and our study shows how family and friends can act as an extended self and create a form of participation when the patients cannot speak for themselves, acting on behalf of the patients and interacting with health care providers. Our body is part of the dynamic process through which we establish contact with the world around us, and this contact in turn is a presence of both subject and object (Russon, 1994). The phenomenon of embodiment is a part of Merleau-Ponty’s Phenomenology of perception (Merleau-Ponty, 2013) in which he introduced the concept of extended self, illustrated as when the cane for a blind man becomes an embodied tool. In our study, other people, in this case family and friends, can be experienced as part of one’s self (Heersmink, 2020). When the body is not able to move itself or when the ability to provide self-care is reduced, others may help to sustain the self (Wallace, 2019). Mackie et al. (2019) showed that patients in acute care settings, when patients could not speak for themselves, felt more at ease, safer and could better handle the situation when family was included in care activities, which is well in line with our results. Further studies about how the patient, family and health care providers can interact to improve patient participation in acute care are recommended.

Our respondents even described how they tried to be a good patient, interpreted as an expression of a wish for acceptance as a person, to be included in the common ‘we’ in an effort to participate in a team with health care providers, Strandberg et al. (2002), explored the meaning of dependence during care and showed that it is a two-dimensional struggle for existence. In line with our results, the struggle for, and an adaption to the situation, and not to be a burden or a disturbance to the health care providers, the patients try to show themselves worthy of care. Another struggle is to show oneself worthy as a human, with the ability to manage oneself, an ability which is highly compromised during critical care. How this feeling of independence can be supported and understood in acute care is yet to be investigated.

**Strengths and Limitations**

To assess and establish methodological rigour in our study, we used the criteria developed by Lincoln and Guba (1985) and described by Morse (2015). Our analysis was based on a theoretical model of phenomenological hermeneutical methodology according to Lindseth and Norberg (2004) to ensure we used a structured way to explore the lived experience of patients cared for in the ICU. A strength is the narratives from nine patients who had detailed memories from the ICU care, with different gender and different personal experiences who were interviewed about their lived experience. A description of the stages of the research process, setting and the participants was made to give the reader the opportunity to access transparency and transferability. Another strength is that all authors had different pre-understandings of the ICU context, experience, and theoretical knowledge. These pre-understandings were used during the critical reflection to define a new meaning of the phenomenon of patient participation in the ICU.

Despite these strengths, our study has some methodological considerations that could have an impact on our result. Our study was conducted in one hospital, so our findings may not be applicable to other settings and other populations of patients requiring intensive care. The fact that the interviews took place several
months after the ICU period could have had an impact on our results since the memories could have changed due the influence of storytelling by others, such as families. Despite of this, during our analysis our impression was that no further information emerged.

Conclusion

Patient participation during ICU care is more than participation in decision-making processes or direct patient care decisions. An understanding of the concept participation that requires a relationship between health care professionals and the individual patient is necessary. The patient’s relatives play an important role to support person centered care during the entire care process.

Ethical approval

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 (WMA, 1964). Each individual gave informed consent to participate in the study.

Author contribution

All authors have contributed to the conceptualization of the study, acquisition of data, the analysis and interpretation of the data, drafting and revising the manuscript. All authors have approved of the final manuscript.

Conflict of interest

No conflicts of interest have been reported by the authors.

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Appendix A. Supplementary data

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