



Children's Participation in the PICU from the Nurses' Perspective, an Observational Study

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Abstract

Children who are critically ill are vulnerable, and the nurse has a responsibility to meet the child's needs in a pediatric intensive care unit (PICU).

Aim: The aim was to explore the vulnerable child's participation and how it can be understood through the nurses' perspective in the nursing care intervention.

Design: The study design was an exploratory inductive qualitative approach. Data collection was done through observations and interviews. The data from the observations were analyzed through interpretive phenomenology.

Results: The affective elements were viewed as essential to uncover how children participate in the PICU. Three themes emerged through the analysis: Mediated participation, Bodily participation and Participation by proxy. They all highlight a different aspect of the vulnerable child's way of participating in the nursing care given, through nurses' awareness and situated salience. The concept of participation should be redefined and broadened; as participation can present itself through the child's body in diverse ways.

Keywords: Phenomenography; PICU; Participation; Nursing Care

Introduction

Children have the right to participate, influence and decide on their own. They should expect nursing care given in a children's hospital to be following the United Nations Convention on the Rights of the Child [1], if admitted to the Pediatric Intensive Care Unit (PICU) in Sweden, the Patient Safety Act [2], the Patient Act [3] also guards the patients' right to participate, decide on and influence the care they receive. In the PICU, the child's integrity, participation and possibility to influence nursing care poses a particular challenge as the focus within the PICU context is to save lives and stabilize the child physically [4]. It becomes a challenge for nurses to balance between tending to a child's physical recovery and to meet the need of caring and social support in a highly technological PICU environment [5]. As the environment in the PICU is stressful, procedure heavy and with the constant shortage of staff [6].

The PICU work culture and the natural environment in itself is a challenge to patient participation, as the context risks traumatizing children as they become exposed to noisy monitors, ventilators and intravenous pumps [5,7]. The children are cared for by unfamiliar adults, in strong lighting, surrounded by likewise critically ill children and more exposed to painful and traumatic medical procedures compared to children at other wards [8]. Some parents feel that their roles change from child and parent, into patient and visitor [9]. According to sick children's own experience, the presence of the parents that are the most crucial factor for their well-being when they stay at the PICU [10]. Parents of children with severe disabilities, however, experienced that their child's cognitive level and understanding were underestimated [11]. That is worrying since this group of children need a long-term child-centered care perspective [1].

Child-centered care

Child-centered care is used, equivalent to person-centered care, to highlight the child as the center of the care [1]. It comprises the child and his or her family's specific needs when admitted to a hospital [12]. It can mean that the caregivers are given a place to rest and sleep close to the child [6]. Alternatively, it can mean a smooth operating nursing approach, deriving from the child's needs as a person and human being. The latter is a prerequisite to meet both the child's and the family's needs in the PICU context [13,14]. It also proposes to ask for the child's personal view; not the parents view on what they believe the child prefers [15]. To a young child or sedated child, the body might be the contact surface of the surrounding world. The connection to the nurse caring for him or her and the way they can communicate, through body and touch. Leder [16] puts forward the lived body as the phenomenon of being in the world. When the body functions as it is supposed to, it is in the background of the mind, but when not operating as assumed, it shifts to the foreground. Merleau Ponty [17] argues that body and soul are not separate. Instead, they are one entity shaping our consciousness through the body. The body cannot be divided into parts and understood separately. Being healthy or being ill can be understood in distinct ways of being in the world [17]. Leder [16] argues that even if we perceive the world through our eyes, ears, hands and communicate with the world through our expressions in the face, speech and feelings, the body itself is not the object of experience. When nurses touch the children's bodies, they perceive different things and research [18,19] have shown how nurses can distinguish pain from anger through bodily postures, movements and tensions in the PICU and thus act accordingly to alleviate pain. In that sense, we can view PICU nurses as communicating with the children through their hands when touching children's bodies. This assumption also opens for a new way of understanding participation and involvement in one's nursing care. Giving the nurses a voice and tools to truly enhance child-centered care by feeling the children's participation and consent through their body.

Participation

Research [20,21] show that children want to participate in their care, as it makes them less anxious, less fearful and feel appreciated. They became angry and upset if they were not asked [21-23]. Children also verbally expressed the need to engage in communications and become more involved in the decision [24,25]. Although being able to participate or giving consent in the way the law requires is sometimes not applicable in a PICU where the children are in their most vulnerable condition, not able to speak or participate

in a persuasive way. Benner and Wrubel [29] offer a way to understand how nurses' can be involved with their patients as they use the expression "to presence oneself" meaning to be with the patient in an involved way, "in tune" with the patient. Being aware of the patient as a unique person, eye contact, body language, movements, the tone of voice. The meaning of participation can be interpreted as involvement and cooperation as the absence of strategies to promote participation might mean that participation is not established [26]. However, participation and involvement are apparent when a relation is established between child and carer, and a possibility for interaction exists [13,26,27]. This relation opens up to an understanding of participation in the PICU from the child's perspective, as proposed above, by communicating with the children through nurses' hands when touching children's bodies. However, there is limited research targeting the children's possibility to participate in the nursing care in the PICU.

Aim of the Study

The aim was to explore the vulnerable child's participation and how it can be understood through the nurses' perspective in the nursing care intervention.

Method

This study derives from a constructivist paradigm and departs from Benner and Wrubel [29] and Benner, *et al.* [34] descriptions of analyzing everyday manner, as we aim to explore how children's participation is understood from the nurses' perspective in the PICU. The ontology of constructivism sees the reality we perceive, being actively constructed in the individual, social and historical contexts while the truth is being socially negotiated [28]. The nature between the knower and what can be known, can be viewed as transactional and subjective and thus constructed by the knower and the social context holding the construction [28]. Also, the chosen perspective has the potential to make previously invisible things, visible by exploring the lived experiences of the participants and trying to identify and describe the commonalities of the phenomena.

Design

The study design was an exploratory inductive qualitative approach. As there have previously been no studies on children's participation in intensive care, observing phenomena can reveal how individuals act concerning this in their formal context [29]. Observing the phenomenon participation gives the observer the possibility to actively listen or observe the phenomena where it occurs, in its natural setting [30].

Ethical considerations

This study follows the ethical principles and guidelines for medical research involving human subjects under the Declaration of Helsinki [31]. The qualitative researcher is obliged to be open to ethical dilemmas, conflicts and ambiguities that arise during the whole research process [32].

Confidentiality procedures were followed, and all informants participated on an informed and voluntary basis. Information about the study was given at several workplace meetings at each PICU. The informants that chose to participate were informed that it was possible to end their participation whenever they wanted if they wanted. Ethical approval was obtained from the ethical committee at the Karolinska Institute, 2011/244/31-1, as well as from the head of each PICU clinic. The observing researcher informed the nurse at each observation that the observation would cease without questions if a mutually decided sign were used. The nurse could use this whenever she thought that the observing researcher had to leave the room for any reason. The sign was never used.

Setting

Pediatric intensive care units admit children between the ages 0 - 18 years and are all designed for admittance of severely ill children in need of specialized care involving all types of surgery, medicine, various advanced ventilator treatments as well as Cor-poreal Membrane Oxygenation (ECMO) treatment. The two PICU:s included in this study comprise those specialties.

Informants

To capture the clinical nurses' situated perception of the child's participation in the nursing care situation. Intensive care nurses from various backgrounds in education, professional experience, age and gender were sought after. This to allow variation in perception of how children participate on an everyday basis in nursing care situations in the PICU to emerge. In this study, the selection of informants sought was guided by the question: whom can maximize the variation of the phenomena sought after [30]. A total of 12 registered nurses, from two PICU wards in Sweden, all with a specialist nurse degree and with clinical experience in the PICU varying from 1 to 23 years of experience were asked to participate in the study, and all agreed to participate. The informants were ten women and two men, ranging in age from 29 - 62 years. The informants had been working on the current PICU between 1 and 9 years.

Data collection

The first and the last author performed all data collection. Twelve observations with following interviews were conducted between spring 2016 and summer 2016. At two pediatric intensive care units in Sweden. The observations were 120 - 240 minutes long, the interviews lasted 20 - 60 minutes. The focus of the observations was to record actions and conversations in the context that occurred to be able to respond to the purpose. Notes were made on an observation protocol; time, event, communication, context and observer's reflections were noted in chronological order. The data collection took place in the informants' everyday clinical environment.

Observations

This study focuses on the observations. Interviews were conducted with the aim to clarify misconceptions or to deepen the understanding of what had previously been observed. Observing informants in their clinical practice gave the researchers access to everyday situated nursing care interventions, letting the observers capture the nurses' central concerns for the vulnerable child. How they let the child participate in the caring situation, how they organized their body and the movements in the situated nursing care given. Benner, *et al.* [34] put forward that nurse's concerns in the situated caring situation can be uncovered in observations as they show their authentic way of caring in the specific context. Through the observation, one can see things taken for granted and the concerns that prevail in the situation, that cannot be reached in the interview when post- reflection on actions might interfere [33]. Context includes the physical environment, resources on hand, the tempo and energy in the surrounding unit as well as the events occurring [34]. The observers took a passive role, sitting in the corner dressed as the staff to blend in with the environment and not draw unnecessary attention to themselves. To observe means that it is possible to highlight authentic nursing care interventions and start to reflect [35] what they mean or why they are performed.

Interviews

The interviews were intended to deepen, confirm or reject the meaning of the observations by Benner, *et al.* [34] emphasizing that by observing nurses in their clinical work clarified the behaviors and actions of which the nurse then can develop a more in-depth description. A thematic interview guide influenced by Benner and Wrubel [29], Benner, *et al.* [34] and Brykczynski and Benner [33] were used during the interviews. All informants were

asked to describe what had happened previous during the day in the interview. All informants also got the question: did the child participate in the caring situations today, as you perceive it? In what way? Can you describe to me? After these start questions, the interviewer asked informants to narrate their own experience of the situation; the interview guide directed the conversation in the following themes: Communication, participation, bodily communication, non-verbal communication and to listen to the child.

Analysis

The observations were the focus of the analysis, and the interviews uncovered variations of concerns and choices made in the authentic nursing care situations. Benner, *et al.* [34] guided the analysis and the twelve observation protocols and recorded interviews were transcribed verbatim by the first and last author. The interviews were then checked against the audio files and all material were read several times by all the authors. This was done to get acquainted with all data as a whole and to get some understanding of what it conveyed.

The next step contained a search of paradigm cases and exemplars. This was done through an interpretation of the transcribed material. The first and the last author discussed which observations were exemplars and which were paradigm cases. The transcribed interview text added a more in-depth understanding of what and why some nursing care interventions took place [33,34]. Parts in the text were highlighted and given descriptive names that captured the meaning, resulting in preliminary themes of interpretations of children's participation in the authentic nursing care intervention [33,34]. The last step contained labeling and naming the patterns of meaning that were found to elucidate the participation of the child in the nursing care situation [34].

Results

The findings showed that the phenomena participation revealed itself in different ways through nurses' perception of the child's participation in the PICU. The findings highlighted how the nurse made it possible for critically ill children to participate in the nursing care given, through their awareness and situated salience. Described as being "in tune" with the child and the child's bodily movements, the nurse interprets the child's preferences and mindset towards the nursing care intervention, through her hand and touch. Also, the observation of the technical devices gave the nurses a perception of communicating with the child's body rather than with the child *per se*. However, this gave the nurses information and strengthened their perception of the child's participation,

they "listened" to the child's body felt and the physical signs to meet their needs and arrange the nursing care accordingly. Three themes emerged through the analysis: Mediated participation, Bodily participation and Participation by proxy. They all highlight a different aspect of the vulnerable child's way of participating in the nursing care given.

Mediated participation

This theme conveyed how participation revealed itself through the bodily sensations as they were observed and interpreted on a monitor or through a technical device. As medical and nursing actions were carried out to help the vulnerable child, and when it was done with comprehensive care and focus on the child as a person, in the situation, participation appeared as mediation through a monitor or other technical devices. The excerpt below shares the meaning of mediated participation:

"One can feel in the tube when they start vibrating in a particular way, then the blood pressure goes way up, and the child gets worse" (Interview 7).

"But it is an aid to me I can listen and feel and fix and make an assessment, but I see the monitor as an additional aid in my overall assessment of this patient" (Interview 8).

The excerpts above highlights how it is possible to interpret that the child feels better or worse through the monitor. The technical devices supported the interpretation of how the child wanted to lay, be postured in the bed to be relaxed or what nursing care that upset the child. An attentiveness towards the child's bodily language mediated through the devices connected to the child's body was perceived as giving the child an opportunity to participate in its rhythm and needs.

Bodily participation

Participation through the body was conveyed as trying to make the situation manageable for the child by making events less surprisingly for the child, showing ones' presence and preparing the child through soft voice and soft physical touch. The children showed in many ways a willingness to be involved in their care, by head-shaking, moving their body and in many ways with eye movements, for example, by looking questioningly in different situations. As shown by the following observation and interview:

The child needs to get higher up in the bed, the nurse - Can you lift? The child helps, nurses: Nice! Good! (Observation No. 8).

"She very much wants to help and be good, and she is very talented and does things... it does not mean anything, from a medical point of view, one can let a big girl decide... how do you want to lie?" (Interview 8).

When this request was met the child became confirmed explicitly as a separate person, and the child's integrity was respected. Confidence was created by letting the little child suck on his soother, holding the child's arms and legs together, and remodeling the bed and giving pain relief. A minimum of stimuli could be appropriate, and then the body movements were performed in silence and without touch. The focus was on the child. The excerpt below highlights this aspect of participation:

"since she fell asleep just as we came into the ward... we decided to do nothing, until... either if we had to poke her or until she woke up..." (Interview 1).

"Oh, I think a voice is a little reassuring and then also how one touches the child and handles nicely and, and gently. Yes, they are affected anyway, they want, after all, to hear voices and especially if they are sad... that one is talking anyway with a cute voice, I think... I know... it... but I think it is significant" (interview 6).

"The little thing... he is so tense and cranky and yeah giant.. he is tense in his body, he, and his whole face was frowning, and it was hard and... before his... yes elbows and knees were so soft and followed the touch, but they are not like that now, he tries by all means to protect himself... and so... he seems to have a hard time... then, that he was participating, and I do not know, we put him on... dad's chest and he became... huh, very cosy, he just fell asleep there..."(Interview 6).

The excerpt above highlights how participation can be conveyed through bodily touch, reassuring voice and interaction body to body in an interplay with the child's bodily rhythm. By being in conjunction with the individual child's rhythm, sometimes giving access to medication or sometimes hindering examinations. Protecting the child's integrity and "correct" the environment to be aligned with the child's rhythm. Be the safe anchor in the situation were perceived as a notion of participation.

Sometimes the children distinctly showed how they did not want to participate but were not listened to, but manipulated to participate or overruled. Sometimes even with the help of the parents. The following observation and quote describe this:

- I am taking away the pillow - oh, what it is sweaty- now I will put this under the tube, the child shakes his head, the nurse says -not? The nurse removes it (she obeys the child's wish) - you have much air in the stomach, pulling air out of the probe. The child coughs -we need to clean the tube, child shaking his head, looking pleadingly at the parent, nurse - we need.. it is not dangerous! Sucking in the tube (even though the child conveyed another opinion) (Observation No. 3).

"If they say no, then you must think yes you cannot just run over their wish all the time... then one has to find, try and maybe distract, to persuade by the help of the parents or just not do it (Interview 3).

The excerpt above shows the complexity of the nursing care situation when the nurse has the intention to let the child participate (as observed in the excerpt above) and be a part of the nursing care given. However, when the child does not want to engage in the care required, giving the nurse permission to clean the tube, the nurse overruled the child. The interview then deepened the understanding of how difficult it was for the nurse to respect the will of the child. Since the suction was deemed by her to be prioritized on a medical basis, and the nurse could then overrule the child in the name of the child's best interest without further negotiation with the child.

Participation by proxy

In this theme, the parents were perceived as being the bridge to participation between the child and the nurse. As the parents were invited to discuss their child's individual needs, they were given a possibility to comfort their child as well as giving voice to their child's almost invisible, but familiar signs. They were able to give voice to the child's existential needs through the parental love to their child, which opened for participation through the parents, participation by proxy. As shown below:

"For me, it's easier if the parent is present because then I can get some help... with what this child likes and does not like and how they usually want... what seems to me to be really strong may be quite normal for that here the child if I try to turn my head to the way that it does not like at all, it may be... it's an advantage to have the parents there, and I think from the child's point of view it works completely invaluable regarding security and support and yes you know all that emotional "(Interview 8).

"Often, they are drowsy, and so there is not so much communication actually with the patients, but it is through the parents" (Interview 3).

The excerpt above highlights a dimension of participation that can be conveyed by parental involvement in their child's care. This participation by proxy could only be revealed when the parents were engaged in their child's care and trusted to maintain a parental role. A dimension that can only be reached by "being there" with the parents and be attentive to how they gave voice to their child's needs and preferences.

Discussion

The aim was to explore the vulnerable child's participation and how it can be understood through the nurses' perspective in the situated nursing care intervention. The findings revealed that participation occurs in the PICU through the body in diverse ways. By these findings, we argue for a new and broader definition of the phenomena participation. Researchers [26,36,37] argues that participation requires a relationship between the nurse and the patient, a relationship built on a somewhat cognitive awareness. We argue for an even broader view of the concept of participation. We argue that participation can be understood through the Child's body. Building on Leder [16] who argued that the body is partially absent from our consciousness but still communicating with the sounding world. He means that the visceral organs and the sick body can communicate as it does not behave as it used to, the body and the emotions are closely linked and should be understood as a whole. If we can accept this view, participation can be understood as a mediated participation through the technical devices or the body when we touch and feel it, as we found in the theme of Bodily participation. Which is closer to the notion of "being in tune" or "to present oneself" as Benner and Wrubel [29] puts forward arguing that being involved with the patient, paying attention towards eye contact, body language, movements, the tone of voice, opens up for participation. However, a prerequisite for participation seems to be that the child is the starting point for nursing care. Then it is

possible to integrate care that enables the vulnerable child's participation even though medical intensive care is given. It seemed harder to establish a relationship and enable participation when the child was sedated and intubated, requiring high sensitivity in the situation, but it was, according to our study, possible. The findings also revealed that the decisions children might be allowed to be involved in are not always directly related to care rather, such decisions as choosing a posture, a drink or a color on the bandage. Sometimes it is adequate to give children less important thing to choose between, but it requires a nurse with situated knowledge about the affective elements such as feelings, emotions, values, beliefs, empathy, compassion and strength to truly meet the vulnerable child. A nurse that dare to be there and experience the suffering of the child and the parents but always putting the best interest of the child first. From a professional perspective, the affective elements are considered to be one of the dimensions of professional competence underpinning the notion of "being in tune" or to "presence oneself" [29]. They are present in the activities of the health-care environment, being a key to reach and understand subtle signs in the nursing care situation. Unfortunately, "being in tune" is a relatively unrecognized phenomenon as the nursing curriculums seem to have remained relatively skill-based due to the particular need to evaluate, ensure, and maintain standards [38]. We have shown how nurses through awareness can allow the will and rights of critically ill children to prevail, to establish participation in the PICU, in the nursing care situation even when the child is critically ill and very vulnerable. There is always the risk of letting the parents' guide the nursing care risking to ignoring the child's own unique experience of the care given, however, when the nurse worked with the focus on the child as a person, and "saw" the child, worked smoothly and provided holistic care, ways to participate became evident. However, some obstacles and difficulties make the PICU work culture and physical environment a challenge to let children genuinely participate in their care on their terms.

Limitations

In a study, there are always limitations, choices regarding informants, design or time limits. In this study, the aim was to explore the vulnerable child's participation and how it can be understood through the nurses' perspective in the nursing care intervention. Since it is a small study covering two PICU: s it might not apply to other PICU: s around the world. Also, the data collection took place in the workplace which may have hindered some nurses to participate in the study. It may also have been the case that those who agreed to participate in the study may have been the ones most positive to the study, the topic and purpose. Despite these

factors, the authors believe that the informant's background age, gender and education still was satisfactorily varied. Data has been collected through observations and interviews which strengthens the trustworthiness since it catches the nurse's everyday actions and then lets the nurse reflect over this action which increases the ability to highlight the phenomena sought after [34]. The study is made with a qualitative approach which was suitable since it was a phenomenon that would be studied so unconditionally as possible. To strengthen the validity of this study and maximize the variation of the phenomena sought after informants at two PICUs in Sweden were asked to participate. The study team had not previously met the informants or the persons observed. Observation is a valid method when wanting answers to questions about a phenomenon that is difficult for those involved since it might be verbally complicated to describe, as the phenomenon is taken for granted [30]. The authors have tried to account for every step as explicitly as possible to increase credibility. The credibility of the analysis result is dependent upon the availability of rich data. Since the phenomena sought after are universal and not limited to the PICU environment, it is the reader who can determine the transferability [30].

Conclusion

In this study, the findings revealed that the subtle signs nurses' experiences in the nursing care situation could give the children a possibility to participate in their care on their premises, and every person working with children needs to act accordingly, as children have a right to be involved in their care. By training awareness, recognizing the affective elements, become aware of how the body present different feelings and deviate from ones' healthy tonus, age-related control over the movements, PICU nurses can uncover participation as through the child's body in diverse ways, as done with color of the skin in relation to different conditions. We call for awareness and a strategy on how participation can be established and strengthened in various ages at the PICU. The concept of participation should be redefined and broadened; it should be understood and interpreted in a new way within the PICU.

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