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Research Article

They Have Their Whole Life in Front of Them

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Abstract

Objectives: The objectives for the study was to describe challenges in caring for children in adult intensive care units as perceived by the intensive care nurse.

Research Methodology: A phenomenographic method was used since the aim of this study was to uncover nurses´ experiences of a phenomenon in their everyday clinical lifeworld. Setting, eight semi-structured interviews were conducted with intensive care nurses working in two different hospitals in Mid Sweden. Result: The result revealed several qualitatively different internal challenges connected to caring for a critically ill child. Two qualitatively different main categories: Internal Challenges with subcategories Fear and Empowerment and External Challenges with subcategories Learning environment, Another way of working. and Environment.

Conclusion: Children's vulnerable position in health care is clearly revealed in this study as it uncovers intensive care nurses face fear and uncertainty as a result of lack of adequate experience and knowledge when caring for children in the AICU.

Clinical Relevance: The external challenges perceived by AICU nurses when caring for critically ill children are closely linked to the internal challenges. And highlights the need of a systematic and well-designed in-service training and learning environment for nurses working in an AICU. A systematic and close collaboration with a PICU with possibilities to interchange should be a prerequisite when caring for children in the AICU.

Keywords: AICU; Challenges; Competence; Fear; Child; Phenomenography

Introduction

The world made a promise to all children in 1989, and the promise was to do everything in our power to promote and protect their rights to survive, thrive and grow and to make their voices heard and of following the United Nations Convention on the Rights of the Child [1]. Children and adolescents denied their rights could not fully participate in society. Twenty-nine years have passed since the Children's Convention was adopted by the UN General Assembly and children still have a vulnerable position in society. Sweden has strengthened the right of the patient in the Patient Safety Act [2], the Patient Act [3], guarding patients' right to participate in the care of their children and influencing the care they receive. The limited capacity and the uneven distribution of the paediatric intensive care units (PICU) in Sweden are two reasons why children are admitted to adult intensive care units (AICU) according to SFAI, Swedish society of anaesthesia and intensive care (2014). When cared for in AICU the settings are not adapted to children's specific needs, physically, physiologically or emotionally.

Background

Children are not small adults. There are physical, physiological and emotional differences, as well as differences in clinical symptoms and vital signs [4]. Nurses caring for critically ill children in the AICU describes emotional challenges associated with the care of the child, but also in the relationship with the child, and its parents [5]. The differences between children's and adults'

anatomy, physiology and cognitive needs impose high demands on the adult intensive care nurses' specific knowledge about children's needs [6]. Caring for children who require intensive care is thus an extraordinary challenge and require specially trained health care personnel and equipment, as in a PICU.

Therefore, Swedish society of anaesthesia and intensive care [7] recommends that all children three years or younger, or children above three years of age with multiple organ failure and breathing failure with estimated respiratory caring needs exceeding two days should be admitted to a PICU. Despite these recommendations, children under four years were admitted to an AICU during 2017 [8]. SFAI recommends that children, four years or older, can be cared for in an AICU if a shorter intensive care period is expected (24-48 hours). In addition, the admitting AICU should have required medical-technical equipment, and the AICU staff possess and maintain knowledge and awareness of children's specific caring needs [7]. If not, SFAI recommends transfer to a PICU. However, the decision to transfer the child to a PICU are up to the physician in charge, regardless of the recommendations. One should bear in mind that children in cared for in the AICU have an exposed position and are entitled to the same safe and prompt care as adult patients from specialist nurses with adequate nursing competency [1]. The AICU staff will need continuous training regarding child-related procedures to maintain an adequate level of knowledge, ensuring that children receive satisfactory treatment [9]. To care for a critically ill child requires experience and skills at a high and specific level round the clock by all staff in the AICU [7]). That AICU personnel prioritise medical concerns when admitting children with critical conditions is understandable. However, nurses who care for critically ill children must also be able to assess the vital signs of a child and have the knowledge to interpret them adequately [10] as well as being prepared when failure might become manifest. Nurses also need knowledge about the child's cognitive maturity when communicating as well as meeting the needs of the child's parents, who are regularly present and in crisis [11]. In an AICU, the child's caring and physical needs might be overseen and unattended to.

Aim

The aim of this study was to discover and understand the challenges AICU nurses experience while caring for children in their unit.

Method

Objectives

This study is a phenomenographic study, exploring the content of human conceptions [12,13]. As we aim to discover and understand the challenges adult intensive care nurses experience when caring for children in their unit. The primary interest is to understand the individual challenges perceived, rather than aiming at generalisations [14,15]. A phenomenographic approach focus to describe *how* the participants experience a phenomenon [16] compare and interpret these experiences [17,18]. Marton [12] made a distinction between first-order perspective and second-order perspective. In the first-order perspective, the interest lies within how something is, in the second-order perspective the interest primarily focuses on how phenomena are experienced. In phenomenography, one strives to uncover the perception of the phenomena's second order perspective [16]. The participants' understanding of the phenomenon, what is meaningful to them, reflects their basic understanding of the phenomena [18]. Challenges AICU nurses perceive when caring for children in the AICU comprise the second order perspective.

Participants

The data collection took place at two different university hospitals in central Sweden. Participants were chosen through purposeful sample, in order to cover a variety of perceptions of the phenomena [18]. The inclusion criteria for participating in the study was that the intensive care nurse should have experience of caring for children in an AICU at least on one occasion. In order to capture as diverse perceptions of the phenomena as possible, intensive care nurses should have different length of professional experience, different length of experience of caring for children and, if possible, different gender. The selection of participants consisted of eight women between the ages of 28 and 65 years. The participants had worked as AICU nurses with a mean of 11.6 years. They had been employed at the AICUs where the interviews were conducted with a mean of 10 years of which they had cared for children for four months up to 25 years.

Data collection

In this study, the authors considered individual interviews to be the best way to find out how nurses perceive and understand this phenomenon in their everyday clinical lifeworld [18,19]. Interviews

were thematic and lasted 30-45 minutes. The interview guide was designed with two specific, open-ended questions: "Can you tell me about a challenging opportunity when you have cared for a child in the AICU?" and "What are the most vulnerable conditions for caring for children in the AICU?". The answers were then followed up with probing questions like "How do you mean?" or "Can you develop?" [16]. In order to make it explicitly clear what the nurses tried to convey each interviewer checked interpretations with the participants and got them confirmed or denied [18]. The interviews were performed at the unit in a room close by, letting the everyday context where the phenomena exist be present in order to support the participant's perception of the phenomena [19]. All interviews were recorded by a digital recorder and verbally transcribed. The two first authors did all interviews and transcriptions of recorded interviews.

Analysis

The data analysis was conducted in line with the description of a phenomenographic analysis method described by Dahlgren and Fallsberg [17]. The first step in the analysis, familiarisation, meant that authors became familiar with the transcribed interviews. It meant reading and rereading the transcribed interviews several times. The authors then listened to all eight recorded interviews and read through the transcribed material again to get an understanding of the collected data. In the second step, condensation of data, all authors were involved asking questions to the transcribed text: "WHAT are the participants describing", "WHAT do the participants mean?". Then the authors individually marked the statements about the phenomenon that responded to the aim. The individually marked statements were then in the third step, compared, identifying similarities and differences. Patterns were searched for among the statements. This meant going back to the data set and confirming the individuals' statements. In the fourth step, grouping, authors discussed which statements were found to express an understanding of the phenomenon. For each statement, the question HOW was asked – HOW the participant had perceived the phenomenon, what was important to them. Statements similar to each other were grouped. The fifth step, articulation, aimed to catch the essence of the similarities within each group and preliminary descriptive categories emerged. The sixth step was labelling the categories. Authors discussed a descriptive label of the categories. The analysis went back and forth between the fourth and sixth step until the authors felt that they had captured the essence of the perceptions [17]. In the seventh and last step, contrasting, categories obtained were compared concerning similarities and differences in the levels of understanding expressed by the participants at a meta level.

Ethical considerations

Ethical guidelines according to Swedish law [20] was followed, and accordingly, the heads of each clinic approved conducting of interviews. Per the Scientific Council's ethics of research ethics (2002), participants received written and oral information about the purpose and structure of the study. The authors also collected participants' written consent to participate in the study, informed that participation was voluntary, and participants had the right to discontinue participation at any time, without questions or adverse consequences. Participants were told that if they in any way felt disturbed or experienced anxiety a psychologically educated person was at hand. No participant expressed such needs. Participants' statements were treated confidentially.

Results

The purpose of the study was to uncover challenges adult intensive care nurses experience when caring for children in the AICU. The analysis revealed two qualitatively different main categories: Internal Challenges with the subcategories Fear, Empowerment and External Challenges with the subcategories Learning environment, Another way of working, Environment.

Internal challenges

This main category conveys two qualitatively different internal challenges connected to caring for a critically ill child. The differences regarding paediatric patients is that compared to adult intensive care patients the expectation is that they have their whole life in front of them, and the feeling conveyed by the participants is that they should not be sick at all. Which adds extra pressure and emotional stress on the nurse in diverse ways requiring different coping strategies.

Fear

The emotional involvement in caring for a critically ill child causes a mental strain on the caregiver. The emotional challenge increases with the severity of the child's illness. Responsibility lies with the patient – the child – but also towards the parents. To meet the parent and siblings of a critically ill child is perceived as

encompassing existential courage, which means to respond and communicate with a parent in crisis and embrace their suffering. This requires empathy and presence in the situation and triggers emotional stress, and the fear of the worst possible scenario would come true, that a child dies and that this would have been caused by lack of knowledge and experience. The excerpt below highlights this fear:

"I don't want to stand there and take care of a child and feel that I don't have control of the situation; it would be terrible just because it is a child. They have their whole life in front of them so that is the kind of feelings that can pop up". (Participant 4).

"I have worked here only a short time. I do not have much experience of adult intensive care patients, and suddenly I have to take care of a child". (Participant 8).

As shown above, the perception of fear encompasses the affective elements of losing control, lack of knowledge and insecurity. Maintaining paediatric competence is difficult when care periods are few, and the fear of not having the right knowledge and doing things worse for the child is present — adding emotional stress, as caring for children and experiencing a lack of knowledge and experience is a mental challenge and a source of stress that creates fear.

Empowerment

In this subcategory, the qualitative difference in experiencing a challenge in caring for a critically ill child encompasses a sense of growing as a nurse to be in control and being aware of safety. With adequate experience and knowledge about how to care for severely ill children, the complexity can be stimulating and lead to a broader competence. The excerpt below highlights this.

"Anyway, I still feel somehow that I have gained new knowledge and that I have developed both as a person and a nurse. Yes, I am quite convinced that I have". (Participant 2).

"It is an advantage for us who work here. We get a broader competence compared to other nurses". (Participant 3).

"You need to communicate differently, and you adapt to the situation //, you cannot just approach a child and explain that now I will do this and this. If the child is awake, you need to play a little more maybe, depending on the age of course". (Participant 6).

The excerpts above highlight how increased experience leads to a feeling of new knowledge and confidence in nursing care. Confidence to provide the necessary understanding to create space in the nursing care situation for the child to be involved. They are gaining confidence to be able to see the whole child and not just the illness and what is needed to improve the child's condition. The focus is on the patient - the child centre. The situation can be perceived holistically.

External challenges

This main category conveys several qualitatively different external challenges which are connected to caring for a critically ill child. The anatomical and physiological differences between adults and children imply that care and working methods, as well as the environment, needs to be adapted to children's desideratum. Children's general condition can change very quickly, and knowledge of current reference values and dilutions of drugs is therefore crucial for quickly resolving changes in the child's status. Also, the child's cognitive level and age require adapted teamwork.

Learning environment

This subcategory conveys the importance of continued education as a key to acquire knowledge about children. The clinical training offered it is not sufficiently comprehensive to render enough security in caring for critically ill children if a critical situation evolves. There is a desire to learn and to have regular clinical practice opportunities to retain knowledge of children's anatomy and physiology. It is also vital that there is an understanding of and possibility to let the introduction to care for children may take time and that resources are allocated for expert supervision. For instance, to create close cooperation with the PICU which would open up the exchange of knowledge and an opportunity to auscultate and get deepened knowledge, as shown in the excerpts below:

"You must have knowledge of the child's physiology and anatomy, yes and vital signs. They look quite different compared to adults. If you have a baby, they have different anatomy of the throat; among other things, breathing rate, heart rate everything is different in a child //". (Participant 6).

"The paediatric education is only one day; it is just too short. It should be at least an extra half a day with medical lectures". (Participant 2).

"Maybe you should have the possibility to get clinical training. That would be very, very good. Also, to do an internship at PICU. So that you feel that you can apply the theoretical knowledge in clinical practice". (Participant 8).

When the possibility to develop and deepen knowledge fails in the organisation, the responsibility for acquiring knowledge is transferred to the employees' goodwill, as shown in the excerpt below:

"And then it is up to oneself. I mean it is your responsibility. I should go home and read the chapter about children in the intensive care book". (Participant 8).

The intermittent admission of children in AICU leads to acquired knowledge not being regularly practised in the clinic, creating difficulties in maintaining skills, creating uncertainty about what and how to do when.

Another way of working

This subcategory conveys how caring for children in an AICU adapted to adults means that the staffing needs to be adapted towards the child and families caring needs. Different resources, both physical and personnel, are needed around a child, and it affects the workload of the rest of the department. Nursing takes place bedside and often an additional intensive care nurse is required to assist with drugs and various nursing tasks. The teamwork between different categories of health care staff is improved around the child. Colleagues discuss and exchange ideas. In this way patient safety increases adding to improved care of the child, as shown in the excerpt below:

"One of the biggest differences is just that all categories of staff around the child, i.e. the assistant nurse, nurse and physician are disconnected from the rest of the department and focus only on the child". (Participant 4).

The child's need of their parents and parents' close emotional ties to their child permeate the daily work when children are cared for in the AICU. This requires another way than the usual of working around the patient. Parents' expectations can be challenging to respond to. To involve parents in nursing is essential for both the child and the parent in order to preserve the emotional link between them. Involved parents contribute to a better working environment around the child, as shown in the excerpt:

"Yes, but now I have got a lot more experience. Now I am nursing the child together with the parents. Several nurses do not understand it but ... and I still see many who nurse the child instead of nursing through the parents". (Participant 1).

The above statement puts forward the importance of parental involvement in nursing care. Parents in crisis can become an additional challenge, adding stress in the working environment. It is a challenge to be supervised and controlled by the child's close relatives. Parents strong feelings can be overwhelming, and parents may also require support. Responsiveness for parent needs as well as being able to comprehend their situation can ease communication and collaboration as shown in the excerpt below:

"Sometimes nursing staff are complaining about the parents, but I always try to think that if my child had been sick, I had been a hundred times worse". (Participant 2).

Environment

This subcategory highlights how the environment in AICU affects the work situation in diverse ways. The departments are inadequately adapted for the care of children and their families. Sound and light might be too harsh, and often there are no familiar characters on the wall to rest one's eyes on or a place for mum and dad to be anchored as a family in the child's room. The medical technology used might be of adult size, shape and form and needs adjusting to the child's needs. The special requirements that can be placed on a department that cares for children regarding specific nursing and medical technology cannot always be met. It implies challenges in nursing and the working environment. Adequate medical material and equipment is not always available in the department. Emergency drug doses and dilution schemes are not integrated for all patient categories. This means that time is spent on practical and administrative tasks instead of nursing care, as shown in the excerpt below:

"The perfect solution would be if we would have a fixed paediatric ward where all the equipment is designed for children and where all the material, syringe sizes, patch sizes // any dilution lists, and things are just adapted // it would be the most optimal". (Participant 4).

"Now I do not know what it looks like in PICU. They have a little more suitable environment if you say so. There are some more decorations on the walls. A little more relaxed. Something to suit children better. We have grey walls, and we have a sliding wall, and there is an adult in critical condition on the other side if you are unlucky. Strong smells. // You may have a very sick patient and alarms going off all the time. It is not a relaxed environment". (Participant 8).

The citation above raises how the environment might become a liability to a continued need for intensive care as it does not support well-being from a child's perspective. The environment is not designed for children's or their family's needs. Instead, it might be noisy, scaring or causing anxiety for all patients as sounds from adult patients may be scary to the child, and a crying child may cause anxiety in adult patients.

Discussion

The results of this study highlight two main categories; internal and external challenges. The internal challenges, deriving from within the individual nurse, contains the subcategories Fear and Empowerment. The External challenges, derived from the clinical context, contains the subcategories Learning environment, another way of working and Environment.

There is a linkage between the internal and external challenges which become evident in the subcategories learning environment and fear. A lack of knowledge and skills in caring for critically ill children creates uncertainty, stress and render a resistance or fear of taking responsibility for the care of critically ill children. The principal reason is the fear of making mistakes that might harm the child. The lack of theoretical knowledge they experience, creates insecurity in their daily work with children in the AICU. The result also highlights the emotional stress the intensive care nurse is exposed to based on the fear that the child will die and that the nurse caused the child's injury or death. Evidence shows that this fear is justified as mortality increases when children are cared for in a non-specialized AICU [21]. The learning environment becomes provoked by the intermittent care of children in the departments studied. Long periods between care opportunities for the individual intensive care nurse leads to perceived patient safety problems and produces fear in the individual nurse. In order to create more care opportunities, several European countries have chosen to centralise the intensive care of children by allowing fewer AICUs to receive children [22,23]. Since difficulties linked to the fact that care is intermittent makes it challenge to maintain competence and it becomes crucial building a suitable learning environment in the AICU, preferable in close collaboration with a PICU. Offord [24] for instance means that an education program with practical exercises as well as visits to a PICU leads to in-depth knowledge and ability to practice clinical skills. This solution might offer increased self-confidence among intensive care nurses.

What is more, a simulation exercise in between caring occasions might reduce stress and enhance the possibility for nurses to feel comfortable around paediatric patients knowing their knowledge is up to date. The results also highlighted the environment as a challenging external factor, potentially viewed as connected with internal challenges. If we can improve the learning environment, fear might decrease, and the working environment improves. Something that both nurses and the paediatric patient would benefit from. It might also create unnecessary fear and cause patient safety problems when adequate medical materials and equipment re unavailable, and the nurses do not have the education to use medical technology adapted for children.

On the other hand, the result highlights that nurses feel empowered and start to think in a different way when caring for children in the AICU. These two subcategories might be linked as the internal challenge of thinking differently might be the result of developing new knowledge in the clinical context, thus giving the nurse the ability to grow and develop as an AICU nurse, feeling empowered as she can extend her caring competence to omit critically ill children without feeling fear or lack of knowledge. If we do understand the challenges of caring for children in the AICU in this way, we might have discovered a description of a continuum of knowledge development of caring for children in the AICU. It becomes evident that the head categories external and internal challenges interlink in diverse ways which directly affects the quality of care the child receives. It also directly affects the work environment, if there is a learning environment nurses feel safe, patient safety enhances, and nurses develop new knowledge and reaches a level of empowerment. Nursing care should be based on science and proven experience, and lack of knowledge poses a risk to the patient and thus a risk of violation of the Patient Safety Act [2]. The Patient Safety Act in Sweden regulates the healthcare personnel's responsibility regarding the performance of the

duties. The result highlights an imbalance between the perception of self-responsibility and the responsibility of the employer for the work to be carried out. The result shows that the employer does not fully assume responsibility under the Swedish Work Environment Act when caring for children in departments where there is no proper schooling and additional education [25].

Although there are significant challenges in caring for both adults and children in the same AICU, when the perceived challenges are taken seriously and eliminated, it will lead to closer cooperation between colleagues and both experience and theoretical knowledge increases. This will lead to an improved working environment and result in the fine-tuned nursing care that children are entitled to.

Limitations

In every study there are limitations, and in this study, the limitations consisted of the few participants and their homogenous gender. It might be that women have one understanding of the clinical work that is different from men, and this might have influenced the results as a male perspective is lacking. However, in the clinical setting, there are more women than men. Other limitations might be the choice of data collection. If observations instead of interviews were chosen, we had been able to observe the clinical setting as it unfolds itself. The choice of phenomenography as a method is based on the authors strive to uncover new knowledge about how intensive care nurses perceive challenges in caring for children in AICU. The trustworthiness is related to the understanding of the work as a whole, ranging from design, data collection, and interpretation, examining the transparency and coherence toward the practical concerns that motivated the study [26]. We chose a phenomenographic analysis method since the focus was to find what was meaning-making for the individual participant, the differences and variations as well as similarities in the phenomena researched [18,27,28]. Which made it possible to capture the participant's different ways of perceiving the challenges [18] and new knowledge about how we can improve children's care in the AICU became visible. Also, the data collection took place at the workplace which may have hindered some nurses from participating 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 participant's background age and education were satisfactorily varied. Data were collected through interviews which increases the ability to highlight the phenomena sought after [29]. The spread in age and experience in the sample has created the conditions to discover a wide variety of perceptions which is a strength in the study. What emerged during the research process was critically reviewed and examined against other interpretations and possible explanations as suggested by Benner [30]. The applicability [15] refers to the degree to which the findings in the study can be applied to other contexts. Even though the results in this study are limited, it is reasonable to believe that the results may be applicable and transferable to similar situations and contexts. The strength of the qualitative methods used in this study is that they are conducted in a naturalistic setting with few controllable variables [15]. In the best of worlds, all children in need of intensive care should be admitted to a PICU to have the best prerequisites to be cared for following their or their family's specific needs [31]. However, it is not possible for all children to become admitted to a PICU, but they are still entitled to high-quality care, and therefore it is of utmost importance to uncover challenges adult intensive care nurses experience when caring for children in the AICU.

Conclusion

This study reveals children's vulnerable position in health care. This study also uncovers the need for a systematic and well-designed in-service training and learning environment for nurses working in an AICU. A systematic and close collaboration with a PICU with possibilities to share UpToDate "best practice "information should be a prerequisite when caring for children in the AICU. This should be doable through the advances in digitalisation within health care. The internal challenges intensive care nurses face caring for children in AICU produces fear and uncertainty. In addition to fear, there is emotional involvement in the severely ill child and the child's family, whose effects on a personal level might cause emotional stress. This might be a result of inadequate disposal of the external challenges such as a learning environment, another way of working and the environment surrounding the nursing care situation in the AICU. The care environment should be able to adapt towards children and family's needs. Some needs could be meet by giving the family a designated space close to the chid were they can sit close, read to the child or just rest without the fear to be an obstacle to care interventions. Every child should get the care they have the right to and the conditions in AICU should correspond to those in a PICU, at least in a designated section of the AICU.

Implications of Clinical Practice

The challenges AICU nurses' experiences are closely linked to the environment they work within. When there is a lack of child adapted medical devices, uncertainty arises, and nurses need to reinvent solutions to be able to care for critically ill children properly.

Frequent learning possibility through simulations targeting caring for a critically ill child between caring occasions could be one way of enhancing patent safety as well as promoting the feeling of empowerment in AICU nurses.

To enhance the work environment the environment needs to be adapted to the child's and family's needs.

The employer needs to take the lead and provide the nurses with education, training and resources necessary for good and safe care for children in AICU. However, the AICU nurses need to take responsibility for their learning as well as a good and safe work environment when working with children in the AICU.

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Volume 2 Issue 6 June 2019