


# Challenges in Nursing Care of Children With Substance Withdrawal Syndrome in the PICU

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## Abstract

**Introduction:** Substance withdrawal is one of the most common adverse events in the Pediatric Intensive Care Unit (PICU), as the administration of potent opiates and sedative drugs is frequently performed several times each day.

**Objectives:** The present study explored the challenges in nursing care of children with substance withdrawal syndrome in the PICU.

**Method:** The study has an explorative and descriptive semi-structured qualitative interview design, with a strategic selection of informants. It was conducted at one out of three pediatric intensive care units in Sweden.

**Results:** Three different main themes were identified describing the different challenges regarding withdrawal symptoms: *monitor the child's interest, work with structured support, and understand the observation.*

**Conclusions:** There is a discrepancy between the medical perspective and the nursing care perspective regarding children in PICU suffering from withdrawal syndrome. The lack of joint guidelines, language, and nursing diagnoses may lead to subjective evaluations and increase suffering for these children.

## Keywords

pediatrics, practice, qualitative research, research, children, workforce, organizational culture, business concepts

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## Introduction

When a child is admitted to the Pediatric Intensive Care Unit (PICU), the care usually entails a mix of drug infusions. Sedative and analgesic drugs are administered as they enable treatment, and relieve discomfort and pain associated with the treatment of children (Playfor & Vyas, 2000; Tonner et al., 2003; Whelan et al., 2015). The administration of potent opiates and sedative drugs are needed to facilitate respiratory care, prevent accidental self-extubation, and reduce stress and anxiety (Playfor & Vyas, 2000; Tobias & Rasmussen, 1994; Tonner et al., 2003). Many of these drugs are addictive.

## Review of Literature

Delirium and withdrawal syndrome can be both frightening and painful for patients. In addition, delirium is also associated with long-term cognitive problems, leading to morbidity and negative impact on the child. Delirium increases costs both during hospitalization and after discharge, due to

increased need for care (Collet, 2020). Detection, prevention, and treatment of delirium and withdrawal syndrome in children are therefore essential in the acute treatment of critically ill patients. In the PICU many of the administered potent opiates and sedative drugs are addictive and potentially lead to delirium and withdrawal symptoms. The impact the drugs have on addiction or withdrawal symptoms varies

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due to the dose prescribed and the time the drug has been given to the patient. Among children, Midazolam is a commonly used drug with side effects such as tolerance development, dependence, and withdrawal syndrome in subsequent interruptions (Playfor et al., 2006). Another example is Dexmedetomidine which showed a 30% prevalence of withdrawal syndrome in a literature review (Whalen et al., 2014). As an example, the use of midazolam for more than three days might trigger tachyphylaxis as well as physical dependence (electronic Medicine Compendium [eMC], 2014). A study by Ista et al. (2008) and Whelan et al. (2015), describes withdrawal symptoms as agitation, anxiety, high muscle tension, insomnia < 1 h, diarrhea, fever, and sweating. Withdrawal symptoms might be misinterpreted as symptoms of an underlying disease by nurses when caring for a child with different drugs used simultaneously (Madden et al., 2018). A literature review points out that delirium affects up to 65% of patients (Collet, 2020; Svenningsen et al., 2013) who are admitted to an intensive care unit. How common delirium is in a PICU is still unknown, but it is a condition characterized by decreased attention, disorganized thinking, and a fluctuating course throughout the day. Haenecour et al. (2017) showed that when drugs are given to the patient for more than 48 h the incidence of withdrawal syndrome is 35%. This means that at the end of the PICU treatment, withdrawal syndrome is present in 64.6% of the children (Amigoni et al., 2017). If the nurses do not recognize withdrawal symptoms or understand how delirium manifests itself in children of different ages, children are at risk to become delirious and experiencing withdrawal syndrome without anyone noticing. With such as high occurrence as 64.6% of the children having withdrawal symptoms (Amigoni et al., 2017), most children are put at risk and require extended PICU stay including prolonged ventilation process and increased need for attentive nursing care (Ista et al., 2008). Furthermore, about 50% of the drugs used to sedate children (Ista et al., 2013) are licensed (Neubert et al., 2008), which contributes to unclarity and challenges to understand and distinguish between side effects of the drug or withdrawal symptoms (Ista & van Dijk, 2017). When such doubt exists the child might be exposed to unnecessary suffering, as suffering occurs when people don't understand what is going on around them (Piredda et al., 2015; Vincze et al., 2015). This highlights the importance of the PICU nurse's four primary responsibilities; *to promote health, prevent illness, restore health, and relieve suffering* (International Council of Nurses [ICN], 2012). However, this might be a delicate task as there are only two validated instruments for children which measure withdrawal symptoms (Chiu et al., 2017), which in turn creates challenges for nurses to identify and understand signs of withdrawal syndrome. The withdrawal syndrome should be recognized as an advert event in nursing care. It poses challenges for children and care organizations to educate and recognize these symptoms to alleviate children's increased suffering. It is also

a matter of health economy and patient-flow perspectives, as substance withdrawal symptoms prolong PICU hospitalization (Ista et al., 2008). The objective of the present study was exploring the challenges in nursing care of children with substance withdrawal syndrome in the PICU.

## Method

This study is a qualitative explorative study aimed at increasing the understanding of how withdrawal syndrome can present itself in the PICU context. It is a challenge to discover withdrawal syndrome in the clinical care of children. The chosen method was considered appropriate as a qualitative explorative approach that aims to capture the lived experience of a phenomenon occurring in a certain context (Polit & Beck, 2004). The qualitative explorative design aims to guide the analysis of the data based on Benner et al.'s (1999) care domains. The care domains can be understood as *person, environment, health, and nursing*, where *person* is the person who receives nursing care, *environment* should be understood as the care environment surrounding the person, *health* is the state of health and illness at the time of the nursing interaction, and *nursing care* is the nursing care situation itself (Flaskerud & Holloran, 1980).

## Setting

The study was conducted at one of the three largest PICUs in Sweden, with eight beds. Nursing care provides care before and after highly specialized pediatric surgery, for example, thoracic surgery, neurosurgery, or specialized care required for, for example, medical therapy in neurological diseases, epilepsy, infections, sepsis, metabolic disorders, or continuous dialysis (CRRT). At the department, nursing care for the patient before and after Extra ECMO is as well carried out. All types of invasive respiratory care, conventional and specifically, including NO gas inhalations and all types of noninvasive and invasive respiratory care. Furthermore, nursing care is also given to children with congenital malformations requiring intensive care at the PICU.

## Sampling Technique

This study used a strategic selection of nurse informants in alignment with (Polit & Beck, 2004). Nurses with more than five years of clinical experience in nursing care of children with substance withdrawal syndrome in the PICU were invited to participate, to gain as much variation as possible regarding explored the phenomena and to give depth to the result in accordance with Polit and Beck (2004).

## Inclusion Criteria

Nurses with five years or more of clinical experience in nursing care of children with substance withdrawal symptoms in PICU.

### *Exclusion Criteria*

Nurses, with less than five years of clinical experience in nursing care of children with substance withdrawal syndrome in PICU.

### *Selection of Participants*

In the chosen setting, most children are pre-verbal or intubated. This means that nursing care diagnoses are made mostly through direct observations of the child or by interpretations of the information given by the parents. To maximize the variation of the explored phenomenon, data was collected from nurses with at least five years of experience in this PICU. This was considered important in the selection of informants, as Benner et al. (1984, 2001) argue that nurses focus on different nursing diagnoses: mental, physical, and environmental conditions during their various phases of professional practice. As we requested specific knowledge about the phenomena, that is, withdrawal syndrome in intensive pediatric care, we selected a small group of informants with specific knowledge rather than a larger group of informants with an uncertain knowledge level (Flick, 2002).

Information about work experience and education level within the nursing staff was obtained through the head nurse at the unit. This resulted in a total of 10 specialist nurses who were eligible to participate. All 10 specialist nurses were contacted through targeted e-mail. They were informed about the study and received a general request for participation, five respondents answered yes. Five respondents agreed to participate, and the interviews were conducted at the clinic in alignment with the informants' and the first author's schedules. The mean age of the informants was 50.2 years, and their mean number of years of working experience in the PICU was 11.5 years.

### *Data Collection*

Data was collected through interviews as the method was considered beneficial in revealing how individuals act in general and specifically in relation to how a phenomenon appears in its everyday context (Benner, 1994; Benner & Wrubel, 1989). To assist in the interview, a semi-structured interview guide with 13 questions was used. This allowed the interviewer to create an opportunity to access rich and detailed descriptions from the informants. The interview guide consisted of standardized introductory questions about informants' demographics followed by open-ended questions about the topic with a possibility to pose supplementary questions to get as rich information as possible (Flick, 2002; Polit & Beck, 2004). The interviews were performed by the first author and were recorded on a smartphone that was password protected. All interviews were performed in connection to the nurse's ordinary work schedule at the clinic in a separate room to ensure privacy. All interviews

were transcribed verbatim in close connection to the interview. In qualitative research, interviewing is a common method of collecting data. Polit and Beck (2004) raise the importance of having good knowledge about the context in which the phenomenon is explored, to understand and follow-up on answers in the interview. The researchers have all extensive experience in the present field. The questions were designed to give a wide variety of descriptions concerning the aim of the study. The questions were adapted to the interview situation and were, therefore, not posed in a specific order (Polit & Beck, 2012). This allowed for understanding and exploring the informants' lived experiences in depth.

### *Data Analysis*

The analysis was carried out in Swedish and later transcribed by translators into English to ensure a correct translation. In this study, content analysis was used to analyze data. Based on the narrated story or text, data is sorted by themes and patterns by encoding meaningful data parts (Flick, 2002; Polit & Beck, 2004). To focus on nursing challenges, a directed content analysis (Hsieh & Shannon, 2005) was used. In the first step, the interviews were checked against the audio files, and all the authors read the material several times. This was done to get acquainted with all data as a whole and understand what it conveyed. The second step in the analysis consists of deductively linking meaningful parts to domains based on Benner's care domains:

The helping role, teaching, and guiding function, diagnostic and monitoring function (Benner et al., 1984; 2001). Communication and negotiation of multiple perspectives, quality control and management, use competent expertise in clinical setting (Benner et al., 1999).

This step was performed by marking meaningful parts in the transcribed interview text. In the third step, a table was created, with Benner's nursing domains on one side and the meaningful part of the interview text that has a relationship with the specific domain on the other. The fourth step meant that the authors reflected on the entire content of the text to manifest challenges and latent challenges, which are the steps in the content analysis according to Graneheim and Lundman (2004).

### *Ethical Aspects*

The study was approved by a Regional Board of Ethics in Sweden and permission to contact the participants was given by the head of the department. The study was conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013) and the four basic principles of research ethical principles in medical human research. All informants were guaranteed confidentiality and written

informed consent was obtained from all study participants. The participants were informed that the participation was voluntary and that they could withdraw their participation without further explanation.

## Results

This study aimed to describe challenges in the nursing care of children with substance withdrawal syndrome in the PICU. The result reveals that there are many challenges regarding the nursing care of children with substance withdrawal symptoms in this specific clinical context. These challenges are presented in the following three themes: “*monitor the child’s interest*,” “*work with structured support*,” and “*understand the observation*.” These themes address the challenges that occur at bedside in the nursing care which need to be addressed to ensure the quality of nursing care associated with monitoring and understanding how substance withdrawal symptoms are handled within this patient group.

### Monitor the Child’s Interest

There are challenges in monitoring the child’s interests. In the nursing relationship with the child, these challenges become visible and challenge the possibility of protecting and delivering high-quality nursing care from a child-centered perspective. This occurs for instance when the child is being discharged from the PICU and transferred to a specialist care department. The challenge is to adjust the sedation to a manageable level that is comfortable for the child. An example of this can be seen in the quote below:

... like sometimes, when you want a place (at another care level), and you lowered the sedation medication ... I think it’s done too fast, and the child is put on oral support, to transferring the child to another ward in the afternoon (I, 1)

The quote above shows how the adjustment of the sedation level is made rather rapidly, without focusing on the child’s well-being or the quality of nursing care. The challenge in nursing care is to protect the patient’s well-being while meeting the requirements of others, that is, trying to get the patient in a removable condition and thereby allow for new admissions to the PICU. To monitor the child’s interest and create space for nursing care, individual activism may arise, as the quote below shows:

So, when staff arrive from another department to pick up the child ..., I said that it is not possible to send him up now in this state because he’s rather psychotic (I, 3).

This quote illustrates how a caring space is created by emphasizing and augmenting some of the child’s more severe nursing care needs. By creating this space, a possibility to

enhance the nursing care arises and the child is given time to reach a healthier nursing care experience.

### Work With Structured Support

The challenge to work with structured support of various assessment protocols lies within the built-in conflict. The protocols provide support and safety in the nursing care, that is, following ordinations, evaluating the sedation level and abstinence symptoms, while continuing with high-quality nursing care to support the needs of the child when lowering the sedation level. Aspects of the informants are highlighted through the quotes below:

... we have good routines, so that we can really prevent this with abstinence, and improve ourselves (I, 2).

In the citation above, the importance of routines and protocols is stated. They are functioning as support in preventing and identifying abstinence symptoms. However, structured support can also present challenges for nursing care, as the quote below shows:

We have many people (health care staff) who come from other clinics to learn. They bring their routines eh, and it’s highly appreciated, but it’s the kids who pay the price for this (I, 5).

The quote above reveals the challenge of applying routines and structured support in a different context than it was designed for, without a critical reflection of what a visible observation means in this new context. This will also affect the child as the support was not developed for this patient group and context. The uncritical use of structured support may give a paradoxical result and render a decreased quality of nursing care and increase suffering for the child. The quote below is also an example of this:

And there was a girl, all her medications were abruptly stopped by some physician ... she spent a long time in the ventilator, and she had surgical problems. So, she had problems with pain. All medications were turned off one evening. Pain management were shut off or lowered abruptly much more than you should. Then you can ... these symptoms, they can be, that you need to put the medication back ... or you need to fix it.

But I think when you have been admitted for a long time and have been seriously ill and deeply sedated, you almost always become abstinent (I, 5).

The conflict within this situation above clearly puts the child at risk of suffering and morbidity. If the child’s needs are overseen because of hierarchical expectations or uncritical following of structured support, the consequence will be

increased suffering for the child. This citation also emphasizes the need for teamwork with a clear priority, the caring needs of the child.

### *Communicate the Observation*

This challenge highlights the importance of communicating and understanding each other in the clinical situation. This challenge highlights the importance of having a joint caring language. Having good knowledge and understanding of different measuring instruments is not enough. It is a challenge to communicate abstinence symptoms, understand what you see, talk about it, and express the correct words for your observations to understand and interpret the child's abstinence symptoms correctly. It is difficult to measure abstinence from the patient's perspective and it needs to be clarified. The quotes below show this:

... difficult for everything to be subjective in any way. After all, we have no scale to measure it (I. 3).

... The hardest thing is with the small children..., where you can't see if the behavior is normal or not (I. 2).

The quotes above highlight how important it is to observe, interpret, understand, and communicate withdrawal symptoms comprehensibly. What is happening and what does it mean to the child? How can this observation be converted from the result of the measuring tool into the child's needs? These are questions that must be posed to provide high-quality nursing care. If the knowledge or experience of a phenomenon is limited in the clinical context, the child will become exposed to suffering that could have been avoided. The quote below highlights one aspect of this:

In an intensive care unit there have always been many strong people around. You have, uh, different experiences, we work in different teams. So, it is also difficult to agree on something ...

Since there is no common language in the care team regarding this phenomenon or ongoing communication about how you should interpret withdrawal symptoms, various innovative terms regarding withdrawal symptoms are created. This leads to uncertainty and subjectivity in understanding and interpretation of signs of withdrawal symptoms.

The difficulty, of course, is to ... eh ..., to gather competence all around, and that you will agree on it. Yes, but it is ..., it is never easy with abstinence.

The quotes show the need to communicate with a uniform nursing care language that reduces the scope for subjective interpretation. A language that raises and strengthens the position of nursing in the clinical context.

## **Discussion**

This study aimed at describing challenges in the nursing care of children with substance withdrawal syndrome in the PICU. The results show that there are challenges in the clinical setting to understand, interpret and communicate the observations of the phenomena. It is important to use the same terminology and language when communicating withdrawal symptoms to understand the interpretation of the child's abstinence and withdrawal syndrome. The challenges become evident in relation to the child's needs and requirements of sedation adjustments, enhanced comfort, and transfer to specialist care departments. There is a need for the development of the knowledge and competence regarding the use of assessment instruments in this clinical context, as well as the development of a caring language targeting withdrawal symptoms.

The most surprising result was the theme and the challenge "to communicate the observation." This indicates that there is uncertain or unclear communication present in the PICU. It might also be a lack of respect for the patient's autonomy or function (Goedhart et al., 2017; Smith et al., 2018). The results highlight a clear discrepancy between the medical language and the nursing care language in the everyday clinical context. The medical terminology is allowed to prevail, while the nursing care language is lacking. It is all about communication and having a common language. The fact that there are no nursing language or nursing diagnoses in the field, unnecessary suffering for the child may occur. Furthermore, the interpretation and description of the observations become subjective and difficult to express and communicate. The nurses do not understand the meaning of the observations while reporting the patient to other nurses. All different interpretations of the observation's complicate communication about the phenomenon of withdrawal syndrome rather than pinpointing the child's needs. It might be helpful to use an evidence-based Standard Care Plan, where the intended care path for the patient is defined in advance (Edlund & Forsberg, 2014; Forsberg, 2017). The results clearly show the need for increased knowledge about measuring instruments; what they measure and their impact on the child. This is essential, not only because it is a reliable way to uncover withdrawal syndrome and delirium, but also as a structured way to develop a nursing care language, so the measures are communicated in an understandable language. Of course, it is crucial to the quality of care to measure and understand the symptoms measured. Therefore, a validated measuring instrument that is well known and understood is needed. There are two validated measuring instruments for children in this context: (1) Withdrawal Assessment Tool-Version 1 (WAT-1) and (2) Sophia Observation Withdrawal Symptoms Scale (SOS) (Chiu et al., 2017). Either of them could be used. Nurses are expected to use a validated measuring instrument, but this seldom happens due to a lack of knowledge and education. It would be an advantage if the

instrument was part of the observations stated in the patient medical records. Thereby, screening for withdrawal or delirium would be among the daily routines. Nurses will also be responsible and active in creating space for high-quality nursing care as they face the challenge of monitoring the patient's interests. At discharge from PICU and reporting the experiences of withdrawal syndrome to other care units, the nursing role's autonomy plays a vital part in protecting the child from suffering. These specific challenges regarding knowledge and competence within this particular clinical context open ethical challenges. According to the International Council of Nurses (2012), ethical challenges must be discussed to develop care, which requires an ongoing evidence-based discussion. The results also uncovered a conflict between the medical perspective and the nursing care perspective. These perspectives must be merged into a caring culture at each PICU to develop the quality of care and to decrease children's suffering from withdrawal syndrome.

### Strengths and Limitations

Since there is an unsolved problem with withdrawal syndrome in the clinical PICU context, regardless of the research in the field, we used another approach to highlight the complexity of this problem. The method used was qualitative design with interviews according to Polit and Beck's (2012). By using qualitative interviews as data collection there is always a risk of repetition or narrow interviews, but in the present study, we reached the richness and depth of the data collected. Furthermore, this study has a limited sample of informants and was carried out in one PICU, which must be taken into consideration regarding the transferability of the study. However, the problem with withdrawal syndrome is global and by the strategic selection of informants with long experience in the PICU, rich data was collected. The informants were familiar with the condition and had several experiences to share, which also might be the same experiences of nurses at other PICUs around the world.

A targeted content analyzing method, using Benner's nursing domains, ensured that the results were connected to a nursing care perspective in alignment with Hsieh and Shannon (2005). The limitations of content analysis might be the process of coding as it might limit the interpretation of the interview text. To avoid this risk, all researchers were involved in reading and analyzing the data.

### Implications for Practice

There are challenges regarding knowledge and discrepancies in nursing care and medical languages which open ethical dilemmas. These challenges may affect the safety and suffering of the child and require attention. Development of nursing care, according to Forsberg (2017), involves an ongoing evidence-based process. We, therefore, suggest joint team discussions scheduled as recurring events in the

clinic, with a dedicated facilitator, and joint care conferences for health care staff where medical and nursing perspectives on withdrawal syndromes and management in children in PICU can be discussed to develop joint guidelines. We also suggest nursing rounds and ethical platforms where withdrawal symptoms in children at PICU can be discussed on daily basis, to decrease the suffering of these children.

### Conclusion

The results showed that there is a discrepancy between the medical perspective and the nursing care perspective regarding children in PICU suffering from withdrawal syndrome. This was evident as nurses, who have more than 5 years of experience with children with withdrawal symptoms in PICU, do not know the correct terminology to report their assessments appropriately to the physicians or nurses. This lack of unified communication between healthcare staff decreases the risk of withdrawal symptoms from medications in this pediatric population. The lack of joint guidelines, language, and nursing diagnoses may hinder the development of the quality of care, lead to subjective evaluations and increase morbidity and suffering for these children.


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