

**Research Article**

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# Caring for Dying Children in the Pediatric Intensive Care Unit, Nurses and Parent's Perspective

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Caring for dying children is complex and requires coordination of all resources. In PICU the main objective is to save lives and ensure vital functions in critically ill children. However due to the child's critical and life-threatening condition, there is always the possibility the child will not survive. The acuity and technical nature of the intensive care context can provide an obstacle in the transition to palliative care and furthermore conflict with the affected families' needs. The study aim was to enlightening caring as it is represented in caring situations of dying children at PICU.

An Interpretative Phenomenological design was applied. The data collection was performed at three PICU in Sweden in two different occasions at 2011 and 2016 [1,2]. Caring situations of a total of 18 children were observed, of these five cases were estimated as end of life care or life-threatening conditions. Additionally, nurses and parents were interviewed in direct connection to the observation. Results showed that for nurses, it was a challenge to change perspective from curative to palliative care. Furthermore, medical examinations and treatment was experienced to disturb the dying child thus causing unnecessary suffering. Parents found it difficult to leave their dying children even just for a moment. At the same time the space in PICU usually did not support closeness and parenting but rather separated the dying child from her/his family.

In conclusion, since it isn't possible to always care for dying children in specialized palliative care units these results illuminate the importance of guidelines and training in palliative care in PICU and other acute pediatric care units. Children and their family ought to have the best care possibly when affected by life-limiting or life-threatening illness.

**Introduction**

Today's pediatric intensive care, PICU, tries to save lives and cure diseases, but sometimes the life support and curative care must be interrupted when the child no longer responds to treatment or if there is no treatment. Deciding on palliative care can be a long and challenging process that involves medical and ethical considerations and, in some cases, suffering for the child and grief for the parents. Before the overall picture emerges, many professionals involved will give their opinion about their area in the care of the patient. Nurses working closest to patients often experience that they perceive the need for palliative care before the physician, but the physician makes the decision. In addition to healthcare staff feeling secure in the decision, the parents should receive information and support in this severe situation. The conclusion given should be a loving memory for the parents to carry with them and the child's suffering should be alleviated. In order to get there, a workgroup that works jointly for the child's best interests and includes the parents in the care is needed.

**Background****Palliative care and children**

In 2011, almost two million children needed palliative care in the world [3], but only two per cent of these children had access to palliative care [4]. In a global perspective, the most common reasons for children requiring palliative care are defects related to birth, neonatal complications and nutritional deficiency [3]. According to Article 24 of the United Nations Convention on the Rights of the Child, all children have the right to healthcare according to their needs. According to [3], pain problems are a common denominator for many in need of palliative care, but the availability of opiates is limited in large parts of the world. Another reason why palliative care is lacking in some countries is the low quality of the palliative education given to healthcare staff [3]. The palliative care for children in Sweden is under development but has not come as far as, for example, England, where the experience of caring for children at the end of life is spread [5]. Most children who die in a

hospital die in the pediatric intensive care unit (PICU), [6]. There are three PICUs in Sweden, and they care for children up to the age of 18. Pediatric Intensive Care often means a painful trauma for children and the healthcare provider must consider whether the care given is beneficial for the child [7]. The palliative care should be put in place if the given care cannot cure the patient, but as long as there is doubt, life-saving care must be prioritized [8]. If there is a discussion about the child's state of health and possible need of transition into palliation, there are many professions involved in the discussion [9]. This may mean that the child is given additional painful intensive care during a period [7]. Autonomy might be threatened if the child is sedated or heavily influenced by his or her condition. Each person has the right to decide on his or her life and to be able to make the right decision, and it is necessary that information is given on an individual level [7,10]. The assessment is challenging as the child's capacity to make decisions is related to the cognitive and emotional maturity, which varies from child to child [7]. In the PICU parents often get this information and has the right to decide on their child's behalf, which can be challenging to handle when the parent's future for the child disappear [7]. Being a parent facing such a situation one might wonder what the child might be aware of and how one can address such a question with one's child. Turning to research [11] with children affected by cancer, it turns out that children from five years and up are sufficiently aware of their situation in order to be able to participate in discussions and planning on palliative care themselves. From the age of 14, the child is routinely included in the planning of palliative care [11]. For the parents to feel secure with their decision, the healthcare staff can provide information about the disease, both in writing and orally, discussing treatment options from diverse perspectives. The information needs to be given several times, and the person giving the information must be honest and objective. Parents may also be interested to know what current research says about the current illness and if there is any possibility of a second opinion from another health care provider [12].

To tell a parent that their child is dying is a difficult message to deliver, according to healthcare professionals. In order to give parents room for grief and questions in connection to the message, place and time must be chosen carefully [13]. The care given to the palliative child and relatives can be of direct importance for the relatives' possibility to handle the grief and perception of their last memory of their child [14]. In addition to grief, parents can also suffer from guilt and powerlessness. There may be religious, cultural or other things to consider [15]. The parents are in a situation where they might feel that they have lost control and they are in an awkward environment [14]. It has been found that it is better with one contact person within the healthcare team instead of everyone informing the parents. The risk of different messages decreases, and the healthcare staff gives a higher degree of confidence and security to the parents [16]. The nurse is then in a position of power when contact with the parents is well established. This position must not be abused by influencing the decisions that parents make; the nurse should only provide information and be there to listen [7].

## A worthy ending

The nurses are present to give the patient a peaceful and dignified end to life [17]. In order to provide the required palliative care, it is of utmost importance that the nurse is updated on research on palliative care as well as possessing skills to carry out palliative care, which is each nurse's duty [18]. According to [27], some nurses state feeling uncertain about providing palliative care to children as they lack experience and practice. Nurses experience that treating the symptoms, comforting parents and managing their own emotions as most difficult in the transition into the palliative care process [19]. Hence, a dialogue is needed on palliative care in order to discuss, among other things, pain treatment, medication and doses as well as ethical aspects, especially on occasions when life support treatment is interrupted and phased out [5].

Mitchell S, et al. [9] found in their study that nurses feel that the palliative care plan is created too late in the caring process. Unlike care where the outcome of the disease can be seen early in the process giving the family time to prepare together with a healthcare professional known to them [13] time to prepare for life-threatening, critically ill children in the PICU is more unpredictable [9]. Lifting the issue of palliative care with parents and children can be perceived as there is no hope for the child's life [13]. It makes it difficult to know at what time palliation should be lifted for discussion [20].

## Aim

This study aimed to describe the PICU nurses and parents experience of ending life support treatment in order to switch to palliative care.

## Method

To be able to describe the intensive care nurses' experiences of ending life support treatment and switching to palliative care in the PICU, the information needed to be retrieved from intensive care nurses with experience from child-intensive care. A qualitative design was chosen for the study as it can be used to describe several people's experiences of a phenomenon [21]. Interviews were considered appropriate as it allowed informants to share their experiences in their own words, instead of the author of the study constructing answer alternatives in advance as in the quantitative design [22].

## Selection

Firstly, criteria were created for suitable informants [21]. Inclusion criteria were that nurses should have specialist training in intensive care since this was the study context. They should have at least one year's work experience from the relevant department to have been able to gain experience of palliative care in the child-intensive care department. Only then was the manager at the relevant department contacted to apply for a permit to carry out the study. When a permit was obtained written information about the study was sent out to all nurses in the department. Two nurses reported their interest in participating and another six nurses were deliberately asked to participate, which resulted in a total of eight interviews booked. Two of the planned interviews

were cancelled due to workload at the department, so totally of six interviews were conducted. Five women and one man participated in the study, and they had different experiences of working with palliative children, but all had experience of caring for palliative children under the age of two.

### Data collection method

The data collection was performed at three PICU's in Sweden on two different occasions in 2011 and 2016. Caring situations of a total of 18 children were observed, of these five cases were estimated as end of life care or life-threatening conditions. The nurses and parents of these 9 children were asked to participate in the interviews. Six nurses and nine parents were interviewed in direct connection with the observations. In the interviews, informants were asked to give their view on their experience in their own words [23].

Observations were conducted bedside lasting 120-240 minutes. Field notes were taken, observing nurses in their everyday practice. The aim was to explore what nurses do when engaged in nursing care situations with vulnerable children. The validating interviews, following the observations, lasted 30-60 minutes and were recorded at the workplace in a separate room. The intention was to capture the meaning of the nurses and parents experience of the nursing care situation that had been observed. The informants were asked to describe their experiences, thoughts and feelings about the nursing care that had occurred prior to the interview.

Although it is not common to use an interview guide in phenomenology, in this study one with thematic questions influenced by the background of the study, research question and purpose was used as inspiration for the interview questions [24]. The questions were open-endedly constructed [23].

Before the interview started, informants were informed of the purpose of the study, the right to refrain from answering specific questions, that the interview was recorded and on confidentiality, which in this study meant that no informant would be mentioned by name and that isolated events that could be derived from a person would not be included in the result [24]. The recording was done on the interviewer's mobile phone. When the informant received a question, they spoke without interruption to avoid affecting the informant's story of the phenomenon sought after [23]. Each interview ended with the question of whether the informant had anything further to add to avoid an abrupt end [24].

### Data analysis

Observations and interviews were coded with numbers according to the order in which they were carried out to connect the observation with the interview and to guard the informant's identity. When all the interviews were completed and transcribed, analysis began. The analysis primarily focused on the observations. The transcribed interviews deepened, confirmed or denied the analysis. Qualitative content analysis was used to systematically analyze the transcribed interviews [25] and an inductive approach was chosen [25,26]. The analysis consisted of three phases, which moved back

and forth between foreground and background, between situations and the practical worlds of the participants. The analysis began in conjunction with data collection and transcription of interviews. Observations, as well as transcribed interviews, were read several times to get a preliminary understanding of what the data described. An alteration between closeness and distance, reading and understanding was performed. In the second step, open coding was performed. In the open coding, meaning-bearing units were marked as corresponding to the aim of the study. This phase resulted in 22 codes that were written down in the margin of the prints. Codes were then rechecked against aim and research question, in order to see if the code could describe an experience and further contribute to the overall understanding of the phenomenon. The codes were then divided into six subcategories depending on which part of the palliative care process they involved. Through the abstraction of the subcategories, three categories emerged. Together, the three categories described the nurses' and parents experience of the phenomenon. The experiences were then presented in the result.

### Ethical considerations

Confidentiality procedures were followed, and all informants, nurses and parents, participated in an informed, independent and voluntary basis. They were informed that they could cease participation at any time. Parents were informed about the aim of the study and were asked for permission to observe the nurse caring for their child. Ethical approval was obtained from the ethical committee (2011/244/31-1) as well as from the head of each clinic.

All informants agreed to be recorded. Recordings and transcriptions were saved in the author's computer with a password, to minimize the risk of outsiders being able to access the material. The documentation was also saved as security against possible plagiarism suspicions [23].

### Results

The result that emerged from the analysis shows that it is a complex and challenging ethical decision to end life support care in favor of palliative care in the PICU. There are many caregivers involved in the decision to transit into palliative care, which means that the decision-making process can be long and lead to unnecessary suffering for the child. An ethical dilemma is also that the interprofessional decision-making process sometimes may delay the time to transition into palliative care as the final decision is hard to make. Other ethical aspects to consider when transitioning into palliation are the parents' and the child's understanding of the situation and in what part of the process, they find themselves. Three main categories emerged during the analysis: "The irrevocable life", "Last time of life," and "Separating us".

#### The irrevocable life

In this category, how the nurse and parents understand the child's medical and general condition in connection with failing treatment is conveyed. This knowledge about the temporality and approaching end of life through changes in the child appears

through daily care. The child felt different, acted differently; the pattern of movement changed; there could be an influence on the cognitive ability and physiological changes. In this way, it created a holistic image that could be understood as the beginning of palliation.

Furthermore, for nurses, it was a challenge to change perspective from curative to palliative care. The following quote is an example of this:

*"It is noticed that first, it is the external motor and neurological and then it is also seen that the organs begin to fail" (Interview, n. 4) [27].*

*"He is in pain when he is awake, and then I understand that you have to make it easier for him. It is almost now difficult to see when he coughs and is awake; you see that he is panicking" (Interview, p. 12) [22].*

Depending on the state of health the child used to be habitually, it could be a challenge to determine how the present state of health affected the child and its future, as shown in the quote below:

*"Parents are accustomed to a certain quality of life for the child that they interpret as okay, and if you are not healthy in the initial situation, then you do not expect it to be healthy, so then you continue the care a little longer" (Interview, n. 2) [13].*

*"You have to fight to get involved, unfortunately. I think this is a great grief, that you do not become... if you do not grab it yourself and fight for it, you become.... So, then you are spoken over your head" (Interview, p. 29) [28].*

The above quotes show that the acuity and technical nature of the intensive care context can create obstacles in the transition to palliative care and conflict with the affected families' needs. It is difficult for the parents to get involved in the way they want and feel they need. It is also challenging to find a time that could be considered the best time to start a discussion about a transition into palliative care. The above quotes also show the importance of having a holistic image of the child. It also means that the person who holistically views the child also takes on an ethical responsibility in a complicated process. The following quote is an example of this:

*"You cannot cherish life at all costs, you have to think about what is ethically worthy and a good death" (Interview, n. 4) [27].*

There is an ethical dilemma in the foreground as the nursing care in the PICU aims to cure and not to facilitate a good death. This can be seen in the following quotation:

*"So, starting palliative care is not what we do; it is not what we are used to or skilled at" (Interview, n. 3) [29].*

One of the emerging ethical dilemmas was the ability to make decisions about how far the life-sustaining care would continue before it would be interrupted.

### Last time of life

In this category, the nurses' and parents experience of the palliative care process that takes place in the PICU is conveyed after

a decision to transition into palliative care has been taken. Each decision about palliative care was an individual situation and dealt with in accordance with the nursing staff's own past experiences. Although there is a lack of a general plan for palliative care, there was a common goal, that the last time of life would be peaceful and free from pain and the child should be allowed to integrate with his family to the extent it was possible for the child to be awake. The following two quotes are an example of this:

*"I communicate just as usual. I am there with the child and talking as usual, soothing, yes like that. I do not talk about the child's death. I do not think this is my task" (Interview, n. 6) [23].*

*"When you fight and fight and fight and expose the child for a lot and realize that this will not work and transit to palliative care and do the best of the time that is left. Instead of spending time in hospitals with cuts and treatments and unpleasantness then you can perhaps make the best of it and sit out in the sun and eat ice cream instead" (Interview, n. 3) [29].*

*"We feel that we want to minimize all adult contacts that just can be minimized" (Interview, p. 5) [30].*

*"... Then you have to offer them if it is a small child maybe they want to baptize the child before and then maybe they have special wishes about how the end itself should go to and we try as far as possible to accommodate them" (Interview, n. 1) [12].*

The quotes above show how fragile life can be and how parents and nurses are intertwined in a whole life during the short time of palliation. It is to build bridges through chaos side by side with the parents to reach the child and to anchor the parents in closeness with the child in the present. Furthermore, medical examinations and treatment were experienced both from the parents and nurses view to disturb the dying child thus causing unnecessary suffering. Parents found it difficult to leave their dying children even just for a moment.

### Separating us

In this category, the relationship between the critically ill child's relatives and the nurse is conveyed. In this relationship information, support and accessibility were components that contributed to trusting the nurse during the last period of life. At the same time, the space in PICU usually did not support closeness and parenting but rather separated the dying child from her/his family. The following quotes show this:

*"I often experience that as a nurse I am important in communication. Doctors have their meetings... The parents come back after these meetings and are sad and have a lot more questions and a while after this conversation they often think about this conversation, bring in what has been said and then come to the follow-up questions (Interview 5) [30].*

*"It does matter that they are not standing by the bed. It is like this; it is something new, what is it now" (Interview, p. 1) [12].*

*"it is difficult when he is connected here on cords, and so it does not matter if how many flowers you have around so it will always*

*feel in the heart so that yes, they cannot do more than they do as well as. I think it is in the situation because he looks like he is sleeping in principle as well" (Interview, p. 9) [25].*

These quotes show that it is the healthcare provider that was closest to the child who also received the follow-up questions and earned the trust to be a part of the last shivering time of life. The quotes also reveal a relationship of power in which the nurse possesses medical knowledge the parents need. The knowledge that was shared with the parents aimed to be objective, hiding the nurses own private opinion. To support the parents meant to take on an ethical challenge, it is part of the professional role but could mean that the nurse also became affected as a person when being there this last difficult time, when life and death separated the child from the parents. The parents wanted to become a whole family, even if it was for a short time. Being away from all technological devices, being on their own with their child, being together, giving all the love they had for their child these last moments. They wanted to "own" the transition from life to death, letting it be their private moment. However, support for parents varies depending on workload, described in this quote:

*"I think we do what we can, but it is not always that we have time or are enough. We usually have another patient for whom we should care that may also be very ill. Most people do the best they can, but it is not always enough" (Interview, n. 6) [23].*

## Discussion

Since it was the lived experiences that would be examined through interviews, a qualitative method was used which is a fruitful method [31]. The quality of the study is not governed by the number of interviews but by the interviewer's content [32]. The length of the interview is essential, and interviews in this study are of satisfactory length. Since the interviewer is active in the environment in which the informants were present, it was important to present the informants' understanding of the phenomenon. For that to be guaranteed, the questions had to be profound and the answers clear [32]. An argument that strengthens the quality of the interviews is that the informant spoke as long as they wanted; they did not get interrupted [32]. The interviews have been analyzed by the person interviewing, and the interviewer strives to describe only the words and meaning that have been conveyed [32]. Using the [25] content analysis, the authors considered contributing to the quality of the study. Qualitative content analysis has long been used in nursing studies and is used to analyze the written and said word, which in this case applies.

In intensive care, the desire is to cure. There is advanced equipment, and the knowledge and skills are advanced, but mortality is higher in a PICU than in a regular department. Therefore, there should be preparedness for more advanced palliation than in a regular department. The last time in life is valuable, and the discomfort of intensive care should not adversely affect the quality of life. There are three ethical principles to consider in healthcare according to the National Board of Health and Welfare's guidelines [34], the human dignity principle, the need and principle of

solidarity and the cost-effectiveness principle. The human dignity principle can apply in this case; autonomy is always threatened during PICU treatment due to sedation and severity of the disease. Also, according to the same principle health services should not cause unnecessary suffering.

The cost-effectiveness principle is subordinate to all other principles, but intensive care is expensive, and from a cost-effective perspective, it is wrong for intensive care patients who might have benefited more from palliative care [1]. Sometimes it may take time for parents to reconcile with the decision on palliation. A problematic ethical dilemma might occur. Continuing care at the parents' initiative after what is considered a reasonable time to land in the situation creates unnecessary suffering for the child. To avoid these situations, information to and support for the parents are vital. Another aspect to consider in the palliative care process is the possibility of organ donation, which can put time pressure and distress on the process. However, that ethical discussion is out of scope for this study.

The results show that there is a demand for supervision in ethics. The National Board of Health and Welfare [33] recommends supervision of ethical issues, and the Swedish Nursing Association [8,17,18] proposes ethical rounds where it is possible to reflect on difficult decisions, which interruption of life support treatment might be. To alleviate suffering and to care for both the body and soul of the dying person was the purpose of the palliative care that Dame Cicely Saunders founded in the middle of the 20<sup>th</sup> century. In this study, there was very little that emerged about the care of the child's soul. What was visible was that children should not have to suffer and that they should get quality care. One reason for this is that it may have become a priority to alleviate unnecessary suffering. Another reason the author pondered is whether it is the attitude to the sedative drugs that are available at a child-intensive care department. That everything can be cured by letting the child sleep through difficult moments instead of allowing the child to be awake with good pain relief and anxiety-suppressants. The sedated person has a harder time paying attention to the surrounding environment for discomfort. Instead, the focus is on parents in palliative situations, and this is in line with Bloomer M], et al. [29] findings that when children become palliative, more focus is on the family than earlier in the process. The desire for a quiet and gentle end of life that the family can remember with warmth might become the primary goal.

An intensive care unit is an unfamiliar environment that can create concerns, even for those families who have previously spent time in hospitals. There is a great need to get information and be treated with respect in all situations [34]. According to this study and a study by Butler A, et al. [30] the parents want to participate and make decisions about the continued care. The results of this study show that information is the key to open for parents to become involved. However, the results awaken thoughts of how we as co-workers prepare for meeting death and how we should support parents to love and be with their child the last grasping time of their child's life. A moment that should be full of love [3].

The informants mentioned that sometimes, they feel that we start the discussion about how the last days, hours or moments should be arranged very late, missing the possibility to make the best care we can give in such a situation. It is desirable that this discussion takes place earlier in the caring process of dying children, together with their parents. If it is possible to address treatment restrictions, reasonable expectations are given of what care can be given, and when it is not possible to do anything more [35-38]. It will give the parents a possibility to prepare, they may have understood and pondered for a while on how they want the end of life to become. In this way, a difficult task disappears, which can otherwise appear in the acute phase [39-42].

## Conclusion

Ending life support care and transitioning to palliation is a difficult decision. Sometimes intensive care can cause unnecessary suffering even with the best of intentions. Many are involved in the decision of palliation which is a challenge for healthcare staff. A large amount of energy is given to help the parents through a challenging time. The caregivers aim to make the child's last moment in life as pleasant as possible and relieve suffering and create loving memories for the affected family. In conclusion, since it is not possible to always care for dying children in specialized palliative care units, these findings illuminate the importance of guidelines and training in palliative care in PICU and other acute pediatric care units. Children and their family ought to have the best care possible when affected by life-limiting or life-threatening illness [43-46].

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## Conflict of Interest

Author declare no conflict of interest.

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