


Decision-Making Process for the Implementation of the Child Therapeutic Support Limitation Plan: Nurses' Experiences

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Abstract

Aim: To present nurses' experience in the decision-making process for implementing a therapeutic support limitation plan in the PICU. **Method:** Qualitative exploratory research was conducted through semi-structured interviews with 25 intensive care nurses from January to June 2019. The textual corpus was then submitted for content analysis. **Results:** Two categories emerged: the nurse and decision-making process of the TSLP and ambivalence of the participating nurse's feelings in implementing the TSLP. These categories are interrelated in that the decision-making process mobilizes the ambivalence of the participating nurses' feelings. **Final considerations and implications for practice:** The starting point of communication between the health teams consists of acquiring information about the concerned child's end-of-life care plan with no prospect of cure and with some form of therapeutic limit admitted to the PICU. Therefore, this study helps to map possible research gaps on the topic and mobilize researchers to build educational materials, protocols, and tools for comprehensive care that can be used by nurses when faced with ethical dilemma, such as decision-making through TSLP.

Keywords

therapeutic support limitation, care in pediatric therapy units, nurse, decision-making process, end-of-life care, palliative care

What do We Already Know About This Topic?

We know of studies that describe nurses' experience with end-of-life care in pediatric oncology, but little research has been done on nurses' experience regarding end-of-life decisions in the PICU.

How Does Your Research Contribute to the Field?

It provides the communication points needed to make a well-informed, non-regrettable choice to implement end-of-life care for children.

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What Are Your Research's Implications Toward Theory, Practice, or Policy?

This study contributes to mapping possible research gaps on the subject. Consequently, it mobilizes researchers to build educational materials, protocols, and comprehensive care tools that can be used by nurses when they face ethical dilemma, such as in cases of TSLP-related decisions.

Introduction

Pediatric intensive care units (PICU) involves advanced technology care and short hospital stays that aim to restore the health of critically ill children. However, in some situations, death is inevitable, and invasive therapies result in prolonged suffering. In pediatrics, suffering is associated with pain, fear, failure to satisfy basic human needs, and concern about parents.¹⁻³

Although mortality rates, which currently fall between 4 to 10%, in the PICU and neonatal intensive care unit (NICU) are declining, death in a PICU can be a long and painful event. Thus, the Therapeutic Support Limitation Plan (TSLP) has become an increasingly frequent practice in the context of intensive care in Brazil.⁴

TSLP aims to define the best therapeutic decision for procedures with little therapeutic benefit related to the suffering or pain experienced during such procedures. This has become increasingly frequent practice with regard to patients with no possibility of recovery and for whom the suspension of such strategies can result in death.⁵

Implementing the TSLP on children has been widely discussed in the Northern Hemisphere. End-of-life decisions are complex processes that involve parents and health professionals, such as physicians, nurses, and ethicists.^{2,6} In Brazil, end-of-life discussions more often permeate the field of pediatric oncology. However, the participation of nurses in the decision-making process remains underexplored.

A study carried out in 3 Brazilian hospitals identified that out of the 54 children who died in the PICU, only 25 had begun the TSLP. Of these, respiratory and cardiovascular systems were the main dysfunctional ones.⁷ In Spain, most TSLP implementation in the PICU was among children with neurological disorders or significant cognitive impairments. This study showed high involvement of the medical and nursing staff, along with parents, in decisions regarding the TSLP.⁸

It is generally agreed that decision-making should involve a multidisciplinary team, which includes the family and, when possible, the child. In literature, this constitutes an ethical dilemma that requires greater investment in research, particularly in the context of Brazil.^{7,9}

Therefore, this study presented nurses' experience in the decision-making process for the implementation of TSLP in the PICU.

Method

Qualitative exploratory research was conducted to attempt the first analysis of a new research topic. This type of research involves the exploration of a new field of knowledge in a given setting.¹⁰

Exploratory research on pediatric nursing is widely used in Sociology and offers an important foundation for describing newly emerging issues in the practice of care.^{11,12}

Data Production Procedures

Data were obtained through semi-structured interviews conducted between January and June 2019. The use of semi-structured interviews as the main source of qualitative information offers an objective way to acquire information, directing the participants to maintain the focus of the narrative.¹³

Flexibility to continue the inquiry process based on open questions allows the researcher to delve deeper into a particular topic.¹² In this sense, the semi-structured interview was conducted with 3 open questions that involved the identification of feelings about decision-making for implementing the TSLP and monitoring of a child's end-of-life care.

Data Analysis

Empirical material was subjected to Bardin's content analysis.¹⁴ The objective was to present what lies behind the manifest content, transcend what is said, and articulate the factors that determine the narrative. In this study, the first step (pre-analysis) consisted of mapping the information to be analyzed, ie, the records of semi-structured interviews. The second stage (exploring the material) consisted of reading the material and selecting a textual corpus that answered the research question. Finally, for the third stage (results treatment), the process of identifying recurring narratives in nurses' speech and interpretation was used.

Participants of the Study

A total of 25 nurses participated in the study. All nurses were female and had at least 5 years of experience in PICU. Age average was 40 years old in Hospital 1 and 45 in Hospital 2. They monitored the deaths of 16 children in the PICU: 12 from Hospital 1 and 4 from Hospital 2. Of these, only 10 had

their TSLP recorded in their medical records. In this sense, 2 categories emerged: nurses' experience with the decision-making process in implementing the therapeutic support limitation plan for 10 children and the end-of-life care of 16 of them.

Nurses with at least 6 months of experience with the implementation of TSLP or monitoring the end-of-life of children admitted to the PICU, where the child had not undergone cardiopulmonary resuscitation (CPR) or brain death (BD) protocol, were included. Nurses who were on leave during the data collection period were excluded.

Setting

The study was conducted in 2 PICUs, which are referral centers in southern Brazil. The first has 13 beds, with an average of 350 admissions per year and an annual mortality rate of 9.6%. The second has 12 beds, with an average of 500 admissions per year, and the mortality rate varies between 7 and 10%. Both are linked to higher education institutions, being internships and teaching fields for students and residents in the field of healthcare.

Ethical Aspects

This study was approved by the research ethics committees of the hospitals, which were the setting for the research and guided by the ethical principles of anonymity, privacy, and confidentiality (number 0063.0.002.001-08).

Results

Two categories emerged: the nurse and decision-making process of the TSLP and the ambivalence of participating nurses' feelings in the implementation of the TSLP. These categories are interrelated in the sense that the decision-making process for the implementation of the TSLP mobilizes the ambivalence and feelings of the nurses who participate in the process.

To contextualize the involvement of these nurses, it is necessary to highlight that shift change constituted a fundamental moment for exchanging information about the children's end-of-life care plan. Of the 25 nurses, 69.21% became aware of the TSLP during that time, 19.23% acknowledged that this was the only opportunity they had to discuss the matter, and 23.07% associated shift change with the doctor's announcement. The second most relevant source was communication of medical duty, which was responsible for 61.53% of the information, with 26.92% being exclusive.

Therefore, there were few spaces for dialogue for nurses to elaborate the ambivalence of their feelings toward the decision-making processes. Participation in this research was when they reflected on their professional practice in view of this phenomenon.

Furthermore, the time period between the registration of the TSLP in the medical record and the moment of death ranged from a few hours to 5 days, which is an important factor for the implementation of physical and mental comfort care for the child and his/her family. This is because 5 days' waiting period for death can be considered a very long time that mobilizes feelings of anguish and fear in everyone involved in the process in a place where the culture has installed silence on the topic.

The Nurse and the Decision-Making Process Regarding the TSLP

The TSLP decision-making process is an ethical dilemma faced by PICU nurses because it may raise issues related to the patient autonomy of a child whose best interest may be to continue to invest in their cure. While it is recognized that the child is in the process of dying, as there is no possibility of recovery, nurses are faced with the omission of information when they interact with the parents to reduce their suffering.

[...]We skipped it to ease this situation for the parents because what was keeping her alive was the medication, it was the norepinephrine and the dopamine... and that's a dilemma. (E5)

However, when the nurse is involved in the decision-making process, they play the role of mediator of information about the TSLP. The dialogue between the medical team, the nurse, and the child's family was considered essential for the TSLP, since feelings of guilt and regret could arise if the team chose to implement the plan without fully informing the child's legal guardians.

Despite their active role in promoting dialogue, nurses' involvement in decision-making processes in end-of-life care emerges passively and consensually to the conduct defined by the medical team. There is a question regarding the maintenance of life support measures for children without the possibility of recovery; however, the dynamics of legal competences are a point of impasse and doubt in the team. The lack of effective and clear communication between the team and parents raises another ethical issue: How well informed the child's legal guardians are to participate in such decisions.

I talked to the doctor, and she said that I had no legal authorization to do this (suspend the vasoactive drugs), so I went back there and explained... to the parents. And, she (the doctor) was right not to have changed anything at that time, even because the mother might regret it and accuse the doctors, the team, of having hastened the death...(E11)

As the child progresses in the end-of-life care, parents undergo feelings of acceptance of their child's death. They also are faced with issues like authorizing the start of the

TSLP protocol, life maintenance treatments based on clinical assessment by the health team, and consent. Parents were not well informed about the child's prognosis and the impossibility of cure; therefore, they draw this information from their observations of uneasiness and tension among health professionals.

[...]Until the point came that they themselves, the parents saw: look, turn it off because that's what's holding him here. Let's end his suffering... (E107)

[...]So much so that in the middle of the night the mother called me, and she said that she understood everything that was going on and that the heart still continued to beat because of the drugs [...] And she asked me to talk to the doctors to suspend all these medications...(E11)

Thus, the decision-making process for implementing the TSLP involves 2 professional categories (physicians and nurses) and the child's family.

Ambivalence of Participating Nurses' Feelings in the Implementation of the TSLP

Nurses experienced feelings of guilt when they realized that the child would die and that there was no longer any therapeutic possibility. Therefore, they sought tranquility and acceptance through the exercise of faith, in which the decision to end the child's life was part of a greater being and not of the health team.

So sometimes, we also feel guilty for waiting for her to die, even though you know that at that moment you have nothing more to do for her, so what you end up doing is sometimes praying... Because you don't know, you have nothing else to say, so let someone up there decide the right moment. (E6)

From this perspective, the decision-making process beings with the family. Chronicity of the disease becomes a way of accepting the child's end-of-life process with greater tranquility. Nurses reported that the frequency of the child having to avail health care services prepares the family to trust the medical team and accept the child's final course of life.

I think that, if I was a child with a chronic illness, who had already been admitted to the ICU several times, the family would be already familiar with the team. So, when the therapeutic limit is reached, the family would demonstrate confidence in the team and calmly accept the loss of this child. [...] (E9)

Despite the family's acceptance, the decision-making process arises amid the ambivalence of feelings in nurses who rationalize the TLSP implementation process as a limitation of life support, with death as a way to promote patient comfort.

...we are limiting life support, but at the same time we are giving comfort to the patient. (E5)

The rationalization of feelings helps nurses work internally in the process of accepting the child's death, as they use scientific knowledge to promote end-of-life care for these children.

Discussion

Decision-making process in the implementation of the TSLP involves the participation of 3 actors: nurses, medical teams, and families. The nurses' role consisted of mediating information between the medical team and the family, owing to their scientific knowledge of the TSLP, the child's clinical condition, and the family's experiential aspects during the child's end-of-life care process.

Despite actively participating in this dialogue, the nurses had few opportunities to discuss the TSLP, with the shift change being an opportune moment to deal with an issue that constitutes an ethical dilemma.

Studies have shown that feelings of frustration are common among nurses who feel excluded from decisions about patients and families under their care. Studies show that a significant percentage of nurses entertained the idea of leaving the profession due to the moral distress caused during decisions to suspend life support treatment. They vocalize their ambivalence regarding what they feel they should do and what circumstances allow them to do so. Therefore, they experience moral stress in acknowledging that the decision to implement the TSLP in a child's life may cease every chance of recovery.^{15,16}

However, the relationship and communication between patients and their families with the multidisciplinary team are the main elements to improve the decision-making process regarding the implementation of the TSLP and related end-of-life care. Clear dialogue and high-quality information reduces the suffering experienced by children, families, and professionals, offering a space of comfort and care within the PICU for the dying process.¹⁷

In this study, the uncertainties that marked the decision-making process for the implementation of the TSLP may have contributed to the elaboration of grief by the family, who, when they felt prepared to accept the child's non-recovery, took the initiative to request the cease of curative treatment. In this sense, the elaboration of feelings and the possibility of rationalizing death as a measure of comfort for the child allowed the family and the nurse to experience feelings of tranquility flowing from acceptance of the impending death.

The bond established by some families of children with chronic conditions was identified as a facilitator in the decision-making process, as the family established a relationship of trust with the team that took care of their child.

Trust forms as a sacred bond between the child, their family, and nurses, as it favors dialogue and builds pacts of

silence. Even when there is an established bond, talking about the process of dying and the need to decide on the TSLP is difficult and permeated by the unknown emotions about the meaning attributed to death.¹⁸

After arriving at the decision for the requisite TSLP, time feels prolonged and feelings of regret emerge in relation to waiting for death. For intensive care professionals, this feeling may be associated with failure to recover the child's life. If, on the 1 hand, they deal intensely with the theme of death in their work routine, they are also the ones who most resist recognizing death as an inexorable fact of existence.¹⁹

There are records of Australian, Vietnamese, and Spanish nurses who face difficulties in managing end-of-life care, since death instills feelings related to their own finitude.^{20,21}

In this sense, nurses must be prepared not only scientifically, but also emotionally for the decision-making process in favor of the child's best interest, which, in the absence of cure, can be the implementation of the TSLP.

The limitation of the study lies in the use of a convenience sample; therefore, there was no power calculation to convey the sample.

Conclusion

Nurses' participation in the decision-making process about the TSLP is punctual and is consensual in relation to medical definitions. There are few spaces for dialogue between nurses and other members of the medical team, resulting in bilateralism of decisions between physicians and families. Despite this, the nurse emerges as a person capable of mediating information between the medical team and the family and is the key person in promoting dialogue during decision-making.

In this sense, it is important that nurses occupy decision-making spaces in this context, since the lack of participation can result in isolation and moral suffering, translocating the responsibility of decision-making at the end of the child's life to a greater being and not for the medical team and their family.

The starting point of communication between the health teams consists of acquiring information about the child's end-of-life care plan, where there is absence of cure, with some form of therapeutic limit admitted to the PICU. Therefore, this study contributes to mapping possible research gaps regarding the moral distress of nurses in other parts of the world, end-of-life decisions in different cultures, and what it means ethically to health professionals as well as pertaining to the subject. We intend to mobilize researchers to build educational materials, protocols, and comprehensive care tools that can be used by nurses when faced with ethical dilemma like in cases of decision-making that relates to implementing the TSLP.

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