

Advance directives in the context of pediatric intensive care nursing

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Abstract

The objective of this study was to analyze the knowledge and practices of the pediatric intensive care nursing team regarding advance directives. This qualitative research was developed through semi-structured interviews between February and April 2023 with five nurses and eight nursing technicians. The data were subjected to content analysis whose results characterize the knowledge of the nursing team related to advance directives in intensive care and related topics, such as the autonomy of the child and their family, the child's wishes and desires, and respect for the family's wishes. In conclusion, even with facilitating and hindering points for applying the directives, the empathy and sensitivity of nursing professionals towards the wishes and desires of the child at the end of life and respect for the wishes of family members regarding the child are perceived.

Keywords: Advance directives. Hospital care. Intensive care units, pediatric. Ethics, nursing. Personal autonomy.

Resumo

Diretivas antecipadas de vontade no contexto da enfermagem intensiva pediátrica

O objetivo deste estudo foi analisar saberes e práticas da equipe de enfermagem de terapia intensiva pediátrica acerca das diretivas antecipadas de vontade. Trata-se de pesquisa qualitativa, desenvolvida entre fevereiro e abril de 2023 com cinco enfermeiras e oito técnicas de enfermagem, por meio de entrevista semiestruturada. Os dados foram submetidos a análise de conteúdo cujos resultados caracterizam o conhecimento da equipe de enfermagem relacionado às diretivas antecipadas de vontade em terapia intensiva e temas relacionados ao assunto, como autonomia da criança e sua família, desejos e vontades da criança e respeito aos desejos da família. Conclui-se que, mesmo com pontos facilitadores e dificultadores para a aplicação das diretivas, percebem-se a empatia e sensibilidade das profissionais de enfermagem perante desejos e vontades da criança em terminalidade de vida e respeito aos desejos dos familiares com relação à criança.

Palavras-chave: Diretivas antecipadas. Assistência hospitalar. Unidades de terapia intensiva pediátrica. Ética em enfermagem. Autonomia pessoal.

Resumen

Directivas anticipadas de voluntad en el contexto de la enfermería intensiva pediátrica

El objetivo de este estudio fue analizar los saberes y prácticas del equipo de enfermería de cuidados intensivos pediátricos acerca de las directivas anticipadas de voluntad. Se trata de una investigación cualitativa, desarrollada entre febrero y abril del 2023 con cinco enfermeras y ocho técnicas de enfermería, por medio de entrevista semiestructurada. Los datos se sometieron a análisis de contenido, y el resultado caracteriza el conocimiento del equipo de enfermería relacionado con las directivas anticipadas de voluntad en cuidados intensivos y temas relacionados con el asunto, como la autonomía del niño y su familia, los deseos y voluntades del niño y el respeto a los deseos de la familia. Se concluye que, incluso con puntos facilitadores y obstaculizadores para la aplicación de las directivas, se percibe la empatía y la sensibilidad de los profesionales de enfermería ante los deseos y voluntades del niño al final de la vida y el respeto a los deseos de los familiares con relación al niño.

Palabras clave: Directivas anticipadas. Atención hospitalaria. Unidades de cuidado intensivo pediátrico. Ética en enfermería. Autonomía personal.

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The end of life is a complex and complicated subject to address and is currently considered taboo, as it gives rise to many different perceptions and opinions. Furthermore, over time, advances in the well-being of terminally ill patients have extended the lifespan of countless people. In this context, the autonomy and dignity of terminally ill children are elements that guide decision-making at the end of life, a complex and challenging period for both the child in the process of dying and for others involved¹.

At the end of life, as at any other time, human dignity must be respected, and the patient must be involved in the decision-making process regarding their care and treatment. Concerning children, autonomy is exercised by the family or a legal guardian, always seeking the patient's best interests^{1,2}.

Advance directives of will (ADW) emerged to alleviate suffering at the end of life. These instruments help family members deal with the patient's illness and death and offer a better option of conduct for healthcare professionals. ADWs aim to protect the patient's autonomy, guaranteeing the patient's right to be informed about their health condition, to choose the treatment they will undergo, and to allow or refuse procedures and therapies.

In Brazil, ADW are little known, and in the case of children, consent is always obtained by family members and/or legal guardians, who always seek the child's best interests. In addition, communication between the family and healthcare professionals is essential, so that they can inform and advise the family³⁻⁵.

Concerning ADW in pediatric patients, studies with healthcare professionals that investigated care experiences have shown that ADW reduce the trauma of discussions about end-of-life decision-making related to parents and professionals. Furthermore, it is vital that the team is fully involved and informed about the patient's health status to discuss ADW with the family when making decisions, sharing responsibilities in the child's therapeutic decision, and enabling a dignified death⁶.

The pediatric intensive care unit (PICU) is structured to treat complications and care for children with health problems requiring intensive care treatment and monitoring by trained professionals to speed up their recovery. With the evolution of medicine and technological advances, there is a greater chance of curing these diseases. However, many chronic conditions still do not respond to this type of treatment and require the PICU team to adopt a new perspective of care, palliative care (PC)⁷.

Pediatric PC prevents, identifies, and treats children suffering from chronic, progressive, and advanced diseases, and also includes the family and the care team². It should be initiated immediately after diagnosis, prioritizing the relief of suffering and pain control, always preserving the autonomy and will of the child and their family. Given that the main objective of PC is to provide quality of life for the child and their family, the nursing team needs skills that involve care management, enabling parents to remain with the child and respecting the wishes and desires of the parents regarding the care that involves the child⁷.

Therefore, the ADW and PC approaches have similar objectives. Both aim to guarantee patients a dignified death, followed by respect for their choices, and seek to reduce the impact of the difficulty instituted at the end of life. Respecting the patient's wishes and fears during death ensures autonomy, provides human dignity, and alleviates pain and suffering⁸.

The end-of-life process can cause unforeseen events that the people involved must deal with. Therefore, the physician must explain the child's health condition to them and their family, informing them of what can be expected as the disease progresses. In addition, welcoming and truthful communication between family members, the attending physician, and the nursing team involved in the child's care is vital so that their stay in the PICU is less traumatic and allows them to define their ADW⁹.

The main difficulties in implementing ADW are the lack of communication between professionals, family members, and patients, the absence of institutional protocols, the difficulty

in mentioning the end of life, and the lack of specific legislation¹⁰. The lack of understanding of healthcare professionals about ADW, end of life, and PC can cause them to take obstinate actions, prescribing treatments that do not bring comfort and quality of life to the child. The fact that there is no legislation on ADW, in turn, creates insecurity among professionals, who fear legal action by families, which ends up prolonging the process of dying without quality of life⁹.

From this perspective, this study aims to analyze the knowledge and practices of the PICU nursing team regarding ADW.

Method

This is a qualitative, descriptive, and exploratory study developed according to the precepts of the Consolidated Criteria for Reporting Qualitative Research (COREQ) guide. The data presented come from a matrix research developed by a study group from a private higher education institution in southern Brazil. The study was conducted in the PICU of a private hospital in the northeast region of Rio Grande do Sul, Brazil.

Thirteen female professionals (five nurses and eight nursing technicians) aged between 23 and 57 participated. All nurses reported having a specialization: only one had two specializations, one in women's health and the other in intensive care units. Among the others, one is a specialist in emergency care, and three are in intensive care. Among the nursing technicians, only one reported additional intensive care training.

The selection was intentional and non-probabilistic, based on the following inclusion criteria: being a nursing professional, having at least one year of professional experience in the study setting, having experienced intensive care practices, and having improved knowledge. The exclusion criteria were being on leave, on vacation, or away from work during data collection.

Data collection occurred from February to April 2023 through semi-structured interviews

conducted by one of the research authors in a reserved space in the hospital institution where the participants worked on previously scheduled days and times.

A script was prepared for the interview with closed questions to characterize the sociodemographic profile of the participants, as well as semi-structured questions, such as: What do you understand about the patient's right to autonomy? How do you act when dealing with a patient in PC? What do you understand about ADW? How do you develop nursing work responding to patients' wishes and desires? Does the family participate when the patient expresses these wishes and desires? Do you have the ability to care for the patient according to the wishes and desires expressed by the patient and/or their family member?

The interviews lasted between 10 and 78 minutes. They were recorded in audio and transcribed verbatim using Transkriptor software. The material was later reviewed to ensure the accuracy of the information.

The data were interpreted according to Bardin's content analysis in the thematic modality. First, the material was pre-analyzed and explored, with readings and organization of the findings, to identify the units of meaning that responded to the object under study. At this stage, these units met the criteria of exhaustiveness, representativeness, homogeneity, relevance, and exclusivity. Finally, the data were processed and interpreted based on the relevant literature.

The participants signed the informed consent form and were informed about the research's risks and benefits and all other ethical aspects that permeate it. Anonymity was guaranteed by using the alphanumeric system to identify the interviewees: the letters N (nurse) and NT (nursing technician), followed by a number according to the order of the interviews.

Results

The categories presented below emerged from the participants' speeches and represent the nursing team's experiences regarding ADW.

Conceptions about advance directives of will

Nursing professionals' understanding of ADW is related to patients' wishes regarding the care practices they wish to receive. In pediatric intensive care, parents are noted to specify the care they want or do not want for their child.

"(...) it is when the person leaves in writing what they want (...). What they want or do not want to be done. And with children, we do this with the parents" (N1).

"It is very much related to what the patient wants and what they do not want, and we have to respect and do what they want" (NT1).

"What they ask for beforehand or communicate beforehand that they would like to be done" (NT3).

"We give the patient the opportunity to tell us how far they want us to go while they are still alive" (N5).

Relevant information is presented in a participant's speech when she describes her need for medical approval to maintain the family member's wishes and desires in the care provided to the child.

"The father and mother, they can decide, they can define, but according to the physician (...)" (N4).

In the PICU, the parents' permanence and involvement in care can be perceived as a unique moment in which these subjects, equipped with rationality, evaluate the context of their child's terminal life and decide on restrictive care or life-sustaining conduct. In practice, the applicability of ADW can be identified:

"The family said: I don't want you to do this or I want you to do everything (...) when we have this conversation about whether it will be investible or not (...)" (N1).

"We let the parents be present during a cardiac arrest, and they asked to stop, not to do it anymore. And the physician respected that" (N4).

Child autonomy in palliative care

In the understanding of nursing professionals, the child's autonomy is defined by the child's right and desire for certain care. This can be linked to food preferences, entertainment, or even using utensils with emotional meaning.

"When the patient has the right and 'ah... I want this, I don't, I don't want this, I don't want that'. I think it has more to do with that" (N1).

"His right to express his wishes and allow him to say how far we can go as well. In the case of children, we can think that respecting their wishes is even like this: providing the cartoon he likes, respecting the meal he eats, and the times he eats" (N5).

"We listen to what the patient has and wants; we try to make the most even of the food" (NT1).

"It is a right to what they choose for that moment" (NT3).

"Right to autonomy and what they can do on their own" (NT4).

On the other hand, some participants reported that the child's autonomy is entirely linked to the parents' decisions. The child has not yet developed speech or demonstrated discernment or maturity to understand the complexity of their health disease process. Based on this, the child has limited autonomy to express wishes and desires.

"Autonomy actually involves the parents a lot. (...) it's about respecting the mother's opinion" (N3).

"The father and mother have autonomy (...) because in the past the father and mother practically didn't come in to monitor the procedures, and today we know that they have the right" (N4).

"In this case, we here... since these are patients who haven't made any decisions yet, so we respect the parents' decisions" (NT2).

"Autonomy is when the patient can make a decision, but since we are dealing with children, we usually always ask the parents" (NT7).

"(...) The family has autonomy over the child and over what should be done for them at that moment. Whether we can or cannot do things, the family is the one who decides at that moment for everything" (NT8).

Regarding the participants' perception in daily practice, given the child's wishes and desires during hospitalization, simple care was highlighted, such as the desire to eat, drink, draw, or even watch something.

"There was a child of about five years old who had an enteral feeding tube, but he really wanted to drink a grape Fanta, and we went there and bought it" (N1).

"Here in the pediatric ICU, they ask for videos (...). Several times we have printed little animal stickers for them to color (...). All the cubicles have a TV, and they really like to watch DVDs" (N4).

"We deal with children. Sometimes we can't let them do everything they want, but we can respect them, sometimes even the simple act of letting them go to the restroom to pee in the toilet (...) so sometimes providing this care, letting them have a moment of privacy, right? Going to the restroom alone" (N5).

"She asked us for an ice cream, and we promised we would give her the ice cream and the hospital freezer was locked" (NT4).

"There are children who ask to draw a lot, so we print out drawings and get pencils (...) then they color" (NT7).

"He was about four years old, and the physical left a ball there for him to play with, and the ward was very calm, there were few patients (...) and I went into the cubicle, he threw the ball to me, and I threw the ball to him" (NT7).

"If he doesn't want it, he doesn't want it. We can't force him to do things, and then, if he wants to eat, we do everything we can to give him something, especially when he's a child" (NT8).

Significant information presented is the importance of the mother's involvement in child care. The maternal role in the context

of child care in PICU is perceived through bonding and trust, which favors nursing care since there is a relational estrangement between the professional and the child.

"When it's time to administer medicine, he doesn't like the team to administer it, but when the mother administers it, even though it's not recommended (...) to also involve in the care whomever he wants to take care of him in this care" (N5).

Respecting the family's wishes in the context of care

In the PICU, the involvement of parents in care is of significant importance since they live with the child daily and, therefore, are aware of all of their peculiarities. Because of this, it is necessary to respect the wishes and desires regarding the care they allow or do not allow to be performed on the child.

"(...) something really ridiculous: we would bathe her and sometimes braid the hair, and her mother didn't like it. So, her mother told us, and we didn't do it anymore" (N1).

"Regarding food, we always ask the father if he allows it. The other day, a child was celebrating his 2-year birthday and we wanted to make a cake, a cupcake. So we asked the father if he could eat it or not because some people don't allow their children to eat sugar. So, we asked him before bringing it and showing it to the child, anyway" (N1).

"He was a resident here at the hospital; he was breathing with a ventilator and had a gastro[stomy]. So we organized a little birthday party with his mother. We decorated the bed, took pictures, and the mother brought us a piece of cake" (NT7).

"Some parents have refused to let us puncture, give them medication, or do something" (NT7).

"There was a child who wanted to play video games, so we inquired the infection control and the father was allowed to bring the video game

from home. A TV is in the cubicles, so the video game was allowed" (NT7).

"We always try to involve the mother in the care: 'Look, we're going to do this, can you help us? We're going to change the position. Can you help? Can you hold their hand or head or foot?' So, we always try to pull them along. So they feel safe too and know we are doing our best at that moment" (NT8).

A notable statement is made by a nursing technician when she refers to the affection that children and their families develop for healthcare professionals during their hospitalization and how they include them in their daily routines.

"(...) That day, his parents, knowing he had little friends there, asked the three of us to be in the room with him. They would always pass by in the hallway, call, and play with us. His father also said, 'He really liked you guys; it's only fair that now that he's leaving, he has some little friends here with him'" (NT3).

Discussion

Regarding the nursing team's knowledge of ADW, most nurses interviewed were noted to understand the term. ADW are defined as a preliminary tool through which patients express their wishes and desires regarding the treatment they wish or do not wish to receive when they cannot freely and independently express their wishes⁹.

Children's legal guardians should decide unless there is proof that they are not acting in the child's best interests⁸. However, the child's progressive autonomy and wishes should be considered as their intellectual development advances.

In matters involving more immature patients or those with impaired judgment, including them in decision-making is advisable, even within a specific limit⁵. Given this perspective, it is possible to state that nurses have the necessary knowledge to apply ADW within the PICU.

Nursing technicians were not aware of ADW, but they referred to the patient's autonomy. Choosing what to do or not to do in the treatment of patients at the end of their lives is still a dilemma since ADW are little known among healthcare professionals in Brazil. Barriers that complicate the fulfillment of patients' wishes and concerns can hinder the implementation and approach to ADW.

The main difficulty encountered is the lack of institutional protocols, which makes discussing the subject with professionals and family members who may not be aware of ADW difficult. Furthermore, the lack of knowledge on the subject by professionals, the difficulty in talking about death, and the obstacles imposed by the family are also factors that hinder implementation⁸.

The lack of institutional protocols involving ADW explains nursing technicians' lack of knowledge about the term. This is associated with the difficulty of discussing the subject with other professionals and with the family, making it challenging to apply it in the PICU.

The practice of patient autonomy in the PICU was reported with great uncertainty, as the nursing professionals were divided in their statements. Some reported that the child's autonomy may be linked to desires and simple day-to-day care. The rest stated that autonomy is entirely linked to family members since the child is not yet mature enough to decide for themselves.

In the PICU, the patient's autonomy is absent or restricted, so legal guardians are responsible for the child's interests until the child reaches the level of development and maturity that allows them to participate in decisions about their life care¹¹.

Human dignity and autonomy must be respected at the end of life, as at any other time. Thus, while a child's understanding may change with age and the stages of cognitive development, it must be valued and respected at all times of life¹².

Aiming at dignity and avoiding suffering at this time, there is a growing incentive to discuss such matters with the child's legal guardians and

to plan shared decisions with the health team⁶. Multidisciplinary interaction is a facilitating factor that promotes spaces for discussion and the possible feasibility of ADW.

When asked about the patient's wishes and desires during hospitalization in the PICU, the professionals demonstrated great empathy and sensitivity and reported simple nursing care practices. The nursing team working in the PICU faces daily situations that demand reflection and a return to the principles of bioethics. Understanding the end of life and accepting death is essential to conducting professional actions within the PICU¹³. When the nursing team can provide comfort through the care provided to the patient at the end of life, it establishes itself as a facilitator for applying ADW.

Regarding the wishes of family members about the care of the child at the end of life, all participants demonstrated understanding and comprehension of all requests made. Communication between the nursing team and the family within the PICU is vital and must be carried out clearly, effectively, and with very specific communication. This reduces the feelings of insecurity and anxiety of the family, making the bond between the team and the family more substantial and more satisfactory^{5,6}.

To improve care, the team must combine its skills to help the patient adapt to the life changes imposed by the disease, enabling moments of interaction between the patient and their family so that the child changes their thinking and does not think only about the disease. It is vital that the nursing team performs comforting actions and basic care that the child needs to fulfill the patient's wishes and desires¹⁴.

The participants mentioned the mother's involvement in the simple day-to-day care of the child in the PICU as a way of bringing together people who have an affinity with her. In addition, it strengthens the maternal bond with the child since the mother spends most of the time with the hospitalized child.

Some physicians act problematically when faced with the family's wishes regarding the child at the end of life, as they do not respect

the family's autonomy in this situation. Deciding the best care and treatment for the patient should not be treated only as a technical issue, as it is necessary to preserve the autonomy, rights, and dignity of the individuals in this situation¹⁵.

When the physician is aware of ADW, decision-making in cases of patients with terminal illnesses in an advanced stage becomes more straightforward and more comfortable since the professional better understands the need to respect the autonomy of the patient and their family. In addition, the professional can provide adequate information to the child and family about the prognosis and explain in detail the care and treatments available^{15,16}.

In pediatrics, end-of-life is a condition identified by a physician in a child or adolescent suffering from a critical and incurable disease¹⁷. In this context, family consent will always be an obstacle to the implementation of ADW since it is difficult to accept the interruption of the life cycle. Furthermore, under no circumstances will it be easy to convince the family that the best option for their loved one at this time is comfort before death⁶, so communication from healthcare professionals at this time is essential to explain the benefits and possibilities of treatment.

In the place where the research was conducted, there is still no palliative care physician working in the PICU or a PC team, which makes implementing ADW a challenge since the PC team reinforces the importance of these directives as a way of respecting the child's autonomy and promoting dignity in the end-of-life process. PC in nursing focuses on comprehensive patient care and involves everyone around them, such as family, caregivers, friends, and multidisciplinary team, aiming to reduce physical, psychological, and spiritual pain¹⁸. Still, the PC team allows patients to express their wishes and desires with the assurance that they will be met⁸.

In addition, the lack of legislation on the applicability of ADW is a challenge. In 2012, the Federal Council of Medicine¹⁹ enacted Resolution 1,995, which defines ADW as a set of prior wishes expressly expressed by patients regarding treatments and care they wish or do not wish to receive if they cannot decide

for themselves. Despite this resolution, no law addresses the subject, so ADW has no legal support and generates several discussions when applied⁴.

Concerning nursing, the Code of Ethics for Nursing Professionals determines that ADW must be respected²⁰. However, if the nurse feels insecure due to the lack of specific legislation, they can find support in Art. 22, which refers to the right to refuse to perform activities that do not offer safety to the professional⁴. The lack of legal support and the lack of knowledge on the subject by professionals is a challenge for the application of ADW since it can generate legal implications, given that letting a patient die can be understood as professional negligence.

Final considerations

Most of the research participants know ADW. Thus, the research objective is met since the participants understand what ADW is in

the PICU. Other terms related to ADW were also addressed, such as patient autonomy, end-of-life, respect for the wishes of family members, legislation, and bioethics.

In addition, points that facilitate and hinder the applicability of ADW in PICU were presented, contributing to nursing professionals' ability to guide patients and their families correctly and to the development of new research on the subject.


Despite the lack of knowledge of some participants about ADW and the lack of a PC team at the institution where the research was conducted, it was possible to observe the sensitivity and empathy of the nursing team regarding the wishes and desires of the terminally ill child. In addition, the team demonstrated respect for the requests of the family members regarding the patient. This makes it possible to provide comfort in daily care and comfort the family members, enabling and respecting their requests to offer a more serene and peaceful stay for the child and their family.

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Eduarda Regina Dal Pizzol organized and developed the research, article writing, and final review. Cléton Salbego was a researcher and co-advisor in all study stages and the final manuscript writing. Fernanda Gava Salcher participated as a researcher and advisor in all study stages and the final manuscript writing. Rossano Sartori Dal Molin participated in writing the final manuscript.

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