Process of dying in a pediatric intensive therapy unit

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Abstract

The recurrent experience of the nursing team in a pediatric intensive care unit is not enough to accept the death of a child, since they bring feelings like guilt, failure and denial of death. The objective of this study is to discuss how nursing professionals deal with the death and dying process, and identify the impacts caused during this process in pediatric intensive care units. The methodology chosen to conduct the research was qualitative and exploratory-descriptive, employing a content analysis proposed by Bardin. We conclude that there are some important gaps in the nursing process in dealing with death and dying in pediatrics. Dealing with this process is extremely painful and requires the pursuit of continuing education in health.
Keywords: Intensive care units, pediatric. Nursing. Death.

Resumo

Processo de morrer em unidade de terapia intensiva pediátrica

A vivência da equipe de enfermagem em unidade de cuidados intensivos pediátrica não é suficiente para aceitar a morte de uma criança, que gera sentimentos como culpa, fracasso e negação da morte. O objetivo deste estudo foi discutir como os profissionais de enfermagem lidam com o processo de morte e morrer, e identificar os impactos causados na assistência durante esse processo nas unidades de cuidados intensivos pediátrica. Optou-se pelos métodos qualitativo e exploratório-descritivo, utilizando a análise de conteúdo proposta por Bardin. Conclui-se que existem algumas lacunas importantes no processo da enfermagem ao lidar com a morte e o morrer na pediatria. Lidar com essas questões é extremamente doloroso e requer busca por educação permanente em saúde.
Palavras-chave: Unidade de terapia intensiva pediátrica. Enfermagem. Morte.

Resumen

El proceso de morir en la unidad de cuidados intensivos pediátrica

La vivencia del equipo de enfermería en la unidad de cuidados intensivos pediátrica no es suficiente para aceptar la muerte de un niño, la cual genera sentimientos de culpa, fracaso y negación de la muerte. El objetivo de este estudio fue discutir cómo los profesionales de enfermería lidian con el proceso de muerte y con el hecho de morir y, también, identificar los impactos causados en la asistencia durante ese proceso en las unidades de cuidados intensivos pediátricas. Se optó por los métodos cualitativo y exploratorio-descriptivo, utilizando el análisis de contenido propuesto por Bardin. Se concluyó que existen algunas lagunas importantes en el proceso de la enfermería al lidiar con la muerte en la pediatría. Lidiar con este proceso es extremadamente doloroso y requiere la búsqueda de una educación permanente en salud.
Palabras clave: Unidades de cuidado intensivo pediátrico. Enfermería. Morte.

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Declaram não haver conflito de interesse.

The end of life is an extremely complex, controversial and debatable subject, as it involves every person in all societies, since everyone sooner or later faces their own end of life. However, although humans fear death, in some circumstances it may bring relief with the end of suffering. As for health professionals, the death of a patient brings frustration, feelings of defeat and powerlessness[1].

The daily experience of the nursing team when attending to the dying in a pediatric intensive care unit (PICU) is not enough for the professionals to be able to accept the death of a child, since the end of a young life generates feelings like guilt and failure in the professionals, leading them even to the denial of death[2]. Although death is part of the daily life of health workers, it remains incomprehensible, especially in pediatrics, where dying is generally considered an unnatural event[3].

In 1998, the World Health Organization (WHO) presented a specific definition for pediatric palliative care: *active total care of the child's body, mind and spirit, and also involves giving support to the family.* According to the WHO, palliative care should begin when chronic disease is diagnosed and be developed concomitantly with curative treatment[4].

The scientific literature records the difficulty of professionals to accept child death as something natural 5. In a society that denies death, professionals lack the psychological attributes that help them to attend to the final stage of children and neonatal patients 1.

The main objective of this study is to identify the perception of nursing professionals regarding death and the process of dying, and as a secondary objective to point out the shortcomings, reinforcing the need for permanent education in this context.

Therefore, the research presents the following question: what is the perception of nursing professionals regarding death and the process of dying experienced in pediatric intensive care units?

Method

Qualitative exploratory-descriptive research was used, involving the participation of thirty nursing professionals, through a recorded, and later transcribed, interview, which was collected in four pediatric intensive care units of a large hospital in Curitiba, the capital of the Brazilian state of Parana. The collection instrument was a semi-structured questionnaire, with the following questions:

- How do you feel regarding death and during the process of dying?
- How do you feel about expected death and unexpected death?
- How can nursing care contribute at this time?
- What feelings did you experience during the process of dying and the event of death?
- After the death of a patient, do you have and/or need any support to face this loss?
- Do you understand the cause of death?
- Does this affect the work process?
- Does this affect the care of other patients?

The analysis of content [6] allowed the comparison between elements of the *corpus* (words or sentences) and the grouping of elements of similar meaning. Forming categories based on the instrument used, each topic was analyzed defining eight categories.

As the research involved human beings, the project was submitted for evaluation by the Comitê de Ética em Pesquisa (CEP - Research Ethics Committee) of Faculdade Pequeno Príncipe, in accordance with Resolution 466/2012 [7] of the Conselho Nacional de Saúde (CNS - Brazilian National Health Council), and the study was started after the evaluation and approval of the board. Participants were given the Free and Informed Consent Form and the objectives of the research were explained. In order to ensure anonymity and confidentiality, participants were identified by the words enfermeiro (E - Nurse) and técnico de enfermagem (ET - Nurse Technician), with ascending numbers according to the order interviews were conducted.

Results

Sample profiling

Twenty nurse technicians and ten nurses were interviewed, with only one male participant. The sample population also consists of 67% of respondents aged between 20 and 30 years, 20% between 31 and 40 years and 13% between 41 and 50 years.

The interviews were answered by professionals working on the following wings of the four pediatric intensive care units: 30% in the general units; 30% in cardiology; 20% in the neonatal unit; and also 20% in the surgical ward.

The analysis of the statements' content was done according to the instrument, distributing the statements in eight categories, subdivided by divergent answers between nurses and nurse technicians, presented in Table 1 - Categorization of Questions and Answers.

Table 1. Categorization of questions and answers

Categories		Answers
How do you feel regarding death and during the process of dying?	Common	Difficulties in dealing with the patient and family Empathy with the family during the process of dying and death
	Nurse	Powerless before death / acceptance
	Technician	Powerless before death / non-acceptance
How do you feel about expected death and unexpected death?	Common	Acceptance
How can nursing care contribute at this time?	Common	Nursing care and family support
	Nurse	Understanding therapeutic limits
	Technician	Without understanding the therapeutic limits
What feelings did you experience during the process of dying and the event of death?	Common	Sadness and anguish
After the death of a patient, do you have and/or need any support to face this loss?	Common	Difficulty in expressing feelings
Do you understand the cause of death?	Nurse	Understand the complications and evolution of the condition
	Technician	Do not understand the complications and evolution of the condition
Does this affect the work process?	Common	Affects the working climate
Does this affect the care of other patients?	Common	No, or no longer affects Affects the work environment Provides perspective on the work done
	Technician	Works demotivated

Category 1: How do you feel regarding death and during the process of dying?

The participants' responses showed how nursing professionals felt regarding death and during the process of dying, and were divided into four subcategories. Regarding the difficulties in dealing with patients and their families, empathy and feelings of powerlessness, there was no difference in the narrative between nurses and technicians. As for the sense of being powerless followed by the acceptance, or not, of death, there was divergence between the narrative of technicians and nurses.

Difficulties in dealing with the patient and family

"*Very sad within the work environment* (...) *Of course at home, in the family, it's another feeling, but, here, over time we end up getting attached to the children, and it's very sad for us too, because here we too are one family*"(TE7).

Empathy with the family during the process of dying and death

"*I suffer for the patient, I worry about the family, I feel the pain of the family as if it were mine. This process is very sad*" (TE17).

Powerless before death / acceptance

"(...) *We feel a bit powerless. We are here doing everything for the patient to go home, and when we do not have this, the disease causes the patient to not have a good prognosis. This is a bit sad as a professional and as a person* (...) *we must be strong to give strength to this family at this moment* (...) *we are here to help. Whatever we can do for the patient to die well, we are always doing*"(E10).

Powerless before death / non-acceptance

"*Actually, as health professionals, we never want to lose, never, you never ever want to lose* (...) *It's the same as parents who never want to lose, but we do everything we can, do you understand?*" (TE4).

Category 2: How do you feel about expected death and unexpected death?

When questioned about how they feel about expected and unexpected death, there was disagreement among professionals. For the nurses, it is easier to accept the expected death; on the other hand the nurse technicians said that they find it easier to deal with unexpected death:

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Acceptance

"With expected death, we have time for the family to be able to say goodbye to the patient" (E6);

"With the expected, I think you suffer before, during and after, you will always suffer. And with the unexpected not; it happens at that moment, and you were not expecting it (...) It hurts more" (TE11);

"The unexpected is easier for us to endure than the expected because, with the expected, you already know that this child may no longer be there on your next shift" (TE8).

Category 3: How can nursing care contribute at this time?

Divided into three subcategories, the narratives on nursing care were unanimous in pointing out measures to support and comfort the family. The understanding and respect for the therapeutic limits were also emphasized, since, from the point of view of the nurses, there are limits to what is possible to do within what is acceptable. The nurse technicians presented a different perspective, which was highlighted in another subcategory and indicated lack of understanding of the therapeutic limits, revealing the effort to overcome the inevitable end to the last consequences:

Nursing care and family support

"I think that, in general, it provides comfort for the patient, in a way, a farewell without pain, without suffering. And for the family, a more psychological, emotional comfort (...)" (E1).

Understanding therapeutic limits

"If there is something within the therapy that can help, like analgesia, some medicine to relieve this suffering, I think the nurse can discuss with the medical staff a way to relieve the pain or any suffering that this patient is going through (...)" (E1).

Without understanding the therapeutic limits

"Nursing care is you giving comfort, trying to relieve if there is pain, until the last moment, you trying to do everything possible so that the patient does not die (...)" (TE).

Category 4: What feelings did you experience during the process of dying and the event of death?

This category revealed that nursing professionals suffer by attending to the death and dying of patients, as presented in the subcategory:

Sadness and anguish

"It is sad, death is always sad, even more so for a child ... Sometimes you try not to cry in front of the father and the mother, but there is no way not to cry" (TE10);

"I have already experienced some deaths. Some of them affect you more, others affect you less, but they still affect you. We end up becoming sad"(E10).

Category 5: After the death of a patient, do you have and/or need any support to face this loss?

Difficulty in expressing feelings

"Depending on my sadness, on how much I get attached, there is no way to avoid crying (...) I cry, go to the bathroom, drink some water, try to breathe (...) And I try to put in my head, in my heart, that it was what had to happen" (E8);

"I do not need it, but it shocks you. The day ends there; it's hard for you to recover and continue like this" (TE11).

Category 6: Do you understand the cause of death?

The understanding of the cause of death differs at each professional level, generating two subcategories that can be associated with professional training:

Understand the complications and evolution of the condition

"Yes (...) it is thoroughly discussed during the multidisciplinary visit (...) and I can understand the pathologies and reasons very well. For me, this part is well resolved" (E6);

Do not understand the complications and evolution of the condition

"We're always going to end up questioning: why so young, so small ... it was such a simple thing. Some things I'll never understand (...) Was it the mother's fault? Was it the fault of the nursing staff? Whose fault was it? Sometimes there is not a culprit, but we will always question" (TE7).

Category 7: Does this affect the work process?

The first response to the question is negative, and suggests that attend the death of patients does not affect the professionals. However, during the course of the testimonies, it becomes evident that, in some way, the work process is affected.

Affects the working climate

"*It affects the whole team (...) When there is a death, it is different, the day becomes different. If it is a child you dealt with for a long time, the week becomes different (...) I think it affects, but of course you get up and carry on worrying about the other children; you try to protect the others even more*"(TE2).

Category 8: Does this affect the care of other patients?

Regarding consequences, influences or interferences for the nursing professional when accompanying patients' process of dying and death, four subcategories were identified.

Does not affect

"*No. It has already affected, but now it no longer affects*"(TE6); "*For me no, it does not affect (...) The team understands that the patient has rested, died, but we must continue because there are other patients who need us (...)*" (E22).

Affects the work environment

"*I think so. For example, when you have two patients, side by side. The mother of one has just seen her friend's son (...) die, and she will also see it in you. I think the impact is on everyone, the team, and the other mothers...*" (TE5).

Provides perspective on the work done

"*I cannot tell if it affects it directly, but you're always aiming to be strong and to take better care of the other patients, to try again*" (TE2).

Works demotivated

"*We try to keep our composure, but we get very sad (...) We get kind of down. It should not affect us, but there is a sadness in our heart ... I think our performance could be better (...)*" (TE14).

Discussion

The study showed that, for nursing professionals, the longer the time of contact with the pediatric patient, observation of the child's development and interaction with the family, the greater the difficulty in accepting the patient's death. Scientific literature corroborates this finding, indicating that familiarity is sufficient to establish a bond so that the loss of the other results in suffering, making it part of the routine of the nursing professional to attend to the suffering of the person receiving the care, thereby sharing the

moments of pain and sadness with the family [8,9]. In pediatrics, this involvement is even more intense [8].

This process significantly affects the lives of nursing professionals. The way each of them seeks to understand death and accompany the patient, according to their professional experiences and personal beliefs, makes a difference in the form of coping. Studies show that, over time, the routine of experiencing painful experiences generates defense mechanisms that prompt professionals to try to remain indifferent to the circumstances that previously afflicted them [3,8-10]. Thus, as in society, which attempts to ignore death in daily life, nursing reproduces this defense mechanism.

The analysis of the statements from the nurse technician team shows that these professionals are even more unprepared to deal with patients' deaths. Often their training is exclusively technical, and it is restricted to care focused on healing, without a greater contextualization of the patient's physiological dimension or the philosophical, social and spiritual perspective of the health-sickness process, aiming at curative assistance and neglecting care in its entirety.

Studies show that, when faced with the death of a child, one experiences several feelings, and powerlessness is the most common among nursing professionals [3,11-13]. The difficulties of coping with death and dying in care emphasize the need to reflect on professional training and the importance of including the topic of "death" in the disciplines of health courses, especially in nursing [9]. It is necessary to have philosophical discussions and to approach the technical aspects regarding the care provided to patients who have no possibility of a therapeutic cure.

The discussion during technical training and higher education is essential to assist professionals in providing care to patients and to understand the topic and nursing care without themselves being severely affected by the situation. Faced with death, nursing professionals, especially nurses, try not to show feelings related to their own frailty, because they believe that if they do, they will convey insecurity to the grieving family. Therefore, in order to reinforce the image of their professional competence and to support the family, conveying trust and ensuring support, professionals tend to hide their own suffering [13].

Although dealing with the death of patients is difficult for nursing, in general, expected and unexpected death were understood in different ways. It was revealed that the variation is indicated

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by the difference of professional category, but also reflects the way in which each team faces the process of dying and death, considering, also, the past experiences of each person.

Unexpected death is more difficult to overcome because it often involves feelings of frustration, especially in cases in which the child has a good prognosis [3]. In the case of expected death, there is a period of evolution, albeit slow or fast, to face the process.

The way each member of the nursing team understands the role of care also varies according to their professional category and personal experience. Research has shown that participants consider care in general, as well as family support, to be important. Understanding the value of nursing care [14] requires an ethical conception, of respect for the other in their totality, since care consists of perceiving the suffering of others and adopting measures to allay it.

There was no consensus among nurses and nurse technicians regarding whether or not to prolong the suffering. For the former, in addition to measures of comfort, it is essential not to perform unnecessary procedures, especially when they only prolong the suffering of the patient. On the other hand, from the perspective of the nurse technician, comfort measures are important, but measures adopted to prolong life should always be considered, taking into account all possibilities.

There are varied feelings while dealing with the death and dying of patients. Studies point out [3,11-13] that compassion, indifference, powerlessness, anxiety, guilt, denial, emotional involvement, empathy, anguish, and sadness are the most common feelings among nursing professionals. In accord with scientific literature, this research revealed that the interviewees also suffer while dealing with patients' death process.

Nevertheless, it is worth making a small digression on how this suffering can be identified, since the interviewees, at least at first glance, did not admit to the problem. However, when asked about the feelings that the situation caused them, the most cited were sadness and anguish. This paradox allowed us to identify the difficulty implicit in the narratives of nursing professionals when expressing their feelings, associated, according to the scientific literature, with feelings of insecurity and failure [13]. This interpretation reinforces the fact that the interviewees affirm the need for support to face the situation.

Regarding the understanding of the cause of death, the answers differ according to the professional category and experience. However, it is clear that, because of their training, nurses have a greater understanding of the complications and the evolution of the condition. However, the nurse technicians cannot always interpret what led to the child's death, and this leads them to question death from various perspectives and to seek a guilty party. This guilt may be ascribed to the therapy adopted, the delayed search for the health service, and failure during care, among others.

The imminence of death and the process of dying interfere not only with nursing practice, but also with the work environment, as they generate additional concern with the other patients hospitalized in the unit and with their relatives. The concern with the families is due to the emotional shock of witnessing the dramatic situation of other patients. The way they demonstrate this concern denotes the humanized care of the nursing team both with those involved in the situation and with the other patients and their families.

It is important to highlight the difficulty of dealing with the presence of those accompanying patients within an ICU. Because it is a place full of equipment, where noise is constant and the degree of tension is high, due to the complexity of patients' health status and the permanent fear of death, the presence of people accompanying patients is an additional cause of anxiety for the team [15].

In addition to continuous training of these professionals, professional specialization, management of work processes, psychological support to those involved, among other issues, the participants pointed out the need to improve the physical environment. To overcome these difficulties, it is necessary to improve the workplace, allowing the presence of people accompanying patients without this becoming an additional problem for the team. The inadequate physical structure of the work environment can be considered a factor that impedes the humanization of the institution [15,16].

The team also indicated that attending to patients' process of dying can generate more consideration regarding the quality of care. Once the flaw is identified, the nurse begins to better observe the risks to which the patient is submitted. For professionals more exposed to dying and the death of patients, the need to reflect and deal with issues that permeate this process is as essential as technical and scientific development. For the full

exercise of the profession, nursing must reconcile practice and norms with ethical conduct.

The aim of professionals and of the institution is to save lives. However, if this goal is not achieved, especially in pediatrics, the situation may give rise to feelings that interfere with the care process[17]. One of these feelings is job demotivation, which, to a certain extent, is something expected in nursing professionals[18] who have a very close relationship with patients and relatives. While this closeness can be beneficial to care giving, it also tends to make professionals more vulnerable to stress at work. Respondents report that, after witnessing the death of their patients, they work demotivated for periods ranging from hours to days or weeks.

We know[3,19] that nursing work seeks to ensure humanization and the integrity of care giving. Precisely because of this, when those assisting must intervene in the process of dying and the death of a child, disturbing feelings arise, and are difficult to accept. Studies[11,17,19] have shown that there is little or no reflection regarding death during training and permanent education of these professionals. There is evidence[10,13] that lack of contact with the topic in health courses results in unpreparedness to deal with the processes of dying and death. Nursing professionals do not find support even in the work environment and, therefore, develop their own coping mechanisms and resist recognizing death as a fact inherent to human existence.

Final considerations

This study analyzed some gaps in nursing work when dealing with death and dying in pediatrics. It is evident in some statements that the team treats patients as a "second family," and the workplace as a place where they can seek support for their expectations. Even so, the process of dying and death are extremely painful for both the grieving family and for professionals who deal daily with the situation.

According to the interviewees' narratives, a great lack of resources, both material and psychological, to deal with this process was identified, since they all live in a society that seeks to deny death. There is a lack of means to deal with the situation in the collective and professional spheres, as well as from the biopsychosocial and spiritual perspectives. Given this, it seems imperative to foster permanent education that allows the team of nursing professionals to deal with the subject with less distress and suffering, since it is still perceived today as a major focus in the curative field to the detriment of humanized care during the process of dying[5].

Another extremely necessary measure is to stimulate the knowledge of the team, making the nurse identify the weaknesses and seek resources to provide the necessary support, through training, discussions, research, among others. In this way, the work can flow in a less traumatic way for the professional and be more humanized for the patient and his family.

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