ORIGINAL ARTICLE

Palliative care for hospitalized children: perception of the nursing team
Cuidados paliativos à criança hospitalizada: percepção da equipe de enfermagem

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ABSTRACT

Objective: To understand the perception of the nursing team of an intensive care unit and pediatric hospitalization about palliative care for hospitalized children.

Methods: A descriptive, qualitative study was conducted with a large hospital pediatric intensive care and hospitalization unit's nursing team. Fourteen nursing professionals participated in the study, including nurses, technicians, and nursing assistants. Data were collected through semi-structured interviews and treated under content analysis.

Results: The interpretative analysis of the interviews allowed the construction of three categories: “The knowledge of the nursing team about palliative care in pediatrics”, “The challenges of the nursing team in performing palliative care in pediatrics”, and “The benefits of palliative care in pediatric care from the perspective of the nursing team”.

Conclusions: The lack of knowledge and training of nursing professionals on palliative care are factors that can hamper their implementation and consolidation process in units that care for children with no possibility of cure, in addition to favoring decisions to be under the responsibility of the medical category, compromising the role of the multidisciplinary team and depriving patients of the benefits of palliative care.

Keywords: Child, Nursing team, Palliative care, Pediatric nursing, Pediatrics


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INTRODUCTION

Recently, the development of new technologies in pediatric health has increased the survival of critically ill children. To the same extent, these advances have increased the number of children with severe chronic conditions with no possible cure.

This scenario has generated a demand for a new care model that values comprehensive care for pediatric patients, understanding that there is much to be done for patients with no therapeutic possibility of cure, not only in their terminal state but throughout their journey of the disease. From this perspective, palliative care (PC) is a promising path for comprehensive care for people with diseases that no longer respond to curative treatment.

The PC proposal is relatively recent in the history of health care. PC officially emerged as a distinct practice in health care in the 1960s, in the United Kingdom, through the pioneer physician, nurse, and social worker, Cicely Saunders. Her work sparked the palliative care movement, with a greater emphasis on combining additional care, teaching, and research.

With ever more advances in the discussion on this topic, the World Health Organization (WHO) defined, for the first time, in 1990, the concept and principles of PC and redefined the term in 2002. The PC focus was established to control pain and other physical, emotional, social, and spiritual symptoms, to improve the quality of life of patients and their families. Over time, this concept has evolved, breaking with the centrality of the initial idea of terminality or impossibility of cure and beginning to emphasize conditions that may be subject to disease-modifying treatments.

The WHO defined pediatric PC in 1998 as active and total care that involves the physical, mental, and spiritual aspects of children and their families. In pediatrics, PC should be included in the care routine of eligible children and adolescents, and improving such care is extremely important, as it is used to improve the quality of life of children and adolescents at any stage of their treatment.

PC consists of an eminently humanized and multidisciplinary care approach. In this context, nursing plays a central role in assisting the patient and family in their multiple needs, emphasizing their protagonism and co-responsibility during the care plan, including the family as a central part of the care team.

Given the importance of PC in the current scenario of pediatric health and the relevance of the role of nursing in this context, this study aimed to understand the perception of nursing professionals about palliative care in hospitalized children.

METHODS

Study type and location

This was an exploratory and descriptive study using a qualitative approach. The study was conducted at the pediatric intensive care unit (PICU) and the pediatric inpatient unit of a large public hospital in Belo Horizonte, Minas Gerais, Brazil. The institution serves about a thousand patients daily, providing care exclusively through the country's Universal Healthcare System (SUS). This hospital offers the population of Belo Horizonte and the outlining metropolitan region several medical specialties and is also a reference for emergency care. The PICU has 10 beds and a multidisciplinary team consisting of physicians, nurses, nursing technicians and assistants, physical therapists, occupational therapists, nutritionists, and speech therapists. The pediatric inpatient unit has 36 beds and a multidisciplinary medical team. Considering the two sectors, the nursing team comprises 12 nurses, 60 technicians, and eight nursing assistants.

Participants

The research participants were professionals from the nursing team (three nurses, nine nursing technicians, and two nursing assistants) totaling 14 individuals, who provide direct care to palliative care patients. As an inclusion criterion, professionals in activity (i.e., without leave or vacation) were accepted, who belonged to the nursing team of the PICU and pediatric inpatient care unit sectors, with a minimum of six months of work experience in the sector and who agreed to formalize participation in the research by reading and signing the consent form.
Informed Consent Term (FICT). There were no dropouts during the study.

**Procedures for data collection**

Data were collected through individual interviews with a semi-structured script containing eight questions regarding the study's objectives. This script was prepared by the researchers and contained a heading with items characterizing the participants (age, sex, time since graduation, time working at the hospital, and specifically, in the pediatric - PICU or inpatient unit, and professional category of their nursing field), in addition to the following open-ended questions: 1) According to your knowledge, what characterizes palliative care? Is there a difference between palliative care in adults and children? 2) Do you consider that PC is given in this unit? 3) What are the main benefits of palliative care for children? 4) Are there challenges to implementing palliative care in pediatric care? 5) Have you had the opportunity to learn new experiences or have a professional review concerning palliative care in pediatrics? 6) What is the role of nursing within the multidisciplinary team in palliative care in pediatrics? 7) Does the nursing team receive any emotional support concerning the care provided to patients in palliative care?

The interviews were conducted by a single researcher who was not part of the hospital's staff. They were conducted in a reserved place, in the hospital, on a day and time agreed upon with each participant, before or after working hours, and involved professionals from the three work shifts (morning, afternoon, and night). The invitation to participate in the research was made personally by the researchers for all shifts, and for those who agreed to participate, formal authorization procedures were performed by obtaining the informed consent and scheduling the interview were done.

The interviews were recorded using a voice recorder and later transcribed for analysis and conducted until the data saturation criterion was achieved. Data collection was considered saturated when no new element was found, and adding new information was no longer necessary, as it did not change the understanding of the phenomenon being studied.

**Data analysis**

After collecting and transcribing the interviews, the data were empirically organized and categorized for analysis. The content analysis technique was used. The professionals' speeches were coded in A1, A2, and so on to expose the content without identifying the participant.

**Ethical aspects**

The study followed the ethical precepts of research involving human beings, respecting Resolution no. 466 of Dec 12, 2012 of the National Health Council. Participants were assured confidentiality of the information obtained through participation in this study. All participants signed the informed consent form, and the research was approved by the Research Ethics Committee under decision nr. 3.912.328 (CAAE 29609620.8.0000.5129).

**RESULTS**

Fourteen professionals from the nursing team participated in this study, most of whom were nursing technicians (64.3%), female (92.8%), with a median age of 26 years (Table 1). One nurse (8.3%), 21 technicians (35%), and two nursing assistants (25%) declined to participate.

The content analysis from the interviews identified three thematic categories: “The knowledge of the nursing team regarding palliative care in pediatrics,” “The challenges of the nursing team in performing palliative care in pediatrics” and “The benefits of palliative care in pediatric care from the perspective of the nursing team.”

**Table 1 — Characterization of interviewed nursing professionals (N = 14). Belo Horizonte, 2021.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional category</td>
<td></td>
</tr>
<tr>
<td>Registered Nurse</td>
<td>3 (21.4)</td>
</tr>
<tr>
<td>Nurse technician</td>
<td>9 (64.3)</td>
</tr>
<tr>
<td>Nurse Assistant</td>
<td>2 (14.9)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>13 (92.8)</td>
</tr>
<tr>
<td>Male</td>
<td>1 (7.2)</td>
</tr>
<tr>
<td>Age (y)*</td>
<td>26 (20 - 62)</td>
</tr>
<tr>
<td>Years since graduation*</td>
<td>8 (4 - 25)</td>
</tr>
<tr>
<td>Years of working in the health sector*</td>
<td>10 (2 - 18)</td>
</tr>
</tbody>
</table>

*median (max-min).

**The knowledge of the nursing team regarding palliative care in pediatrics**

This category analyzed the content of the interviews carried out with the nursing team about the knowledge of these professionals regarding palliative care in pediatrics and their participation in formal training strategies on the subject.

The analysis of the reports by the interviewed professionals identified conflicting discourses regarding the participation of professionals in training processes on PC. While some professionals reported never having participated in training on the subject, other interviewees reported participating in updating processes on the subject inside and outside the health institution. According to some interviewees, the PC theme is not sufficiently addressed at the pediatric inpatient unit, and the knowledge they possess is insufficient and is due to past professional training processes (undergraduate nursing) or lack of individual initiative, as expressed in the following report:
“Honestly, no [referring to having participated in formal training on PC at the institution]. There was one day when we got together and talked about palliative care. I knew what it is because I myself researched the topic.” (A14)

However, some professionals have reported institutional training initiatives for PC. However, these initiatives were not specific to pediatric care and did not seem to have taken place systematically. Among the institutional training strategies available for PC that were mentioned there is promoting lectures on the subject at the hospital and the creation of a commission to deal with the PC hospitalized patient caseloads.

“There is a committee that they take the cases for discussion, but it is not a course in which everyone can participate. There are lectures from time to time.” (A9)

Based on the analysis of the interviews, it was possible to identify that implementing some team training strategies for PC appears to be the result of an individual's position by some professionals who recently joined the team. An example is the palliative care commission, according to the following reports:

“It all started with that doctor from the unit. She sat with us and talked about what palliative care was all about.” (A2)

“Not here in this sector. I was reassigned to this pediatric sector, but in the other sector, yes. There is a very good doctor there. I believe everyone knows her. She is responsible for palliative care.” (A6)

Despite the PC training strategies apparently not being implemented in the pediatric inpatient unit, many interviewees reported learning about PC during their day-to-day work at the unit, from the exchange of experiences between the professionals of the multi-professional team.

“Just today I saw an ICU nurse doing a Lanskyscale. She told me that this is an assessment of the child's performance: if he plays, if he gets out of bed, that sort of thing.” (A3)

A professional interviewed mentioned the difference in access to information regarding PC at the Institution, depending on professional training, citing that nursing assistants are a category that encounters more difficulty in learning about PC because there are lesser possibilities of accessing information and training strategies offered to them at the Institution. This could partially justify the different perspectives on PC training processes presented in this category.

The challenges of the nursing team in performing palliative care in pediatrics

This category describes the challenges faced by nursing professionals in providing palliative care to hospitalized children.

The nursing team pointed to the lack of knowledge on the subject as an important challenge for performing palliative care in pediatrics. This situation may be linked to the lack of institutional training for the qualification of the interviewees. In this sense, members of the nursing team also stated that the lack of information, protocols, and training directly impacts the care provided to the patient and family. This lack of specific training for those who care for PC patients can divide the team's opinion or even reduce the importance that professionals give to palliative care.

“PC needs to be discussed further. I think the biggest challenge is getting people to understand what palliative is. I think the institution itself should promote more events on this, have courses, lectures.” (A14)

“I think that the team training is more than a challenge. Some professionals are not qualified to work with palliative care, which raises doubts by family members and other professionals, especially for a nurse who ends up being a reference for technicians.” (A4)

Uncertainties surround the conduct of the nursing team, particularly when the child's clinical condition changes. The team members sometimes feel unprepared to act when faced with everyday situations with the child and the demands of the family. The professionals' reports indicate just how family members face difficulties in understanding what PC is and in accepting their child's health condition, which can influence the behavior of the nursing team responsible for the child's care.

“The biggest challenge in palliative care is to make the family understand that we are not trying to kill their child. Families still have a lot of difficulties accepting, and that is a really difficult issue. There is no way you can keep telling a family that the grief will pass.” (A13)

“Parents cannot accept death. I think this is for everyone […]. They don't understand, they always say that this is euthanasia; 'you are trying to kill my son. He arrived here well, and now you tell me he will no longer live'. I think that would be a real challenge for the team to have to deal with the parents and their pain.” (A6)

The difficulties faced by the family's acceptance can be aggravated by a professional's unpreparedness by team members assigned to the sector without prior palliative care experience. For the nursing team members, the professionals in this category who started working in the pediatrics sector did not understand palliative care and often believed that the child was abandoned by the professionals.

The unpreparedness to meet the needs of children and adolescents undergoing PC results in a team waiting for the doctor's prescription and a physician-centered care type of decision about what is best for their patients. The nursing team pointed out that there are
deficiencies in the medical team regarding palliative care and the lack of knowledge resulting in a multidisciplinary team vulnerability, as observed in the following report:

“Without a doubt, the first thing is that the doctors talk to each other. When I arrive for my shift and a doctor does not follow the instructions, then it is sometimes uncertain if the patient is to be given medication, and so we nurses end up being even more dependent on instructions. I think the team has to be more united.” (A7)

“We have communication problems between professionals, in addition to the family’s difficulties in acceptance, the doctors on duty who are not even aware of specific patients. They don’t like to prescribe medication for pain, and there are also those problems in the unit such as newly graduated professionals and are assigned to work in the ICU.” (A2)

In their narratives, the members of the nursing team expressed that the difficulty of communication between professionals leads to errors and greater variability in the care of the patient. Thus, the impact of the lack of effective communication regarding the provided care to the child and family members was identified in the reports by the interviewees.

The professionals suggested that there should be more interaction between the different shift workers and more meetings where all the multidisciplinary team members can participate in improving relationships. Some mentioned that the team needs protocols that guide professional actions, which could significantly improve safety and understanding of the actions performed by team members.

Participants reported that, often, PC interventions are not carried out by the nursing team because they are not included in the medical prescription or that differences in opinions between professionals interfere with communication while not respecting the decisions of the multidisciplinary team. Still, others have also reported that the lack of communication impairs the therapeutic relationship that must be established between the team and the patient, and compromises the establishment of a relationship of trust so that effective and participatory care can be achieved, in which the patient and family members can express their decision.

“Look, here in pediatrics we have fantastic people […], but what is lacking is communication. Sometimes we sit down, try to define something, then a doctor comes and changes everything, so the team becomes lost.” (A11)

“Talking more about this topic, especially during the night shift, where things happen, and you end up depending on the doctor on the morning shift because he follows the patient more closely, as opposed to the on-duty doctors, who sometimes don’t even know what’s going on.” (A5)

The benefits of palliative care in pediatric care from the perspective of the nursing team

The analysis of the interviews showed that PC is viewed mainly as the comfort and care offered to children with no possibility of cure and to their families, using medication as a pain reliever and to promote quality of life.

“A safe and comfortable death, helping the family during the loss of that loved one, we always speak the truth about that patient’s health and illness, being able to comfort the family, to help relieve the pain.” (A2)

“The benefit is to alleviate the pain, to help the family to understand, to show the family in some way that we are not killing their son or daughter, to alleviate their own suffering. I know the earlier you are diagnosed with palliative care, the easier it is. Both for the team and for the family.” (A8)

In other reports, some professionals also mention respect for the grieving process and the family’s decision as part of the treatment as a benefit of PC, favoring the autonomy of the patient and family members. Additionally, spiritual aspects were mentioned, emphasizing the importance of respecting the child and their family’s religious beliefs and values.

“I think that beliefs, values, religions, compassion, humanization, respect, and human dignity must be respected. Respect the family when a family asks to let their child die at home with friends.” (A3)

“In addition to pain relief, caring for and supporting family members whatever their decision, without judgment.” (A10)

In addition to the benefits already mentioned, the nursing team members also pointed out that the use of toys, drawings, films, and animation are resources that can be used to reduce suffering and pain.

“The benefit of palliative care for the child is everything it encompasses, such as pain relief and support for family members. In addition, it is possible to create a more pleasant environmental experience for the child through conversations, games, toys and drawings, making it feel to them that the treatment is not so painful.” (A4)

“I think that in these cases those Doctors of Joy fit in very well, they transform them to a child’s reality they can relate to.” (A6)

DISCUSSION

This study made it possible to understand better the perception of nursing professionals who work in pediatric care units that offer PC to children. During this process, the perspectives of these professionals were
revealed as to the meaning of PC, its potential, and challenges. Despite recognizing the importance of PC in pediatrics, this study evidenced the lack of knowledge on the subject and the fragility of training strategies available at this service. These results agree with other studies that demonstrated the lack of specific training on PC, and the knowledge by professionals working in this area is mainly related to professional experiences and personal initiatives[11-14]. A study carried out with 37 health professionals from a pediatric intensive care unit involving a nursing team, physicians, and physical therapists showed that the participants were not prepared to care for the patient under PC due to a lack of knowledge, inadequate training, lack of uniformity in assistance, and little involvement of the multidisciplinary team[15].

Other studies have also evidenced the centralized decisions concerning palliative care in the physician category, the lack of participation by the nursing team in the decision-making processes, and the lack of interdisciplinary actions. In one study carried out in a national reference unit in pediatric oncology, nine health professionals from different backgrounds were interviewed. Results identified communication failure between different professionals’ practices in caring for children with no possibility of cure and the physician’s centralized actions[16].

In the interviewees’ speeches, planning and decision-making on PC are central to the figure of the physician, with little autonomy from other professionals. It was possible to observe that both communication and decision-making are the responsibility of the medical team, lacking clarity in the definition of palliative care and the necessary limits for the practice carried out in this situation.

Some professional categories end up being barred from their care due to institutional obstacles, reluctance from managers, legal constraints, or barriers related to physician authority[16-17]. In this context, it became clear that the attributions of the multidisciplinary team were weakened, depriving the child and the family of the benefits of multidisciplinary care, in which these different experiences by professionals can enrich the care of children who are beyond the possibility of cure.

Assistant to children in palliative care requires technical-scientific knowledge and the appreciation of a multidisciplinary team, constant team member communication, and teamwork while valuing the nursing professionals’ contribution to PC.

Nursing is essential in the importance of palliative care, as it is within its competence not only in technical procedures but also through attention to the emotional aspects of the child and family. Nurses must be prepared to deal with death and, simultaneously, be supportive of family members[12]. The professional autonomy of nurses is an essential factor in providing comprehensive care, care safety, and commitment to the patient. For this autonomy to be recognized, professionals should undergo periodic training, develop and improve protocols and systematize nursing care, so that nursing work processes can be better respected by other professionals at these institutions.

Palliative care in pediatrics is the responsibility of the multi-professional team, and all those involved in this process must have adequate training and psychological support to perform in such a key position. Therefore, continuing education and teamwork are fundamental for better patient and family care[18-19].

Hopefully, this study may contribute to fostering a multidisciplinary discussion on assistance to children undergoing PC, favoring the emergence of intervention proposals on this topic.

CONCLUSION

The lack of knowledge and training of nursing professionals concerning palliative care can hamper its implementation and consolidation process in units that care for children with no possibility of a cure. This lack of training on the part of the nursing team favors making decisions about the care of children in PC under the responsibility of other professionals, especially in the physician category, compromising the role of the multidisciplinary team and depriving patients of the benefits of palliative care.

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Manuscript writing: BYFA, SRO
A critical review of the text: BYFA, SDT, SRO
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