

Chronic Disease and Pediatric Palliative Care: Nurses' Knowledge and Practice In Light of Human Care

Doença Crônica e Cuidados Paliativos Pediátricos: Saberes e Práticas de Enfermeiros à Luz do Cuidado Humano

Enfermedad Crónica y Cuidados Paliativos Pediátricos: Saberes y Prácticas de Enfermeros a la Luz del Cuidado Humano

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ABSTRACT

Objective: The study's main goal has been to analyze knowledge and practices of care nurses about palliative care for children with chronic disease, in the light of the Theory of Human Caring. **Method:** It is a qualitative study developed with twelve nurses from two reference hospitals in pediatrics. Data were collected through semi-structured interviews and analyzed from Content Analysis and Theory of Human Caring. **Results:** From the analysis of the empirical material, the following categories emerged: Knowledge of assistant nurses on palliative care; Situations eligible for the promotion of pediatric palliative care and Palliative care for children with chronic disease in nurses' care practice. **Conclusion:** There are weaknesses in the knowledge of participants that made it difficult to define palliative care, influencing the adoption of such care in caring practice. Medicalization was described as the main palliative action performed by the participants. However, measures of comfort, communication, and spiritual care were also approached as means to relieve the suffering of children with chronic diseases.

Descriptors: Chronic disease, Palliative care, Nursing care, Pediatric nursing, Nursing theory.

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RESUMO

Objetivo: Analisar saberes e práticas de enfermeiros assistenciais sobre cuidados paliativos à criança com doença crônica, à luz da Teoria do Cuidado Humano. **Método:** Estudo qualitativo desenvolvido com doze enfermeiras de dois hospitais de referência em pediatria. Os dados foram coletados mediante entrevista semiestruturada e analisados a partir de Análise de Conteúdo e Teoria do Cuidado Humano. **Resultados:** Da análise do material empírico emergiram as categorias: Saberes de enfermeiras assistências sobre cuidados paliativos; Situações elegíveis para promoção de cuidados paliativos pediátricos; e Cuidados paliativos a criança com doença crônica na prática assistencial de enfermeiras. **Conclusão:** Existem fragilidades no saber das participantes que dificultaram a definição de cuidados paliativos, influenciando na adoção desses cuidados na prática assistencial. A medicalização foi descrita como a principal ação paliativa desempenhada pelas participantes. Contudo, medidas de conforto, comunicação e cuidado espiritual também foram abordados como meios para amenizar o sofrimento de crianças com doenças crônicas.

Descritores: Doença crônica, Cuidados paliativos, Cuidados de enfermagem, Enfermagem pediátrica, Teoria de enfermagem.

RESUMEN

Objetivo: El propósito del trabajo es analizar el conocimiento y las prácticas de las enfermeras asistentes sobre cuidados paliativos para niños con enfermedades crónicas, a la luz de la Teoría del Cuidado Humano. **Método:** Este es un estudio cualitativo desarrollado con doce enfermeras de dos hospitales de referencia en pediatría. Los datos fueron recogidos a través de entrevistas semiestructuradas y analizados a partir de análisis de contenidos y Teoría del Cuidado Humano. **Resultados:** Del análisis del material empírico, surgieron las siguientes categorías: Conocimiento de las enfermeras asistentes sobre cuidados paliativos; Situaciones elegibles para la promoción de cuidados paliativos pediátricos; y Cuidados paliativos para niños con enfermedades crónicas en la práctica de cuidados de enfermería. **Conclusión:** Existen debilidades en el conocimiento de los participantes que dificultaron la definición de cuidados paliativos, lo que influyó en la adopción de estos cuidados en la práctica asistencial. La medicalización se describió como la principal acción paliativa realizada por los participantes. Sin embargo, las medidas de comodidad, comunicación y cuidado espiritual también se abordaron como medios para aliviar el sufrimiento de los niños con enfermedades crónicas.

Descriptorios: Enfermedad crónica, Cuidados paliativos, Atención de enfermería, Enfermería pediátrica, Teoría de enfermería.

INTRODUCTION

Chronic diseases (CD) are conditions that have a long progressive course, with an uncertain prognosis, usually without therapeutic possibilities of cure. Those diseases limit the patient's life, exposing them to periods of remission and clinical exacerbation, generating the need for continuous and sometimes complex care, whether at home, in an outpatient clinic or hospital.¹

Despite the increase in survival, it is estimated that 25% of the total infant deaths in the world annually are due to some form of CD.² In Brazil, their prevalence increases according to the age group, affecting 9.1% of children under the age of 5 years old, 9.7% from six to thirteen years old and 11% of adolescents between 14 and 19 years old.¹

In this perspective, the therapeutic paradigm, centered on disease and cure, opens space for care with a focus on the child as a developing human being and on their quality of life, such as Palliative Care (PC).

Thus, professionals must know and develop PC in a complementary way to interventions of a curative nature. In pediatrics, PC must constitute active care for the body, mind, and spirit, and should be promoted gradually, from the diagnosis, through a relationship of confidence and truth with the child and their family, to promote quality through prevention and relief of suffering, assessment and treatment of pain and other problems.³⁻⁵

The World Health Organization (WHO), as well as the Ministry of Health of Brazil, recognize that it is the ethical responsibility of health systems and the multidisciplinary team, in particular nurses, to offer PC.^{5,6} Among health professionals, nurses are the ones who have the greatest potential to connect with the suffering child and, thus, develop an empathic and harmonious closeness, capable of transcending care for the emotional, social and spiritual dimensions and therefore, providing humane care in their care for children with CD.^{4,7}

For the effectiveness of PC by nurses, it is essential to qualify their assistance by identifying their knowledge and practices directed to children with CD, therefore, they must adopt a nursing theory that guides their assistance. Thus, the Theory of Human Care (THC) brings its concepts and paradigms completely immersed in the humanistic ideology, in which the relationship of being with oneself, with the other and with the universe, assumes the focus of the nurses' care, this fact corroborates the philosophical bases of PC, as well as, it makes it possible to base and systematize nursing care.⁸ Thus, this theory is understood as a guiding tool for the performance of pediatric PC.

Therefore, this study aimed to analyze the knowledge and practices of nursing assistants about palliative care for children with chronic illness, in the light of the Human Care Theory.

METHODS

This is a descriptive exploratory qualitative study, which took place in two reference hospitals in the care of children with CD. The research scenarios were Pediatric and Neonatal Intensive Care Units (PICU/NICU), and Pediatric Medical Clinics, as it is understood that these are the sectors with the highest number of children with CD who need PC.

From a total of 58 nurses working at the data collection site, only 12 participated in the survey, since they met the following inclusion criteria: work during the data collection period; have, at least, three months of experience in the institution's pediatric sector. At first, the sample size has not been defined. For this purpose, the theoretical saturation criterion was considered, from which the data collection

was completed when there was a recurrence of information collected in the participants' speeches.

Data collection took place between the months of October 2015 and January 2016, in reserved spaces and chosen by the participants themselves within the institutions, from Monday to Saturday, in the morning, afternoon and night shifts, through semi-structured interviews. The speeches arising from the interviews were recorded employing digital recording, with subsequent transcription and later presented to their respective deponents so that they would guarantee the reliability of the statements.

As a way of ensuring anonymity, pseudonyms were used to name each participant. These were chosen according to the characteristics presented by each participant in their statements, which alluded to the THC. Such words were: kindness, relief, empathy, delicacy, involvement, finitude, compassion, presence, dialogue, guidance, self-awareness, and benevolence.

The categorical content analysis technique was used to perform the data analysis, since this search for meanings in the phenomena investigated through the participants' statements, being guided in three distinct phases: organization and systematization of ideas; exploration of the material and treatment of the results obtained; and interpretation of results.^{9,10} For analysis and discussion of the results, the THC was also used.

It is noteworthy that this study followed the ethical and legal principles related to Research Involving Human Beings contained in Resolution No. 311/2007 of the Federal Nursing Council and Resolution No. 466/12 of the National Health Council, having been approved by a Committee of Research Ethics under protocol No. 1,268,255 and *Certificado de Apresentação para Apreciação Ética* (CAAE) [Certificate of Presentation for Ethical Appreciation] No. 48333415,3,0000,5183.^{11,12}

In order to allow a better understanding of the study design, collection of empirical material, as well as analysis and interpretation of data, in this research, the *Crerios Consolidados para Comunicao de Estudos Qualitativos* (COREQ) [Consolidated Criteria for Communicating Qualitative Research] were considered as a support tool.¹³

RESULTS AND DISCUSSION

It was observed that among the 12 participating nurses, eight (66.7%) were located in the medical clinic sector, two (16.6%) in PICU and two (16.6%) in NICU. Only one reported having a postgraduate degree in pediatrics and another reported having completed a PC training.

Through content analysis of the speeches, it was possible to identify three thematic categories: Knowledge of assistant nurses on palliative care; Situations eligible for the promotion of pediatric palliative care and Palliative care for children with chronic disease in nurses' care practice.

Knowledge of assistant nurses on palliative care

About the PC knowledge, most participants reported having little information about this care approach, either because it was not included in the curriculum during their academic curriculum, or because it is still a topic little discussed in care services.

I know very little. In fact, here we don't even hear about PC. (Goodness)

Here we don't talk about PC. Therefore, I have difficulty even speaking. I don't even know if I'm saying it right (Relief)

We don't know much about PC. (Involvement)

I don't have that much depth on the subject. Maybe I don't know what it is. (Finitude)

In my academic background, there was no discipline related to it [PC]. (Dialogue)

I don't know what PC would be, specifically. (Benevolence)

Despite mentioning little knowledge about PC, when defining these, they used terms such as "help", "improvement", "soften", "comfort", "continuous", "quality of life" and "dignified death", which are present the concept and guidelines of PC defined by WHO.

Anything that may help, not in the medication form, the treatment of the child and influences its improvement, improving hospitalization here serves to be palliative. (Goodness)

It goes beyond medication, [...] it is a set, it will depend on the need. It is the one that will soften, but not treat, it is more of the care itself to be able to continue the treatment and withstand the symptoms that will appear. (Relief)

It is the care that we have and can offer in everyday life. (Empathy)

[...] the one that we could intervene to give greater comfort and greater possible care to that child, even without the prospect of improvement. (Delicacy)

I understand PC as something continuous and preventive. One who will promote adaptation, not cure, because it is chronic, but who will promote comfort. (Involvement)

PC, in my understanding, is that care that you will do regardless of the patient's diagnosis. (Finitude)

I understand that PC is you offering a quality of life to

a person who does not have a good life prognosis. It is to provide a dignified death, with quality. Continuous care. (Compassion)

PC is more special care that offers quality of life to the [...] patient since they no longer have curative measures. May they arrive more calmly and with more dignity for the days that remain. (Presence)

I think it is more about nursing care as a whole. (Guidance)

It is continuous care, paying attention to sequelae, worsening of the clinical picture. It is very much related to the issue of comfort, healing, finitude, treatment, [...] more about continuity. (Self-awareness)

PC is this care that you try to minimize, [...] intending to improve that patient's quality of life. It is offering comfort measures both physical and spiritual, psychological support. (Benevolence)

Situations eligible for the promotion of pediatric palliative care

It is noticed, in this category, that the participants associate the PC with serious clinical conditions in which curative therapeutic measures are no longer effective, as well as, at the end of life stages. And they also point out chronic diseases as eligible conditions for this care in childhood.

When one talks about PC, I remember the cancer patient a lot. In all cases that have a child who has chronic diseases, [...] many times they don't even have a very good prognosis. (Relief)

Especially the neurologically impaired children. Neuropathies, cardiopathies, autoimmune diseases such as purple. (Empathy)

PC would be addressing those patients who would have a not so positive prognosis, [...] that child with no prospect of improvement. (Delicacy)

I think palliative is much stronger in the issue of bedridden chronicles. (Involvement)

I believe that the PC is that care when the patient is practically with a bad prognosis, or is in a terminal phase. [For children] it is more geared towards neurologically impaired ones. (Finitude)

PC is you offering a quality of life to a person who has no prognosis, that is, [...] a person with a chronic disease. (Compassion)

Patient in a state of advanced cancer, who no longer has a possible treatment. A chronic patient that we just improve the quality of life. A child arrives with a very large tumor, so for me, it is more palliative. (Presence)

Related to the patient without prognosis. You are just [...] bringing comfort, until the moment they die. It is terminal patients. (Dialogue)

Specific disease is more kidney and diabetic that we work with this part of palliative. (Guidance)

It is the care that is performed in the child, who does not have a prognosis for the cure of their disease, but that need care throughout their survival. The first idea that comes to mind is the oncological issue. (Self-awareness)

Palliative care for children with chronic disease in nurses' care practice

It is observed that the participants emphasize the relief of pain and suffering, either through the administration of medications or through the performance of comfort measures, such as the PC that they perform in their care. And they do not differentiate these measures from the nursing care they promote in their daily lives.

The people of the Nursing [team] tried to do everything possible for her not to feel pain, gave her medication, left her in a comfortable position. (Relief)

It is medication, even helping, talking to the mothers, because they are very stressed. We try to alleviate this suffering. (Empathy)

All the care we try to provide would be to improve the symptoms of that disease or problems that we could alleviate, but that would not necessarily come to cure. (Delicacy)

In the case of neonatology, minimal handling is a PC, very important for the child's comfort. Hygiene would be, it is part of the treatment, it is not curative, so it is palliative, it is comfort. (Involvement)

Here, I even act [...] despite being a pediatric clinic. We put a compress because he [the child] is having an allergy, nursing things. (Finitude)

So we offer what we have here for him [child]. All the care that is done, but we know that there is no cure. Provide more humanized assistance. (Presence)

We will carry out comfort care knowing that it will not cure their disease, and [...] we will plan care within that

period. (Self-awareness)

I provide assistance to minimize pain, comfort measures. This is what I mean by PC. I try to offer comfort to that baby in all ways, whether in pain, in noise, or in the bond with the mother. (Benevolence)

However, it is possible to see in the statements that nurses still have doubts about whether they actually perform pediatric PC.

I don't even know if I play this role of dealing with palliative care, I don't even know if that is it. (Goodness)

When you discover [the disease], you are still very small [the child] and then it is difficult for you to say that you provide PC. (Guidance)

Within the infant universe, the child with chronic disease starts to interact less and less and becomes passive in the face of pain, does not cooperate with the treatment and, generally, takes the blame for being sick. The Theory of Human Care proposes to these children care based on a true relationship of trust and acceptance between the nurse and the suffering being (child and their family), in the physical, sociocultural, emotional and spiritual dimensions.^{14,15}

PC are considered propellants of the process of restoring balance and health through actions of care and healing (healing) that allow not only to alleviate physical discomfort, but also restlessness and disharmony in the subjective dimension of the being, resulting from the process of getting sick.^{14,15}

How the nurse understands pediatric PC depends on both their pre-existing knowledge and professional experience, as well as their existential experience, that is, their ability to "look at themselves" and "feel themselves" as a being-in-the-world capable of transcending their "I" to the "Other". Therefore, to promote PC authentically, the caring relationship must be permeated by respect, empathy, compassion, dignity, by the feeling of caring for the child's "being-in-the-world", and recognizing the child as a sacred being.¹⁶

In the speeches presented, it is evident that nurses understand the essence of the PC philosophy, however, they have difficulties in defining them as

an approach that aims to improve the quality of life of patients and their families, in the face of a disease that threatens life, through the prevention and relief of suffering, early identification, impeccable evaluation and treatment of pain and other physical, social, psychological, and spiritual symptoms.¹⁷

This is justified by the participants themselves as a result of the lack of information on the theme during academic

training and within the assistance routine. The biomedical, curative and hospital-centered health model also limits adherence by patients, families, health professionals, and managers to other care approaches, which seek to complement the well-being of children.¹⁸ Besides, there is also the stigmatization of PC when associating them with cancer and stages of finitude of the life.

Research carried out with nursing academics demonstrates the lack of information about PC during the undergraduate course, as well as the students' unpreparedness to promote this care.¹⁹ Other studies^{18,20,21} showed that the assistance provided by professionals who had some degree of training in PC was different from those who did not, and that these professionals had greater difficulties in applying PC in their daily practice.

In order to achieve the ideal care, THC understands that there must be a harmony between what is perceived and what is experienced. Thus, difficulties in the knowledge, understanding, and definition of pediatric PC appear as an important barrier for them to be offered and experienced in all its fullness.^{22,23}

Insufficient knowledge about pediatric PC opens room for interpretation as end-of-life care, to be offered only when there is nothing more to do. This conception can restrict the provision of this care to children with chronic disease, as well as influencing their existential experience and that of their caregivers when they fall ill.

It is noteworthy that children with diseases who have the possibility of cure but that may fail are eligible for pediatric PC; conditions that require complex and prolonged therapy; strict PC situations since the diagnosis and severe and non-progressive disabling conditions.²⁴ Thus, nurses who work in pediatric services should be aware of these indications in order to offer PC to children who meet these conditions.

Child-oriented PC are conceived by participants as acts of charity, help, and compassion capable of alleviating signs and symptoms, bringing relief to pain and suffering, as well as the quality of life, providing strength to children and their families so they can manage to face the disease. Thus, Nursing, whose essence and moral ideal of the profession is to care, understands that when offering PC it is possible to transcend physical care and meet the subjective, emotional and spiritual world of being cared for and the nurse, experiencing full therapeutic moments of love, affection, compassion, and welcome.^{7,25}

Pediatric PC are based on scientific, ethical, humanistic, and phenomenological precepts that seek authentic and multidisciplinary care with a focus on the child. It also aims to share knowledge, emotions, feelings, desires, and anguishes, so that care needs are identified, which nurses can intervene to help them restore their balance and harmony.^{7,26}

The therapeutic interventions in PC developed by the participants were, for the most part, directed to the use of medications to control signs and symptoms, as well as

comfort measures, which were not intended to cure the child's disease. It is noteworthy that these care procedures were referred to as nursing care, however, without demonstrating a systematization of these, as recommended by the Nursing Process. These findings were common to those found in other studies, as evidenced in an integrative review study that mostly comprised publications from international journals.²¹

Communication was also scored as a strategy to promote PC concerning the extension of care to the family. Communication is essential for the establishment of a caring relationship in which the caregiver allows themselves to lower the barriers around their "I" so that the nurse can transcend their care and must be continually strengthened.²²

The continuity of care mentioned in the speeches is fundamental within the palliative perspective, since the child affected by CD can have a long survival. Which also means the prolongation of their suffering if it is not holistically assisted. Thus, it is recommended that PC be offered at all levels of health care, including home care, in order to ensure continuity.^{3,4}

The palliative philosophy, as well as the THC, emphasizes the need for spiritual care when suffering. This care was approached by "Benevolence" as a synonym for PC without, however, delimiting who should be offered or citing it as a daily action to be developed by the multi-professional team.

Care for the spiritual dimension is considered in several studies²⁶⁻²⁸ as essential for those who experience the illness process, whether for the child and their caregiver or the nurse. Viewing the child as a spiritual being, who suffers and needs to be seen, understood and fully attended to, is still a challenge for health professionals, including nurses. Nevertheless, it must be considered in the practice of PC so that they assume an integral and transpersonal character.

Thus, it is understood that to achieve transpersonal care, the palliative nurse must share their scientific knowledge with their aesthetic and artistic knowledge, their awareness of the "I", the sensitivity to the child's suffering, and the intuitive ability to recognize the needs that emerge from this patient at the time of care.

CONCLUSIONS

Herein, it was observed that flaws in the participants' knowledge about pediatric PC caused difficulties in talking about the theme, as well as in adopting this approach in healthcare practice. The understanding of this care encompassed assistance aimed at children with CD, but who needed complex and intensive care, with a poor prognosis, often associated with terminality.

PC were also perceived as nursing care itself, however, this perception becomes mistaken, since this care transcends a single discipline or professional class. The speeches

brought relief from the pain and suffering of children with chronic diseases and their families as objectives of this care approach, but that was not always seen in a complementary way to curative therapy.

These conceptions influenced the practices of PC for children with chronic diseases, since the participants demonstrated difficulties in directing them to patients who, even when it was impossible to cure, could experience the disease without an early prognosis of death.

In this context, medicalization was described as the main palliative action performed by the participants. However, measures of comfort, communication, and spiritual care were also addressed as a means to alleviate the pain and suffering of children and their families.

Thus, although nurses had knowledge about PC, their care practices in the scope of this care were still poorly developed and systematized. Thus, it is evident the need for continuous training of these professionals, through institutional incentives for theoretical and technical training on PC, as well as the adoption of institutional protocols for the promotion of safe, authentic, and comprehensive care for children.

It should also be noted that the small number of participants in this research prevents the generalization of the results, although, it allows the replication of the study for the investigation of the theme in different realities. The lack in the scientific literature of original research that addresses pediatric PCs in chronic situations was characterized as a limiting factor for further discussion of empirical data.

Given the aforesaid, it is recommended to carry out studies that address the theme, to expand and deepen the knowledge of Nursing on pediatric PC and thus allowing the qualification of the care provided by nurses to children with chronic disease.

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