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Performance of the health team in pediatric palliative care

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Update

Abstract

Through a narrative review of the literature, this article discusses and raises reflections on the care relationships established between children, families, and health teams in the context of pediatric palliative care. It is understood that chronic illness implies physical, social, psychological and spiritual imbalances for the child, however a serious disease that threatens life goes beyond the limits of their body and also affects the family and affective environment, so that the family, historically conceived as responsible for care, also needs health care. Therefore, this text focuses on socio-family suffering, reinforcing the humanized understanding, provided by palliative care, of patient and family as a care unit.

Keywords: Palliative care. Family. Professional-family relations. Child care. Humanization of assistance.

Resumo

Atuação da equipe de saúde nos cuidados paliativos pediátricos

Por meio de revisão narrativa da literatura, este artigo discute e suscita reflexões a respeito das relações de cuidado estabelecidas entre criança, família e equipe de saúde no contexto dos cuidados paliativos pediátricos. Compreende-se que o adoecimento crônico implica desequilíbrios físicos, sociais, psicológicos e espirituais para a criança, todavia uma doença grave que ameaça a vida ultrapassa os limites do seu corpo e repercute também no âmbito familiar e afetivo, de modo que a família, engendrada historicamente como responsável pelo cuidado, também necessita de atenção em saúde. Portanto, este texto debruça-se sobre o sofrimento sociofamiliar, reforçando a compreensão humanizada, ensejada pelos cuidados paliativos, de paciente e família como uma unidade de cuidados.

Palavras-chave: Cuidados paliativos. Família. Relações profissional-família. Cuidado da criança. Humanização da assistência.

Resumen

Actuación del equipo de salud en los cuidados paliativos pediátricos

A través de una revisión narrativa de la literatura, este artículo discute y plantea reflexiones sobre las relaciones de cuidado establecidas entre niños, familias y equipos de salud en el contexto de los cuidados paliativos pediátricos. Se entiende que la enfermedad crónica implica desequilibrios físicos, sociales, psicológicos y espirituales para el niño, sin embargo, una enfermedad grave que amenaza la vida va más allá de los límites de su cuerpo y afecta también al entorno familiar y afectivo, por lo que la familia, históricamente concebida como responsable del cuidado, también necesita cuidados de salud. Por lo tanto, este texto se centra en el sufrimiento socio-familiar, reforzando la comprensión humanizada, proporcionada por los cuidados paliativos, del paciente y la familia como unidad de cuidado.

Palabras clave: Cuidados paliativos. Familia. Relaciones profesionales-familiares. Cuidado de los niños. Humanización de la asistencia.

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Family is considered a foundational element of societies[1] and, as the individual's first socialization core, provides psychosocial protection for its members, through the bonds developed, and promotes the culture in which it participates. Family, thus, *can be defined as a nucleus of people who live in a certain place, for a long or short period of time, and who are united (or not) by blood ties. Its main task is the care and protection of its members, and it is dialectically articulated with the social structure in which it is inserted*[2].

Each family has a specific dynamic and is organized according to an implicit set of rules and norms[1]. Although new, increasingly free and democratic family configurations have been legitimized over the years, the family maintains its role of care and protection, characterizing itself as a health system for its members[3].

Care involves construing person projects. Relations between adult and child materialize a structure of social roles. Consequently, the identification process of children and adolescents and the establishment of a meaning to life emerge in relational daily interactions with adults. *Through daily bodily care, adults who care for the child aim at the same time to give the child's body its proper form and shape the child as a unique individual and as a relational person, with its "nature" mastered*[4].

Besides providing well-being, it was up to the family to organize a hygienic space, preaching a disciplined and diligent life[5]. As mentioned above, the family is a subsystem and is directly linked to the system in which it is inserted, being impossible to understand it in its micro-space without first relating it to the whole. Accordingly, the roles assigned to it are part of a society project that aims at preserving an existing order, in which care plays a central role as a mechanism for promoting values, beliefs and behaviors.

Scavone[6] emphasizes that care has been purged from the professional medical field and restricted to the private, affective, and family sphere. The opposition between caring and curing devalues the former by designating it as non-professional and, therefore, of lesser value. Besides being held responsible for the care, the family's effort is thus discredited, although its role is romanticized. Little is discussed about the notion of shared responsibility between family, society, and the state, which is problematic, since the provision of care by the family is permeated by intense suffering.

The family's willingness to provide care requires constant adaptations, for when one of its members falls ill, *the system is shaken and the family needs to resort to its internal and external resources to cope with the disease*[7]. Such effort is even greater when a child becomes ill, for the defense of a construed project, a coming-to-be, is also at stake. When a child is diagnosed with a serious and life-threatening illness, this project and the future envisioned are put into question.

This article sought to discuss and prompt reflections on the care relations established between the child, family and healthcare team within pediatric palliative care. To this end, we selected articles using the narrative literature review method, which refers to the non-systematic selection of bibliographic productions that allow narrating and discussing the topic at hand. We read and discussed the included articles to assemble arguments and reflections to prompt the debate proposed in this bibliographical and qualitative research.

After this conceptual and social-historical introduction to the theme of family, we explain the suffering experienced by the family and the network of affection within pediatric palliative care. Then, after discussing who would be responsible for the care of children and adolescents regarding health, we point out the role of the healthcare team in caring for and supporting both the patient and their family, through empathic and honest communication. Finally, we highlighted the importance of humanized health interventions, considering the intense suffering that children and families experience when facing a serious life-threatening illness.

Social and family suffering within pediatric palliative care

The 20th century saw the control of neonatal and infant mortality rates[8], but also an increase in the number of frail, chronically ill people[9]. In the case of children and adolescents, chronic illness not only affects natural development, but significantly changes daily activities and family relationships.

It goes beyond the limits of the child's body and affects each person and each family in different ways.

The incorporation of new technologies, the use of increasingly effective treatments, the development of various pediatric subspecialties, combined with the proliferation of pediatric (UTIP) *and neonatal* (UTIN) *intensive care units, have allowed the survival of children who until recently were considered unviable and died prematurely. Concurrently, a group of children with chronic diseases with severe sequelae, dependent on technology and often with a reduced life expectancy was created* [10].

The reality of complex chronic illness requires a healthcare approach that fully perceives and embraces the developing human being, understanding them not only in physical, but also social, psychological, and spiritual aspects. Is in this context that palliative care emerges, *an approach that promotes quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual* [11].

Pediatric palliative care is active and encompasses the child's body, mind, and spirit, providing support to the family. It must be carried out by an interdisciplinary team from the diagnosis of a life-threatening illness and evolve progressively according to the needs and individuality of the patient [12]. Congenital and genetic diseases are the main diagnoses that prompt the indication of pediatric palliative care, followed by chronic neurological and onco-hematological conditions [12].

The perspective of the patient and family as a care unit is justified by the understanding that suffering, in its various dimensions, is experienced by both the child and their relatives. As the illness context requires constant care and adaptation [13] – considering the social, psychological and financial impacts involved –, the changes brought up by the disease and the adaptations that the family will be able to make depend on the resources available and the meaning they attribute to the event [7].

Andrade highlights stress, caregiver overload, drastic changes in family dynamics, and impoverishment as factors that affect the care process. *Stress and overload tend to intensify the greater the dependence, the more severe the patient is, and the less help the family member responsible for the care receives* [14].

The caregiver becomes vulnerable by the experience, which becomes a burden, by the restriction of daily activities, by the feelings of fear, insecurity and loneliness, by the lack of support and by the death of the person being cared for [1]. Giving oneself to care often implies giving up life projects [14], and the most difficult is not necessarily the task itself, but the dedication to satisfy another's needs, to the detriment of one's own [14].

The decision on who will occupy the position of caregiver is usually arbitrary [1]. *The imposition to be a caregiver is related to the expected profile, the caregiver's social place, the affective proximity, the social roles to be performed within the families and the lack of alternative regarding the care that is imposed* [14]. Such responsibility usually falls on the female figure – the mother; however, it is necessary to denaturalize this process.

Health care is not the result of a biological determination between the sexes, but of the social relations of sex/gender [6]. Thus, it is not only the woman's responsibility but the whole family's, for *the caregiver is shaped by providing care* [15], in the day-to-day experiences and learning by performing the role, since, regardless of gender, to provide care one needs to be willing. To sustain itself, this disposition seeks grounds in solidarity with the life partner, in the desire for retribution, in the horror of asylum and in the absence of alternatives [9] and is gratified by the feeling of duty fulfilled.

When it comes to a child, the feelings that permeate this reality tend to be intensified, as the severity of the clinical picture and eventual death generate greater emotional mobilization [8] due to precocity, considering that the later the death occurs in the life cycle, the lesser the stress associated with it [7]. In natural evolution, the death of an older adult is more understandable than that of a child, although death itself is considered taboo.

Historically, the child occupies a place of attachment in society, of someone who needs comprehensive care [16]; thus, a child's death involves complex and sensitive nuances, precisely because it is not socially expected [16]. The difficulty in dealing with the early death of a child is thus reflected in the family, in the community, in society, and even in the healthcare team.

In the clinical paths, the diagnoses in many cases coincide, but how patient and family cope will depend on the financial, social, psychological, and spiritual resources available. Consequently, the family needs support to assume the role of care. But such role is not only theirs; there are other actors in this scene who must take the stage to ensure the prevention and relief of total pain and enable a dignified end of life.

Whose responsibility is it, after all?

Article 226 of the Federal Constitution establishes the family as the basis of society and awards it special protection by the State. The National Social Assistance Policy (PNAS) explicitly recognizes the centrality of the family, considering it *a privileged and irreplaceable space for primary protection and socialization, providing care for its members, but which also needs to be cared for and protected* [17].

In health care, especially in primary care services, the family is considered an ally to define promotion, prevention, or curative actions. But authors draw attention to the fact that these services are not always clear about who constitutes the family, object of their practice, *nor about the kinship ties present in it, aspects that have implications in the therapeutic treatment* [18].

Despite its prominence in public policies, the family is not usually adequately understood, let alone provided with sufficient mechanisms and resources to carry out the social protection actions delegated to it. This aspect configures "familism," understood as the transfer of state responsibility to the family institution, as well as the excessive responsibility of the family in caring for its members, to the detriment of society and state participation [5].

Familism is historically legitimized in legal mechanisms that indirectly regulate the family's responsibility for care, such as the Older Adults Statute and the Child and Adolescent Statute (ECA) [15]. These are clear examples of the trend towards the decline of state participation in caregiving, a fact that imposes a great burden on the family, which is then responsible for meeting the needs of its members and of society [7].

The State's omission goes against the shared responsibility recommended in article 4 of ECA, Law 8,069/1990: *it is the duty of the family, the community, society in general and the public authorities to ensure, with absolute priority, the realization of the rights to life, health, food, education, sport, leisure, professional training, culture, dignity, respect, freedom and family and community life* [19].

As stated in the Charter on the Rights of Children at the End of Life [20], children in palliative care must have their personality, individuality, values, life history, and daily routine respected, besides needing adequate support and assistance to ensure their quality of life throughout the evolution, disease treatment, and death process.

Children and adolescents in palliative care, often dependent on life-sustaining technologies, are made invisible and depersonalized. They live confined to bed, connected to various devices, and have weakened family ties due to the overload of the main caregiver. Moreover, they are segregated from society and maintain exclusive contact with the home or institutional environment and health professionals, being completely deprived of access to education, leisure, culture and, consequently, to human dignity.

Consequently, despite having access to the right to health, even if precariously, their other rights are most often neglected. We must therefore recognize these children and adolescents as subjects of rights and provide them with an active voice. Tristán drew up a proposal for a declaration of the rights of terminal ill children, which expresses the need for their protagonism in directing their care, verbalizing their rights in the first person:

I have the right to be seen and conceived as a subject of rights and not as property of my parents, doctors, or society; I have the right to have an say in decision-making, since I'm the one who's sick; I have the right to cry; I have the right not to be alone; I have the right to fantasize; I have the right to play; for even in the terminal stage I am still a child, or behave like a teenager;

I have the right to pain control from my first day of life; I have the right to the truth about my condition, to have my questions answered honestly and truthfully; I have the right to have my needs fully addressed; I have the right to a dignified death, surrounded by my loved ones and beloved objects; I have the right to die at home, if I so choose; I have a right to feel and express my fears; I have the right to have my parents heled to prepare for my death; I have the right to feel anger, anguish, and frustration over my illness; I have the right to refuse to continue receiving treatment when there is no cure for my illness, but rather quality of life; I have the right to palliative care, if I so desire; I have the right to be sedated when facing my death, if I so desire; I have the right to be painless when undergoing diagnostic procedures and treatment for my disease; I have the right to have my parents understand that, although I love them a lot, I am going to a new life [21].

Besides ensuring rights, it is of key importance to consider the level of understanding of the child in palliative care, so that their individuality is respected. This is true both for those who are able to verbalize, and for those who are not, due to their stage of development or clinical condition.

Palliative care, besides representing a public health approach, is a human rights issue [8]. To fully protect and ensure the rights of children and adolescents in palliative care is a complex challenge that involves society's understanding of youth with chronic and life-limiting diseases, the strengthening the social support network, the social-family or institutional context in which they are inserted, as well as the implementation of public policies.

In this perspective, social workers, alongside the multidisciplinary team, plays a key role. With their technical-operative tools, they assess the risk and protection factors experienced by the child, identify their family members and caregivers, and learn about their limits and potential, to assist in the joint construction of strategies for the well-being of the family unit and guarantee the rights of the child in pediatric palliative care. Thus, they corroborate the humanization of care and the role of the family as an active subject in the process, and not as a mere object of intervention [22].

Patient and family

Role of the healthcare team in pediatric palliative care

In palliative care, patient and family make up a unit and, therefore, the latter must be included in the team's perspective [23]. As previously mentioned, the illness progression and the imminence of infant death imply intense suffering for all involved and, therefore, the health team needs to listen, understand, and monitor, meeting demands that are often implicit and require a more attentive and sensitive approach.

In a study carried out in the United States, parents of children who died in pediatric intensive care units reported that complete and honest information, regular and easy access to the medical professional, coordination and alignment in communication, emotional involvement by staff, preservation of the relationship between parents and children, and spiritual support are priorities in this process [24].

In a literature review, Fonseca and Rebelo [25] emphasized the following factors as contributing to the caregivers' role: the support provided by the palliative care team, the previous experience with another care situation, the quality of the relationship with the patient, and the mindset of living one day at a time. On the other hand, the sudden need to play such a role, the associated responsibility, the difficulty in communicating with the medical team, the non-inclusion in the care plan discussion, the unpredictability of the moment, and the frustration of waiting for death were obstacles.

Dealing with a life-threatening illness demands a lot from everyone involved. Therefore, each element of the composition (patient-family-team) must play its role in the best possible way and the three participants must unite in a therapeutic alliance [9]. To this end, health professionals must know how to listen and observe in order to capture the situation experienced by the patient, according to the meaning it has for them [26].

Faced with the impossibility of a cure for the disease, the therapeutic goal is redirected to care through symptom control and efforts to ensure quality of life. In fact, this should be the goal from the beginning in all health relationships, according to the medical commitment to "cure sometimes, relieve often, comfort always" attributed to Hippocrates. Since this new person-focused care relationship requires knowledge of people's biography, relationships, desires, values, and preferences, dialogue is central. Magalhães and Franco state that *the dialogic condition is fundamental in terminality*[27], since, besides dialogue, it includes respect and autonomy.

The professional's personality, therefore, is also an instrument of care[8], with regard to their capacity, availability, and professional potency. Moreover, health and educational institutions contribute positively by promoting actions to improve and train workers. Besides, they provide care spaces for caregivers, welcoming their pain, alleviating suffering, and helping to create coping strategies.

Nonetheless, professionals are unprepared to assist, understand, accompany, and help a human being before death[9]. As pediatric palliative care requires adequate and welcoming communication, professionals must know what, when, and how to speak and even to be silent. *Pediatric palliative care professionals must work in a "relational, humanized, and affective" manner, aware of their thoughts and feelings, with self-care and emotional self-control. Thus, the professional is able to express an "appropriate" reaction when interacting with patients and family members, to reach consensus in end-of-life decisions*[8].

Besides technical competence, palliative care requires interpersonal skills and communication and sharing of decisions play a key role in the provision of care. *The family must be informed about the evolution of the disease, alerted to possible symptoms and to the progress of the final stage*[25]. Such information, which is often characterized as bad news, must be given according to what the patient and family want to know and are prepared to receive, in a progressive, continuous, and accessible manner[28].

Patients have the right to abdicate this information, appointing a relative or someone close to establish communication and share health decisions. On the other hand, it is difficult for a relative to deal with this knowledge, as they do not always know how to manage it with the patient, which can generate a conspiracy of silence[9] and lead to more suffering. This reinforces the importance of the healthcare team's role in developing active listening and effective communication.

Professional assistance at the time of the child's death will directly affect the subsequent experience: mourning. Consequently, strengthening the family and supporting them in performing the shared role of caregiver is essential in their search for meaning for the end of life and for the task of caring[1]. When the family is able to be present, *when there is a feeling of tranquility/mission accomplished about the follow-up process of the departed person, mourning seems to be easier*[9].

Family, society, and the State, represented by the healthcare team, working together, can and should ensure that the patient's life is comfortable, with quality, and that their departure is dignified and peaceful, the end of suffering. And, for those who stay, may only the experienced love endure.

Final considerations

Humanizing is about becoming human, benevolent, agreeable, tolerable; giving or acquiring human condition; humanizing oneself. Palliative care, by facing one of humanity's greatest fragilities – death – requires a humanized approach. This reality exposes the deepest feelings, several vulnerabilities and dimensions of suffering, being a potent situation that, for this reason, requires sensitivity.

The evolution of technical-scientific mechanisms has led death to a place of social isolation[8]. Palliative care was developed in response to such marginalization and in opposition to therapeutic obstinacy and futile interventions, redirecting the focus of intervention from the disease to the person. To see the human being in their biopsychosocial insertion transforms health care, and this transformation, made possible by the humanization of care relations, involves the democratic radicality of the common good[29].

To ensure the common good, we must align the child-family-team triad, with each party assuming its responsibilities and enforcing its rights, and recognize it as a unit of care. Such relationship involves several types of care: self-care, care for others, the task of caring, and profession.

Providing care, therefore, is much more than a moment – it is affection, occupation, commitment, exchange – and involves therapeutic encounters [30] between subjects who seek solutions and meanings for the illness process. *The more care becomes an experience of encounter, of true dialogic exchanges, the more it moves away from an exclusive application of instrumental knowledge, the more the intersubjectivity experienced there feeds back its participants with new techno-scientific and practical knowledge* [30]. Participants in this scenario are the patient, the team, and the family [27].

The encounter between child, family, and healthcare team must result in a human relationship of exchange aimed at everyone's well-being. In this relationship, palliative care finds meaning in respect and protection, as to ensure the inviolability of human dignity at all stages of life.

The word "palliative" derives from the Latin *pallium* and refers to the cloak wore by knights to protect themselves from the weather during the Crusades. To palliate, therefore, means to protect, to support. It is up to us, health professionals, to take care, humanely and competently, of those who have entrusted us with the precious time of their limited life, wrapping the child in a protective mantle, for a dignified life and death. *We are privileged to work with people who are suffering, who are sick, who are dying, because it is at this moment that human beings become aware of their humanity, and that is when they teach. Whoever is around should take the opportunity to learn* [31].

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