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ORIGINAL ARTICLE

Knowledge of pediatric residents about concepts and teaching of palliative care during postgraduate studies

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Abstract

Introduction: Palliative care consists of multidisciplinary assistance capable of improving the quality of life of patients with serious and threatening illnesses, integrating physical, psychological, social and spiritual aspects to the so-called "conventional" treatment, relieving pain and suffering in all its aspects faces. **Objective:** to evaluate the knowledge of pediatric residents about the concepts and teaching of palliative care during postgraduate studies. **Methods:** This is a descriptive, qualitative and phenomenological study. Results: 12 residents of the last year of the medical residency program participated, who, when expressing their conceptions on the subject, presented peculiarities of a care that has been improved over time, breaking paradigms, such as the search for cure and maintenance of life at any time. price, without making room for an approach aimed at the human being in its entirety. For them, this Gordian knot can be resolved with the acquisition of technical skills, communication, rehabilitation and knowledge of the process of dying and death. **Discussion:** Human beings are very innately resistant to facing death naturally, as part of life; this stems from social, cultural, spiritual, emotional aspects and teaching in the health area itself, evidenced by the interviewees lack of knowledge about the dimension of palliative care, without, however, disregarding its importance. **Conclusion:** Such characters do not feel empowered to interact with patients and family members in order to discuss the terminality. These results show a timid posture, and the peremptory need for this topic in professional training.

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INTRODUCTION

In 1982, the World Health Organization (WHO) Cancer Committee created a working group responsible for developing policies for pain relief and palliative care. In 1990, this same group defined palliative care as active and total care for patients whose disease is not responsive to curative treatment, and in 1998 they established the first specific definition for children. In this definition, they suggested that the assessment and relief of suffering should be priorities in the approach, going beyond the biological field, reaching the psychic, social and spiritual spheres, in order to offer active and total care to the child and their entire family[1,2]. In 2002, in a new conceptual review, the WHO no longer distinguished between palliative care for children and adults. The revised definition establishes a multidisciplinary approach with the aim of improving the quality of life of patients with life-threatening illnesses, integrating psychological and spiritual aspects into treatment, preventing pain and suffering, whether physical, psychosocial or spiritual. Also, according to the review, death should be considered a normal process, which should not be rushed or delayed, and the patient and their family members should be offered a support system to assist with end-of-life care in the dying and mourning processes[3].

Data published in 2014 estimated that around 40 million people would need palliative care worldwide, of which 78.0% lived in poor and emerging countries, and only 14.0% received appropriate assistance, which, according to the WHO, is the result of the population's lack of knowledge on the subject, cultural and social beliefs, the lack of competence and skill of healthcare professionals, and even the excess of regulations that restrict the use of opioids and other analgesic medications[4].

In Brazil, palliative care, in its most modern perspective, combining clinical care, training and research, dates back to the late 1950s and early 1960s. The Global Atlas of Palliative Care published in 2014 by the WHO, presented an overview of palliative care around the world. In this document, Brazil received a 3A classification, which means that palliative care is still provided in isolation, insufficient funding, limited availability of analgesics and a small number of specialized services[4-5].

The country does not have any public health policy that specifically structures or guides the development of palliative care, and the regulations are limited to seven ordinances published between 1998 and 2014, providing this care almost exclusively to patients and cancer centers[5-6].

Given this scenario, the National Academy of Palliative Care carried out a survey on palliative care available in Brazil until August 2018. On that date there were 177 specialized services, of which 58% were located in the southeast region, followed by the northeast (20%), south (14%), central-west (5%) and north (3%), with half of these services coming into operation after 2010. In possession of this data, the academy suggested the creation of a National Policy guiding palliative care in Brazil, incorporating it into the healthcare system, guaranteeing diagnosis, treatment, follow-up in specialized centers graded by complexity, and access to essential medicines, in addition to education and training programs for healthcare professionals[6].

Technological advances experienced in recent decades have led to the development of all areas of health care, including pediatrics, changing the profile of patients and their diseases, highlighting prevention as a focus of care, and demonstrating the need for pediatric palliative care in identifying and treatment of children suffering from chronic, progressive and advanced diseases, their families and the teams that care for them, seeking to offer the best possible quality of life throughout the illness process[2,7-9].

However, the teaching of palliative care in medical training is recent, and in many courses, restricted to the discipline of oncology. The definition of palliative care competencies, always aiming at continuous professional development and communication, whether during graduation and/or medical residency, are legitimate demands and a need that is increasingly imposed[10].

Canadian medical schools were the first to try to implement a curriculum focused on teaching palliative care, in 1993. In Brazil, the Federal University of São Paulo was the first medical school to make Palliative Care courses available on an elective basis to undergraduate students from 1994 to 2008, followed by the University of Caxias do Sul with the creation of a mandatory subject of Palliative Care in the year 2002[11,12].

Therefore, the objective of this study was to evaluate the knowledge acquired in graduate studies, relating to palliative care in its multiple dimensions and communication capacity. We believe that such skills would enable these professionals to be able to demonstrate more sensitivity, empathy and compassion in difficult situations, such as those involving death, adverse end-of-life events and bad news, for example. Communication in palliative care involves a complex mix of spiritual, social, psychological and physical issues in the context of the dying process, further resulting in patient dissatisfaction with the care they receive in the case of ineffective communication. Thus, the evaluation of this knowledge can reflect the reality of teaching in medical residency programs, enabling the development of intervention tools in order to train professionals with a broad, human and more sensitive vision[13,14].

METHODS

This is a descriptive, qualitative and phenomenological study, as it seeks to explain reality from the point of view of the people who live it, resulting in a fine, dense and faithful description of the reported experience. The descriptions were documented in a semi-structured interview, whose sample was non-probabilistic and accidental, with 12 residents in the final

year of the Pediatrics Medical Residency Program as subjects. The study was initiated after approval by the Research Ethics Committee linked to the Faculty of Medicine of Botucatu - UNESP (Opinion: 4.836.536; CAAE: 47938921.3.0000.5411), reading and signing of the Free and Informed Consent Form (TCLE) by the participants, guaranteeing the anonymity of their identities. Four guiding questions were prepared for the interview:

1) In your opinion, what is palliative care?
2) How do you classify the teaching of palliative care in your training as a pediatrician?
3) Based on your knowledge on the topic, which patient is a candidate for palliative care?
4) What limitations do you find in implementing palliative care in the unit where you are a resident?

To analyze qualitative data, we applied the "Content Analysis Technique", described as: "a set of communication analysis techniques, which aim to obtain, through systematic and objective procedures for describing the content of messages, indicators (quantitative or not) that enable the inference of knowledge relating to the production/ reception conditions (inferred variables) of these messages", categorizing the statements into three phases: a) pre-analysis, b) exploration of the material, and c) treatment of the results obtained by inference and interpretation, the systematization of the description of the collected data and the carrying out of the floating reading[15].

RESULTS

Twelve third-year residents of the pediatric residency program at a large tertiary university hospital in the interior of the state of São Paulo participated in this study. When expressing their conceptions regarding learning palliative care during residency, they presented the peculiarities of care that has been improved over time, especially in medical training, especially with regard to the management of pain and suffering, aiming to promote quality of life, and comfort for patients and their families.

What is palliative care

To understand the residents' perception regarding the teaching of palliative care in residency, it is necessary to assess how familiar they are with the topic:

> *...care is provided to patients with life-threatening chronic or acute illnesses, aiming at quality of life... (E4)*
> *...offer and guarantee quality of life, both for the patient and their family members, in the face of a certain disease condition... (E1)*
> *...a way of guaranteeing the relief of suffering, treatment of pain, welcoming the family and the patient himself, ensuring and respecting the dignity of the patient and their wishes in light of their clinical conditions... (E12)*
> *...is any form of care aimed at the patient's overall well-being, whether physical or mental... (E7)*
> *...in the pediatric age group, it covers children and adolescents with chronic comorbidities, whether or not associated with the finiteness of life, but which compromise quality of life... (E10)*
> *...represent a therapy that aims to provide comfort and well-being measures that are not necessarily curative... (E2)*

Teaching palliative care in medical residency

> *...I consider it insufficient, with few professionals qualified to apply the discipline to pediatrics students... (E3)*
> *...despite its extreme relevance, teaching is insufficient, both at graduation and during residency... (E9)*
> *...teaching is essential and necessary, but there is a lot to be improved, especially as it is a relatively new area in pediatrics... (E5)*
> *...underestimated... (E6)*
> *...should be understood as an area of medical activity, and not as an "arm" of oncology... (E1)*

Palliative Care Candidates

> *...every patient is potentially a candidate, considering that palliative care is not limited to care provided in the dying process... (E8)*
> *... chronic or acute patients at risk of death... (E7)*
> *...any seriously ill patient, or with illnesses that cause some degree of disability... (E5)*
> *... patients in whom their clinical conditions did not allow them to return to their previous full health conditions... (E4)*
> *...patients with life-threatening diseases and poor prognosis... (E1)*
> *...patients with chronic comorbidities that in some way compromise their quality of life or cause harm in any aspect, whether physical, emotional, psychological or spiritual... (E11)*

Limitations in implementing palliative care in your department

> *...absence of pediatricians trained in palliative care... (E11)*
> *...resistance from heads of departments, who do not allow their patients to be monitored by palliative care... (E12)*

...lack of knowledge among doctors, resulting in a lack of referrals and segments... (E4)
...lack of multidisciplinary and interdisciplinary team... (E7)
...specialists whose maxim is cure, not weighing up the benefits and harms of successive invasive interventions... (E8)
...lack of knowledge of the area by parents and professionals, who often view palliative care as a death sentence... (E1)
...lack of effective communication... (E6)
...absence of a doctor-patient-family bond that conveys security... (E3)

DISCUSSION

The term palliative care emerged in society with the need to reformulate the concept and care aimed at patients with life-threatening illnesses, who require constant care. In a very innate way, human beings are resistant to facing death naturally, as part of life; This arises from social, cultural, spiritual, emotional aspects and teaching in the health area itself, which can be evidenced by the lack of knowledge on the part of the interviewees regarding the dimension of the topic, characterizing it by repetitions of "jargon" such as chronic, risk of life, comfort and dignity, however, the appreciation of this care in the speech of residents[16,17] must be recognized.

This paradigm is reinforced in scientific training, which tends to seek healing and maintenance of life at any cost, and sometimes does not provide space for an approach to the emotional and spiritual aspects of the individual. From this perspective, death is often associated with loss and frustration, both by family members and healthcare professionals, the opposite of the concept currently applied to palliative care[17-18].

For those interviewed, the teaching of palliative care in medical residency is insufficient; underestimated. Given this reality, only a substantial change in management and in the undergraduate and graduate curricula of healthcare professionals (such as medical residency) will palliative care be consolidated in Brazil[18].

The training of these professionals must include, among others, communication skills, teamwork, competence in dealing with a threatening illness, management of pain and other symptoms, in addition to support techniques for coping with death and mourning; however, teaching in the health area leans towards technical-scientific training to the detriment of addressing emotional, spiritual and social aspects[18-19].

Working in this field requires not only a deep medical-scientific knowledge, but also a constant confrontation with death and the implications of the dying process, demanding the development of humanitarian and emotional skills, commonly little worked on in undergraduate and graduate medical programs. This professional is expected to be able to act promptly when faced with symptoms such as suffering arising from physical pain, dyspnea, nausea, delirium and constipation, regardless of the cause[18-20].

Palliative care presupposes comprehensive care for the individual and their loved ones, seeking to positively influence their health condition and quality of life, offering guidance, treatment and care even in cases in which there is no possibility of cure; however, identifying who is candidate for this care, constitutes a challenge for healthcare services, and often generates conflicts and confusion regarding terminology, both for the patient and their families, as well as for professionals, undergraduate and graduate students in the healthcare field[21-22].

Many scholars suggest as an option for indicating palliative care the assessment of the degree of capacity and functional dependence, using performance scores, being able to grade the risk of terminality of each patient; however, despite there being specific assessment methods for children, the interviewees' speech suggests lack of knowledge and/or low applicability in daily practice[23-24].

In contrast to the adult population, in which the majority of patients in palliative care have oncological diseases, and whose follow-up is generally carried out in hospices or home care, in the pediatric age group, congenital and genetic diseases are the most responsible for the indication of this care. Chronic neurological diseases and onco-hematological diseases appear next, and at this age, the end of life still occurs, for the most part, in the hospital environment[25-27].

Every year, around 1% of the population dies, whether due to unexpected or predictable causes. Although difficult, the role of palliative care is to recognize individuals in the final stage of life, regardless of the diagnosis, and provide care aimed at improving their quality of life, resulting in an increase in their survival, in addition to controlling the signs and symptoms arising of their pathological condition, and comfort to their loved ones[28-30].

Such conditions impose on the healthcare sector a horizon of great economic and management challenges, aiming to adapt and improve the healthcare model, especially in the training of professionals involved in this type of care[31].

Among the limitations presented by the interviewees, the lack of professionals who have an affinity with this topic, and the resistance of certain doctors, among others in the healthcare field, highlights the need for a broad discussion about medical training at undergraduate and graduate levels. Precise technical assessment is of paramount importance when dealing with patients with threatening diseases, and learning begins in clinical practice. The guidance of preceptors and teachers towards a reading focused on finitude, as well as technical capacity, through teaching throughout undergraduate and graduate programs, are decisive for this careful assessment[18-19,31].

The integration between teaching and assistance in the care of terminally ill patients is the great legacy left by Cicely Mary Saunders, and the so-called Hospice movement, at Saint Christopher's Hospice, in London, in 1967, spreading throughout the world. After more than 50 years, it is still a challenge for graduated professionals, as reported in the statements, which probably extends to graduates of different courses in the healthcare fiedl[32].

Reflecting on academic training, especially on the inclusion of the topic in the undergraduate and graduate medical curriculum, provides density to face the limitations and implications to which these professionals will be subjected; however, it is an important measure, given that, from it, basic elements of training can be constructed and/or revised, in order to expand the universe of professional activity, and also guarantee assistance to patients and their families, involving dimensions that affirm the dignity of the human being beyond of treatment with an exclusively curative bias[33-34].

CONCLUSIONS

Through the reports presented, we can conclude that residents do not feel qualified to interact with patients and family members in order to discuss terminal illness in those with threatening diseases. This study represents a small sample of the great complexity that exists between two concepts still under construction in the training of healthcare professionals: on the one hand, the concept of intensive care, based on technology and the incessant search for a cure, on the other, care palliatives, aimed at maintaining quality of life, far beyond cure.

The results also characterize the timid positioning of professionals, denoting the need to develop programs that, included in the curriculum, can contribute to developing the skills considered intrinsic to the doctor's performance in this type of care, especially communication, terminality, quality of life, comfort, and teamwork, always extending to family members and those who are part of the patient's circle and their sacred ones.

LIMITATIONS OF THE STUDY

The objective of this the study, the complexity of the topic, as well as the characteristics of the population analyzed, limited the exploration of all dimensions of palliative care, especially in the pediatric age group. However, we believe that it contributes to a deep reflection regarding the need for mandatory inclusion of palliative care in undergraduate programs, as well as in all medical residency programs. The need for training doctors capable of working in a multidisciplinary and interdisciplinary team must also be reinforced. Encouraging the active search for knowledge is a fundamental stone in the development of skills aimed at "new palliative care": that which sees life far beyond death.

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