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Therapeutic limitation for children: a systematic review on end-of-life

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Abstract

This systematic review sought to identify difficulties faced by professionals in the clinical management of end-of-life child patients. Bibliographic search was conducted on the SciELO and LILACS databases using the descriptors "therapeutic limitation," "hospice care" and "comfort measures," combined with the descriptor "child." Of the 102 complete studies identified, nine met the established inclusion criteria. The results point to difficulties regarding decision making and therapeutic limitation for infant patients. In conclusion, when professionals feel better prepared to address issues related to the process of death and dying, they can provide more humanized care to patients and families.

Keywords: Hospice care. Child. Right to die. Attitude to death. Health personnel.

Resumo

Limitação terapêutica para crianças: revisão sistemática sobre final de vida

Esta revisão sistemática visa identificar dificuldades enfrentadas por profissionais no manejo clínico de crianças em final de vida. Para tanto, realizou-se busca de artigos científicos nas bases de dados SciELO e LILACS por meio dos descritores "limitação de suporte terapêutico", "terminalidade" e "medidas de conforto", combinados com o descritor "crianças". Do total de 102 trabalhos completos encontrados, nove contemplaram os critérios de inclusão para a amostra do estudo. Os resultados apontam dificuldades em relação à tomada de decisões e à limitação terapêutica de pacientes infantis. Conclui-se que, quando se sentem melhor preparados para trabalhar com questões referentes ao processo de morte e morrer, os profissionais podem prestar um cuidado mais humanizado a pacientes e familiares.

Palavras-chave: Cuidados paliativos na terminalidade da vida. Criança. Direito a morrer. Atitude frente a morte. Pessoal de saúde.

Resumen

Limitación terapéutica para niños: una revisión sistemática sobre el final de la vida

Esta revisión sistemática tiene por objetivo identificar las dificultades que enfrentan los profesionales en el manejo clínico de los niños al final de la vida. Para ello, se realizó una búsqueda de artículos científicos en las bases de datos SciELO y LILACS utilizando las palabras clave "limitación del apoyo terapéutico", "final de la vida" y "medidas de confort", combinadas con "niños". Del total de 102 artículos completos encontrados, nueve cumplieron con los criterios de inclusión para la muestra del estudio. Los resultados apuntan a dificultades con relación a la toma de decisiones y a limitaciones terapéuticas de los pacientes pediátricos. Se concluye que los profesionales cuando se sienten más preparados para lidiar con cuestiones relacionadas con el proceso de muerte y morir pueden brindar una asistencia más humanizada a los pacientes y familias.

Palabras clave: Cuidados paliativos al final de la vida. Niño. Derecho a morir. Actitud frente a la muerte. Personal de salud.

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Illnesses are a common phenomenon throughout people's lives, resulting in several physical, social and psychological changes, referring to a particular and subjective experience. Each subject will have a different perception and different understanding of this complex experience that affects different dimensions of human life. Chronic and noncommunicable diseases are estimated to be responsible for about 41 million deaths per year worldwide, about 70% of all deaths.

About 300,000 new cases of cancer are identified in the world each year among children and young people up to 19 years of age [1]. Children and/or adolescents affected by a chronic disease undergo numerous transformations in their lives, as their routine is altered and limited by the disease. These changes permeate the emotional, psychological and social spheres and affect family, school and hospital issues—such as decision-making and the flow between health services—, bringing a series of consequences for patients and their families [2].

Talking about a chronic and incurable disease, such as some types of cancer in pediatric patients, raises greater anxiety and even a certain fear, as the vital cycle between birth and death becomes very small. The disease interrupts and interferes with what theoretically would be the natural course of life, that is, being born, growing and developing; thus, it destroys projects, plans and dreams of a full and happy future. Therefore, the death of a child is seen as inconceivable and, when associated with cancer, bears anguish and fears among those who maintain a bond and live with them [3], whether they are family members or even the health team that cares for them.

Culturally, in Brazil, there is some resistance to addressing child patients' finiteness of life, both by family members and by the health team that cares for this patient. In the latter, it often awakens feelings of anguish, powerlessness, guilt and denial, which generally interfere in the relationship between professional and patient [4]. This occurs because health professionals are unprepared to handle the dying process: even during training in the health area, there is a deficient and inadequate approach to psychological aspects and even ignorance of the problem of death, as well as a lack of preparation to deal with other difficult situations [5].

Furthermore, students are prepared to deal with illness and avoid death at all costs; consequently, they deal with death through defensive mechanisms, such as denial [6]. Behind the ideology of non-involvement is an attempt to distance physicians from their own finiteness, that of their loved ones, and the limits of medicine in the face of death [7].

Human resistance to address death as a theme is historical and cultural. Evolution is seen in many aspects; medicine has contributed with diverse knowledge and technologies that enable to overcome previously incurable diseases, making it possible to increase the population's life expectancy. But the fact is that, at some point, the human body stops working and death is present. Thus, education for a full understanding of the life cycle, which covers all phases of human development [8], including death, becomes increasingly urgent and necessary.

For professionals who work in children's oncology units, death raises many questions about the ability to reverse the situation and/or about the effectiveness and objectives of the care provided—and this ends up generating suffering and internal conflicts. Professionals who deal with the presence of death in their daily lives complain that daily care awakens feelings of frustration, fear, anguish, lack of motivation and insecurity [9], as the death of a child with a chronic disease is a difficult and painful process.

Given this adversity, when all possibilities of reintegrating health conditions are exhausted and death is inevitable, the importance of addressing end-of-life care for terminally ill patients is perceived. Caring for the dying implies seeking to ensure dignity and comfort until the last minute of the patient's life. For this to be possible, a supportive and welcoming environment is needed, one that contributes to minimize pain, alleviate anguish and reduce avoidable damage, resulting from a body in progressive decline, thereby allowing a serene death [8].

Considering the dignity of the child patient during the illness and the approach of death, the team's decision regarding the most appropriate treatment in this situation cannot represent abandoning the patient or suspending therapy aimed at relieving suffering and ensuring, as much as possible, the physical, psychological and spiritual well-being of the child[10].

Once intense suffering and physical and psychological damage is identified, more appropriate measures are needed for treating these patients, such as orthothanasia, conceptualized as a care practice that takes into account the natural course of life, with death being part of existence. Orthothanasia seeks to alleviate suffering by adopting palliative care and avoiding unnecessary procedures, which only prolong the death process, causing greater suffering for the patient and his family[11].

Working with pediatric patients who are going through the terminal phase of the disease is a great challenge for health teams due to the complexity of the events involved. Palliative care is essential, which requires the work of an interdisciplinary team. From the perspective of interdisciplinarity, it is necessary to think about the team's joint action, so that, guided by bioethical principles, health professionals are able to help the person in their dying process, having the preservation of dignity and the relief of suffering as guiding threads[12].

Thus, when the team decides on therapeutic limitation, the disease is allowed to take its natural course, in order to make this moment less painful and invasive, since the use of artificial and mechanized procedures would bring even more pain, as they are ineffective in resuming life. Therefore, it is believed that health professionals who work with end-of-life patients have the opportunity to develop skills and competencies to deal with the limits of life and can learn to recognize that there are limits to healing, but not to care. The last moments of life should be as valued as the first[13].

One can state that all people involved in the process of the child's finiteness, whether family members or team professionals, suffer in the face of the loss. Therefore, identifying and understanding the meanings attributed to the event can provide the health team with subsidies and relational resources to improve listening to the needs of families and children under treatment, in order to contribute to a more humanized assistance[3]. Therefore, this systematic review aims to identify the difficulties presented by professionals in the clinical management of children in the end-of-life process, based on what has been described in scientific articles.

Method

This is a systematic literature review on health professionals' difficulties in the face of pediatric patient death. According to Sampaio and Mancini[14], it is a type of research that enables, in a clear and explicit way, a rigorous synthesis of studies on a given subject. Literature reviews guide the development of projects, and therefore, require a clear question, the definition of the search strategy, the establishment of criteria for inclusion and exclusion of articles and, fundamentally, a careful analysis of the quality of the selected literature. Its report complies with the Preferred Reporting Items for Systematic Reviews[15].

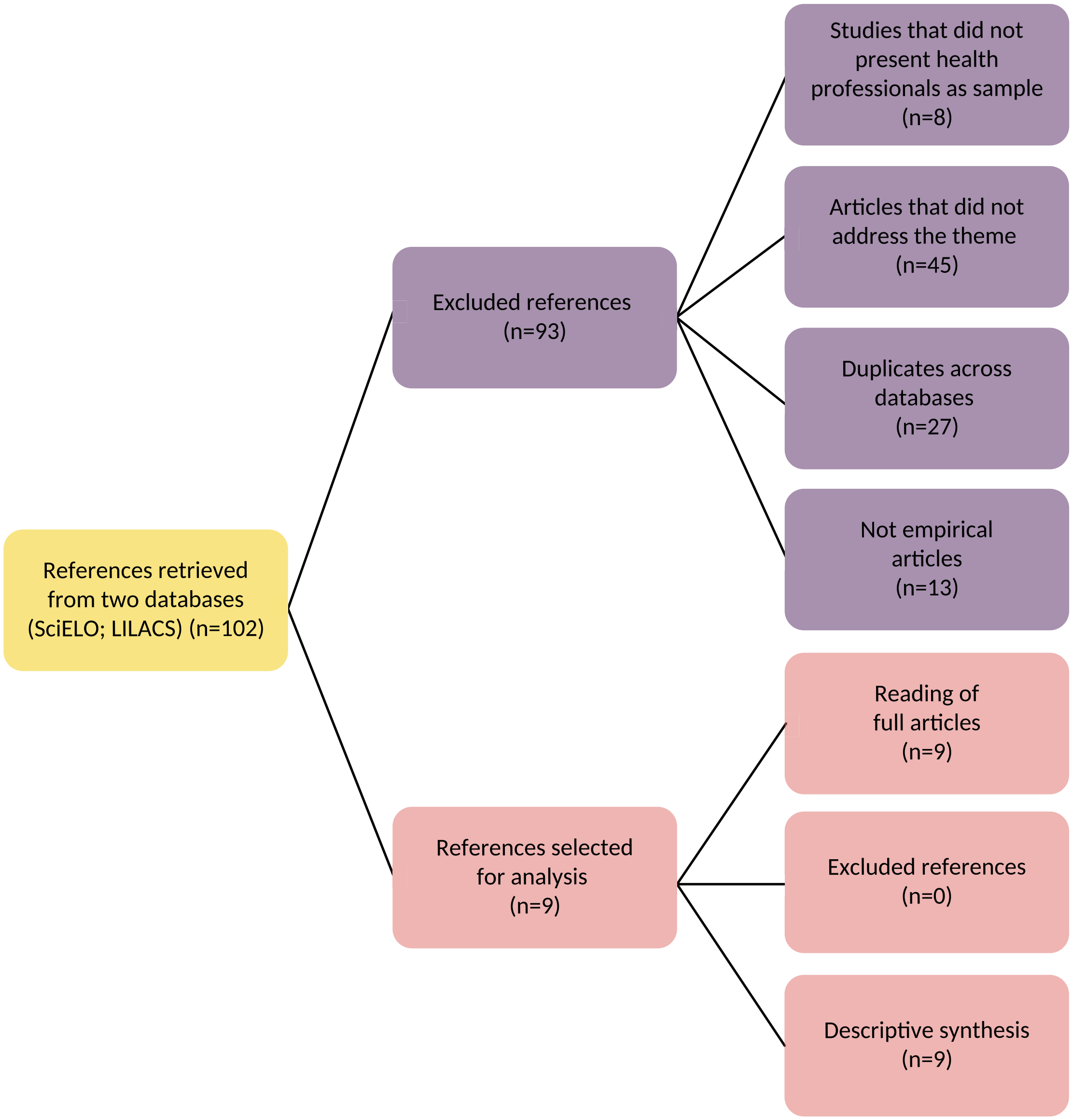
The following keywords, in Portuguese, were used in the search for articles: "*limitação de suporte terapêutico*" (limitation of therapeutic support), "*terminalidade*" (terminality), "*medidas de conforto*" (comfort measures) and "*final de vida*" (end of life), combined with the descriptor "*criança*" (child). The searches were carried out in August 2019 in the SciELO and LILACS databases, chosen for providing access to the full text of Brazilian and international publications.

After the search, a total of 102 complete works were found: 71 in SciELO and 31 in LILACS. The titles and abstracts of the works were read independently by two referees in order to delimit the sample of works to be analyzed in full.

After the analysis, nine works were chosen for the study sample, as they met the following inclusion criteria: report information about the difficulties presented by professionals in the clinical management of children in the end-of-life process; be written in Portuguese, English or Spanish; be a study published between January 2008 and December 2018; be a qualitative article; be an empirical article; and to have health professionals as a sample.

The exclusion criteria were: theoretical articles, theses/dissertations, books and annals; and incomplete articles. Therefore, 93 articles were excluded, for not having health professionals as a sample (eight studies); for not presenting information related to the difficulties demonstrated by professionals in the clinical management of children in the end-of-life process (45); for being duplicate articles (27); and for not being empirical articles (13). The inter-judge concordance rate was 96.5%. Disagreements were settled through reassessment by a third judge. The article selection procedure is detailed below, in Figure 1.

Figure 1. Article selection procedure



The information taken from the selected articles were grouped into a presentation domain that considered the authors, objectives, sample, instruments, results obtained and discussion. Study results were analyzed based on the congruence and repetition of the topic of interest, being classified into categories related to relevance for analysis and adequacy to the proposed objective. After reading the articles in full, two independent evaluators chose the categories to be analyzed.

Results

Data analysis was carried out from the exhaustive reading of the selected articles.

After reading and identifying the articles that discussed the finiteness of life of children with a chronic disease, nine articles remained for analysis.

The objectives of the studies, their methodological characteristics (sample and instruments) and main results were systematized in Chart 1.

Chart 1. Summary of information presented in the reviewed articles

Authors; year	Purpose of the study	Sample	Instruments
Menin, Pettenon; 2015 [16]	To understand professional nurses' perceptions and feelings in the face of the death and dying process in childhood	Nurses	Questionnaire
Paranhos, Rego; 2014 [17]	To know the ethical arguments of pediatric intensive care physicians from a pediatric intensive care unit in the city of Rio de Janeiro to justify their decisions in cases of limited life support and critically analyze them	Pediatric intensive care physicians	Semi structured interview
Soares and collaborators; 2013 [18]	To understand the vision of a multidisciplinary team regarding a child with leukemia in palliative care	Health professionals	Case study
Santana and collaborators; 2017 [19]	To understand the meaning of the dying with dignity process in an intensive care unit as perceived by nurses	Nurses	Unstructured interview
Fernandes and collaborators; 2018 [20]	To understand health professionals' social representations about terminally ill children and adolescents	Health professionals	Semi-structured interview and associative network or free word association
Afonso, Minayo; 2017 [21]	To study of relationships between onco-pediatricians, mothers and children in sharing difficult news in a public hospital in Rio de Janeiro	Medical	Interviews and participant observation
Silva and collaborators; 2017 [22]	To know the nursing team's experiences of care practices in relation to newborns at the end of life and their families, experienced in the neonatal intensive care unit	Nurses	Semi structured interview
Gomes and collaborators; 2014 [23]	To know the nursing professionals' experiences when giving difficult news to the family of a hospitalized child in a serious situation or in a terminal process	Nurses	Semi structured interview
Carvalho, Lunardi; 2009 [24]	To understand how nurses have been facing the implementation of therapeutic measures that they recognize as futile	Nurses	Semi structured interview

With regard to therapeutic measures, Carvalho and Lunardi [24] understand that, due to the team's difficulty in dealing with the death and dying process and the failure to recognize the impotence to avoid it, professionals opt for life-prolonging therapies, which are nevertheless ineffective in promoting healing. A large part of the nursing team is unaware of the terms "therapeutic obstinacy" or "futile treatment," but recognizes that they are very common practices. For the nursing team, the terms mean prolonging the patients' lives and suffering even if they are beyond the possibilities of cure.

Menin and Pettenon [16] explain that nursing professionals feel unable to deal with situations involving assistance in the death and dying process of child patients. In this case, it is essential that they understand that the care provided to the terminally ill patient provides quality to the life that remains and will enable a dignified death. However, the implementation of palliative care is little discussed and outlined among health professionals, and its concept is still not very clear to the nursing team [22]. There is also a lack of communication in the decision-making process across the different professionals on the team, as this is centralized in the medical team, which demonstrates a paternalistic care model that has the physician as the authority responsible for end-of-life decisions.

Paranhos and Rego [17] corroborate these ideas, pointing out that physicians are aware of the importance of family participation and the right that the family and the child have to decide about the facts of their life. However, it is observed that, in practice, doctors place themselves as holders of knowledge, claiming for themselves the technical and moral authority to decide on behalf of patients, without considering theirs or their families' participation. For Santana and collaborators [19], professionals should pay special attention to family members, in order to establish a bond with them, as this can help to make this experience as less traumatic as possible. A family that is aware and well-informed about the procedures that may occur with their relative facilitates the process.

Fernandes and collaborators [20] point out in their research that different feelings emerge in the health team that works with the finiteness of children and youth patients; professionals experience a variety of feelings such as pain, suffering and love. Such feelings contribute to the reconnection with the essence of humanity and, thus, enable the humanization of care and practices of health team professionals. Working with palliative care in terminally ill pediatric patients involves great suffering for both the health team and the family. Professional practices should seek humanized and comprehensive patient care; therefore, welcoming them and their families is a fundamental measure to provide comfort and relief from pain and symptoms [18].

Afonso and Minayo [21] contribute to these ideas when stating that professionals who perform treatments at risk of death mobilize different emotions, as well as suffer changes in mood. However, if they are better prepared, through continuing education and training, they are more confident in their choices and, thus, there is a decrease in the tensions involved in the process of caring for terminally ill patients. In this way, professionals who seek to understand and work on their emotions ensure adequate actions and better performance with patients and family members.

Professionals' difficulty in dealing with their own feelings related to the finiteness of a child patient's life and the possibility of causing suffering to family members can lead to embarrassment in communicating difficult news. In this situation, some professionals prefer to distance themselves from patients and their families. Health team professionals feel safer to talk about the end-of-life process when the difficult news has already been communicated by the doctor and the family is already aware of the seriousness of the case [23].

Discussion

With the organization of the data obtained, it was possible to extract important information that is more relevant for this analysis. Thus, the nine selected articles were grouped into three categories, based on the central ideas found in the texts and named as follows: health professionals' feelings in the face of the death of a child patient; difficulties in making a decision: limitation of therapeutic support and comfort measures in pediatric patients; difficulties related to care in the death process and the dying of a child patient.

Health professionals' feelings about the death of a child patient

Death is an event that by itself brings about a range of feelings and emotions in the subjects who experience it, whether due to the death of a family member, loved one or even people who are not so close. This is because death represents the finiteness and closure of the life cycle. In the hospital context, where death can be more recurrent, feelings of sadness, impotence, anxiety and fear are common among health teams.

These feelings can be enhanced because they are related to bonding, coexistence and complicity between professionals, patients and family members. The death of a patient is viewed negatively by professionals, as they perceive it as a failure of therapy and care actions; thus, the patient's death is synonymous with failure, impotence, frustration and guilt[25].

According to Souza and Reis[26], when the death is of a child patient, the suffering of health professionals is further aggravated. In their research, the authors report that 100% of the interviewed nurses suffer negative feelings when experiencing a child death, which causes significant impacts on their quality of life.

In this sense, Santana and collaborators[27] address that working with death in childhood is extremely painful and complex, since the academic training of professionals is completely focused on saving lives, and not on becoming familiar with issues involving human finitude. Thus, regardless of professional experience and working time, health professionals always struggle with the death situation, as they feel frustrated and powerless.

For Machado, Souza and Rahim[28], the difficulty in dealing with emotions resulting from death situations can lead to illness in the entire health team, since feelings of powerlessness, weakness and sadness are recurrent in the team. Denial is also a very common behavior in this context, as the professional avoids suffering by not getting in touch with the patient's loss.

Navais and collaborators[29] address that, for the professionals who provide this care, each patient is unique and every effort is made to save them, as the loss of a child implies a tragic and painful meaning, fostering feelings of regret, impotence, shock and anguish. Faced with such difficulties, the team's pediatric grief process is still not recognized, and there is no opportunity for public expression to facilitate the experience of grief. Psychological support and spaces that allow the development and expression of feelings are needed, as professionals need to be supported in their suffering and in situations of vulnerability.

Faced with the circumstances of the death and dying process that the child and their family members experience in the hospital context, Pereira, Bertoldi and Roese[30] corroborate the other authors and report that this work generates conflict for health professionals because it is related to proximity with feelings of pain, death and suffering. Some demonstrate greater sensitivity to the suffering of the child and the family, and others report that there is no difference in relation to the care given to the other children in the unit. Mental health prevention and promotion strategies to reduce anguish, anxiety, fear and concern are effective for qualifying the care of children and their families.

According to Machado, Souza and Rahim[28], it is necessary for each professional to be aware of their limitations and weaknesses so that they can seek coping strategies to better deal with such situations, in order to protect themselves from emotional exhaustion. To address these issues, it is important to create spaces for discussion, development of grief and emotional strengthening of the team, so that there is a reduction in anxiety and other negative feelings that affect the team. Professionals will thus feel better prepared to face the adversities and difficulties that the grieving process causes, which will enable better support to families who also suffer from the loss of a family member.

Limitation of therapeutic support and comfort measures in pediatric patients

Five articles addressed the difficulties in making decisions about therapeutic limitation and comfort measures in pediatric patients. Armijo, Hurtado and Ocares[31] talk about health teams' difficulty to limit the life support of pediatric patients, since, because they are children, there is an almost unanimous need, on the part of the team and family members, to decide on curative rather than palliative interventions.

This occurs because the issue of death is still little studied in undergraduate courses in the health area, since the efforts are geared to cure illnesses. According to Armijo, Hurtado and Ocares[31], with advances in technology, life expectancy has increased. However, the measures taken do not always benefit the patients and, in this case, end up unnecessarily prolonging their lives, bringing great suffering to all involved; the treatment thus becomes disproportionate. This type of conduct sometimes produces and reproduces inhuman practices that generate even more pain and suffering for the patient, in addition to violating professional ethics. Thus, it is essential that there be many discussions and debates about the bioethical issues that this whole process entails.

In this same context, Linhares, Siqueira and Previdelli [32] explain the insecurity of health professionals to make decisions regarding more complex moral conflicts. Their conduct reflects their concern to protect themselves from legal conflicts. Thus, there is great resistance to suspending life support measures, as physicians fear being accused of failing to provide assistance. And, even in situations of terminal illness, there was no record of suspension of life support, and most patients underwent cardiorespiratory resuscitation maneuvers before death. Professionals also emphasize the importance of the family in decision-making, but the medical records did not record the participation of family members, nor consultations with the hospital's ethics committee.

Limiting therapeutic efforts for children with chronic diseases at the end of life should be a decision taken by the health professionals team together with family members and will depend on the particularities of each patient [33]. In this sense, nursing professionals feel insecure to make decisions involving the end of life of patients—both in legal matters, as they do not have ethical support that specifies their performance, and in decisions related to patient treatment [19].

In selected articles on limiting therapeutic support or not, Mazutti, Nascimento and Funis [34] bring in their study the issue of life-prolonging treatments and curative practices that stand out in patients in serious condition; according to the authors, these practices have been changing over time and are currently being discussed again. There is a tendency to favor dying with dignity, prioritizing palliative care and thus providing more humane treatment to the patients, respecting their emotional and spiritual aspects and promoting the best way to spend their last days of life.

Thus, one can see the complexity involved in this decision process about limiting or suspending therapy, and such a decision must always be taken with a view to the best interest of the child, in order to provide an ethical and humanized treatment [10].

Care in the death and dying process of a child patient

Six articles address the difficulties of everyone involved in the process of finiteness in dealing with pediatric grief and issues involving palliative care provided by health teams when the therapeutic limitation has already been decided.

Children at the end of life, due to a chronic illness such as cancer, should receive palliative care. It is essential to be clear that death is not a disease, but a dimension of existence for which there is no cure. When the end of life affects a child, there is no sense of reality, that is, there is always hope for survival, which is extremely useful for the psychological and emotional strengthening of the child, as well as that of their family members. Theagents that facilitate grief do not prevent suffering, but favor resilience.

However, when professionals and caregivers are better resolved in their own questions about death, the child can be provided with better conditions of care and also of dealing with the disease [35]. Hence the importance of providing spaces for listening and discussions about death, whether during graduation, in improvement courses or even in the hospital itself, as a better prepared professional will enable the development of processes and issues that involve death on the part of caregivers and the patient.

In order for the best life-maintaining interventions and the best care models to be determined, it is important that there is a consensus among all those who provide care to the children, that is, health professionals, caregivers and the children themselves, when they are healthy enough for this [36].

Another issue observed in the articles is the difficulty for nurses to accept infant death. In view of the complexity of end-of-life care, it is necessary that, during the graduation of health professionals, palliative care in pediatric oncology is worked on and that all ethical and human issues involved in this process are discussed [37]. Thus, training and continuing education are of paramount importance for health professionals, because it was also found that they struggle with issues related to the care of the family, of the child and of themselves, because there is too much physical and psychological wear and tear [38].

For this reason, there needs to be a new model of care, which prioritizes the patients and focuses on the services provided, demonstrating to them and their families that, in fact, they are assisted by a conscious team that understands their real needs as human beings. This communication contributes a lot to develop care from the perspective of comprehensive care. Proximity to the professional will allow the construction of bonds, with a more effective and conscious practice and the establishment of a relationship of mutual trust, promoting the appreciation of patients and their families, as well as a better quality of life in the last moments [39]. Therefore, it is important that the professional be prepared since undergraduate education, and continuously after graduation, with courses directed to the area, training, participation in congresses, etc., aiming to provide a more humane and qualified service, respecting the limits of the patient and of their interventions.

Health professionals still lack preparation to deal with pediatric death. According to Borges and Gomes [40], issues related to the death and dying process of patients are not effectively addressed during undergraduate education. Most showed ignorance of the psychological stages of the death process. Furthermore, they themselves feel unprepared to deal with death and insecure in the face of a terminally ill patient and their family members.

Situations of patients in the process of death is a part of the routine of health professionals, and it is up to them to communicate news to patients and family members. However, according to Lima and Machado [41], these professionals do not have a theoretical basis or psychological resources to effectively carry out this task. This difficulty is not only related to theoretical incapacity, but also to affective issues that this process raises, as the professionals are faced with their own finitude. This complex moment of approaching death can generate feelings of sadness, anguish and anxiety in family members. Therefore, communication should provide a space that allows preparation for the death of the loved one, as well as a space to dialogue and think about death as something present and inherent to life [41].

One can observe a contradiction with regard to coping with the death and dying process, as those who should have better preparation and conditions to work this process with patients and their families have little psychological framework and coping capacity, which contributes for the lack of humanization in this very delicate process. Attention is drawn to the importance of effectively working on this topic since undergraduate education, so that professionals feel more prepared and confident to work with all the complex issues involving the death of a patient, especially the pediatric one.

Final considerations

From the discussion above, it is important to work with health professionals on issues related to decision-making, as well as the death and dying process, as this process directly affects the quality of life and the end of life of pediatric patients. There are countless repercussions of this process in the subject's life, and these interfere substantially in the emotional and psychological spheres of the child's relatives.

The results allowed to identify the need to expand studies and debates between physicians and health teams on the subject of death and the finiteness of life. The death of pediatric patients, common in health professionals' daily life, is still seen as a great taboo, which makes it more difficult for them to deal with it. For Silva [8], as we expand awareness and understand the finiteness of life, we increase care for this unique and non-transferable experience that is living.

Health professionals who feel more prepared to work with issues related to the death and dying process can provide more humanized care to patients and their families. This care must address all spheres involving the patient and his family, such as emotional, spiritual, and psychological support, among others.

Many professionals find it difficult to make decisions about therapeutic limitations and comfort measures in pediatric patients. There is an effort, on the part of the team and family members, to prolong the life of the pediatric patient, often insisting on maintaining invasive, unnecessary and curative measures and procedures, instead of investing in palliative care. With the evolution of technologies, there are devices that help to prolong life, but what must be analyzed is whether the patient is having some quality of life, if there really is a possibility of cure to keep him in these conditions, or if they are just prolonging the suffering and causing more harm.

In practice, these decisions involve moral and ethical conflicts. There is fear, on the part of professionals, of getting involved in legal issues and being sued for failure to act. Therefore, decisions involving therapeutic limitations at the end of a child's life must be discussed and made by all those involved—physicians, the multidisciplinary health team and the patient's family. Dialogue between everyone, with the aim of prioritizing the quality of life that remains for the child, can make this complex moment less painful for everyone, and especially for the child undergoing procedures and care.

The contributions of the professional psychologist are numerous and extremely important to deal with the aforementioned situations, due to their complexity—whether in supporting the patient and their families, or in supporting the health team that constantly suffers due to losses. Normally, health professionals do not have space or time to talk about their emotions, their anguish and suffering—which, in the long run, can cause psychological illness, such as depression, anxiety and stress. The role of the psychologist in this context can contribute to helping both the patient and their family members, in understanding the new situation they are experiencing, and the multidisciplinary team, so that they can provide comprehensive assistance to the subject and receive support [42].

This work does not intend to stop the discussions related to the theme, but seeks to stimulate studies, debates and reflections so that new research is carried out and disseminated. The study was limited to articles in two databases, with professionals as a sample. Prospective studies, with a broader sample and involving different databases, may increase the panorama of research carried out and further contribute to such an important topic.

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Daniela Trevisan Monteiro contributed to the discussions and reflections on the organization, delimitation of the theme, joint preparation of the text and final evaluation of the article. Danusa Scremin Rolim and Heloisa Toledo da Silva participated in the discussions and reflections on the organization and joint preparation of the text. Aline Cardoso Siqueira supervised the study, especially the discussions and reflections on the organization, and participated in the joint preparation of the text and final evaluation of the article.

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