Acta Bioethica 2023; 29(1): 39-48

PEDIATRIC PALLIATIVE MEDICINE IN BRAZIL: AN ETHICAL REFLECTION OF MEDICAL PRACTICE

Anderson de Almeida Rocha[1], Lurdiano Freitas[2], Juliana Cesconetto[3], Lara Calhau Rebouças[3], Vitória Barreto Salomão[3], Rui Manuel Lopes Nunes[4]

Abstract: The ethical barriers involved in the practice of pediatric palliative medicine remain high and challenging. In terms of medical ethics, attention should be paid to culture, religion and family values, in order to promote adequate care for caregivers, even in case of loss of a patient, promoting a bereavement process with less suffering. The data were qualitatively analyzed by IRAMUTEQ software, with a high degree of significance of essay responses on ethics related to palliative care in pediatrics. Discussions about prognosis, goals of care, and treatment options can be very difficult, as legally supported palliative care alternatives may diverge from the wishes of the family. We conclude that divergences exist between the application of palliative medicine and ethics regarding acceptance and end-of-life management of pediatric patients. Ethical challenges are constantly complex situations in which palliative physicians must relate legal concepts, knowledge and family values, which often conflict. The quality of palliative care depends initially on the ability of specialized professionals to identify and explain the ethical issues that generate conflict or uncertainty, in addition to raising discussions with the family about the medical, moral and legal issues surrounding the difficult situation.

Keywords: pediatric palliative care, medical ethics, medical practice, palliative medicine

Medicina paliativa pediátrica en Brasil: un reflejo ético de la práctica médica

Resumen: Las barreras éticas involucradas en la práctica de la medicina paliativa pediátrica siguen siendo altas y desafiantes. En términos de ética médica, se debe prestar atención a la cultura, la religión y los valores familiares, con el fin de promover una atención adecuada a los cuidadores, incluso en caso de pérdida de un paciente, promoviendo un proceso de duelo con menos sufrimiento. Los datos fueron analizados cualitativamente por el software IRAMUTEQ, con un alto grado de significación de las respuestas de los ensayos sobre la ética relacionada con los cuidados paliativos en pediatría. Las discusiones sobre el pronóstico, los objetivos de los cuidados y las opciones de tratamiento pueden ser muy difíciles, ya que las alternativas de cuidados paliativos legalmente respaldadas pueden divergir de los deseos de la familia. Se concluye que existen divergencias entre la aplicación de la medicina paliativa y la ética en relación con la aceptación y la gestión del final de la vida de los pacientes pediátricos. Los retos éticos son situaciones constantemente complejas en las que los médicos paliativos deben relacionar conceptos jurídicos, conocimientos y valores familiares, que a menudo entran en conflicto. La calidad de los cuidados paliativos depende inicialmente de la capacidad de los profesionales especializados para identificar y explicar las cuestiones éticas que generan conflicto o incertidumbre, además de plantear debates con la familia sobre las cuestiones médicas, morales y jurídicas que rodean la difícil situación.

Palabras clave: cuidados paliativos pediátricos, ética médica, práctica médica, medicina paliativa

Cuidados paliativos pediátricos no Brasil: uma reflexão ética da prática médica

Resumo: As barreiras éticas envolvidas na prática da medicina paliativa pediátrica ainda são grandes e desafiadoras. No que diz respeito à ética médica, deve-se prestar atenção à cultura, religião e valores familiares, a fim de pro-mover um cuidado adequado para os cuidadores, mesmo em caso de perda do paciente, promovendo um pro-cesso de luto com menos sofrimento. Os dados foram analisados qualitativamente pelo software IRAMU-TEQ, com um alto grau de significância das respostas dos ensaios sobre ética relacionada aos cuidados palia-tivos em pediatria. As discussões sobre prognóstico, objetivos de cuidados e opções de tratamento podem ser extremamente desafiadoras, uma vez que as alternativas de cuidados paliativos legalmente suportadas podem divergir dos desejos da família. Nosso estudo conclui que existem divergências entre a implementação da medicina paliativa e a ética em relação à aceitação e manejo do fim da vida de pacientes pediátricos. Os desa-fios éticos são constantemente situações complexas em que os médicos paliativistas devem relacionar concei-tos legais, conhecimento e valores familiares, que frequentemente entram em conflito. A qualidade dos cuida-dos paliativos depende inicialmente da capacidade de profissionais especializados identificarem e explicarem as questões éticas que levam a conflitos ou incertezas, além de levantar discussões com a família sobre ques-tões médicas, morais e legais que cercam a situação difícil.

Keywords: cuidados paliativos pediátricos, ética médica, prática médica, medicina paliativa

[1] Faculty of Medicine, University of Porto, Porto, Portugal, anderson.forbaby@gmail.com, ORCID: https://orcid.org/0000-0003-2704-8402.

[2] Metropolitan Institute of Higher Education (IMES), Ipatinga, MG, Brazil. Fundação Mineira de Educação e Cultura (FUMEC), Belo Horizonte, MG, Brazil, lurdiano56@gmail.com, ORCID: https://orcid.org/0000-0003-4416-3410

[3] Metropolitan Institute of Higher Education (IMES), Ipatinga, MG, Brazil.

[4] Faculty of Medicine, University of Porto, Porto, Portugal. ORCID: https://orcid.org/0000-0002-6178-6890.

Introduction

According to the World Health Organization (WHO), Palliative Care is intended to improve the quality of life of patients and their families, with preventive therapies to reduce pain and suffering when facing potentially fatal diseases*(1)*. There is a fine line between life and death in pediatrics, as well as between scientific advances and ethical issues at the beginning and end of life. Thus, the limit on the use of invasive treatments to prolong patients' lives is questioned in relation to their negative consequences for the child's physical and mental health*(2)*.

In 2017, the Brazilian Society of Pediatrics instituted a protocol on the conduct established for the administration of Palliative Care in each patient, to reduce possible doubts from the medical team in their conduct, however there are other discussions, such as religion, culture and family values that directly interfere in choosing the best treatment for the patient*(3)*. In this context, chapter I of the Code of Medical Ethics points out that in irreversible and moribund clinical situations, the physician must avoid unnecessary procedures, diagnosis and treatment and must provide adequate palliative therapy to the patients under their care, which provides support for situations where there is divergence between the parents' wishes and the child's health and well-being*(4)*.

Palliative medicine is intended to break social and cultural barriers, provide holistic care to patients, seek multidisciplinary reflections, to obtain better joint results, and ensure that the right to dignity is respected throughout the process, however, some conditions of care in the pediatric context, they have a high degree of complexity, requiring considerations that go beyond medical protocols*(3)*.

Pediatric palliative care in Brazil is performed in most cases in a hospital environment, within intensive care units, especially children with threatening diseases, without prognosis or in the terminal phase. However, they must be started with the diagnosis, such understanding is still poorly understood not only by family members, but also by the medical team, and its application in these terms is still ineffective. Therefore, the dissemination of the concept of Palliative Care is inefficient, since there is little offer of professionals trained to work in palliative medicine, triggering the application of futile treatments that reduce the quality of life of patients*(3,5)*.

The implementation of Palliative Care has greater resistance in situations that involve greater family vulnerability, such as in cases of spontaneous abortion when the gestational age of the fetus is not compatible with life, however, parents insist on invasive treatments that lead to greater suffering. In this context, Federal Council of Medicine in Brazil (CFM) resolution 1.805/200616: Art. 1; implies respect for the wishes of patients or their legal representatives, however, it is up to physicians to inform the therapeutic options to be implemented, as well as their consequences for a better choice , which provides greater comfort for family members*(4,6)*.

In addition to health professionals, family members have difficulty dealing with the conduct proposed by palliative care, due to the lack of information and for putting on the agenda their personal, spiritual and psychological values and feelings about death*(7)*.

In the ethical context of pediatric palliative care, it is necessary to reflect on the medical practice of such care, within the medical community in Brazil, since the child in his/her vulnerability undergoes interventions beyond their understanding and acceptance, such processes being left to position of caregivers, family members and doctors, which can generate ethical conflicts with reflection on the quality of care provided, going against the concepts of human rights and palliative care.

Methods

The study provides data analysis in different spheres, for qualitative data was used the IRAMUTEQ software, version 0.7 alpha 2*, as an interface of the R statistical program capable of multidimensional analysis of texts and questionnaires. Methodology applied in the doctoral thesis from which this article is derived. IRAMUTEQ creates a Dendrogram (dendro = tree) is a specific type of diagram or iconic representation that organizes certain factors and variables. It results

from a statistical analysis of certain data, in which a quantitative method is used that leads to groupings and their ascending hierarchical ordering - which in graphic terms resembles the branches of a tree that are successively divided into others. That is, it illustrates the arrangement of clusters derived from the application of a "clustering algorithm".

The pre-testing process of the questions was carried out with pediatricians from the institution where the researcher works, to analyze the perception of these professionals as to the applicability of the questions and their objectives in relation to the various questions about pediatric palliative care found in the scientific literature. The tool was validated and 236 questionnaires were subsequently sent to physicians on the roster of the National Academy of Palliative Care, between the months of July 2018 and December 2019, who worked with this care in the Brazilian child population, of these questionnaires 25% were used, which made the sample saturated, without interfering with the statistical result, showing $p<0.05$.

The bibliographic material was obtained by searching the Scielo, Lilacs, Cochrane and Pubmed databases for articles published until 2020, selected for their relevance in the scientific literature. The ethical recommendations proposed in resolution 466/12 of the National Health Council of Brazil in 2012, which prescribes ethics in research with human beings, were maintained. The research was approved by the Research Ethic Committee (CAAE) number: 09142319.9.0000.0012. Opinion number: 3.227.573, in Brazil, and approved by the Scientific Committee of the Faculdade de Medicina do Porto, in Portugal. The authors declare that all methods have been carried out in accordance with the relevant guidelines and regulations as per the Declaration of Helsinki.

Not applicable to patients. Free and informed consent form presented at clinicals.

The study population will consist of physicians who work with end-of-life children, in public institutions and individuals in Brazil, members of the list of institutions of the National Academy of Palliative care. The sample will consist of data obtained in interviews from a qualitative way for reflection and foundation of the proposal and for the quantitative analysis of these for composing the statistical results and understanding the reflections. Numerical data will be subjected to statistical analysis and qualitative data will be transcribed in its entirety, preserving the identity of the author, in the search to promote an assertive reflection on the theme. The Project will be submitted to the Committee of Ethics in Research. The participation of respondents will be free and will be formalized through this Informed Consent Form. will be discarded those questionnaires that prove to be incomplete. The risks involved in research consists in the non-acceptance of institutions and professionals to join the research; in the possible anxiety generated from the model of the instrument of assessment; in the translation and adaptation of the questionnaires, as there are cultural and linguistics involved, which may reduce the sensitivity of the test application; at the discomfort in answering the survey.

The research will contribute to improving the patient's quality of life pediatric. It will promote discussion on the challenge of implementing care palliatives and the suspension of futile treatments. Will carry out the mapping of the Brazilian pediatric palliative care services. Intends the elaboration of strategies for applying palliative care tailored to the profile of each institution and of each patient. It will allow knowing, evaluating and analyzing the financial impact of the futile treatment in pediatrics.

To participate in this study, you will not have any cost, nor will you receive any financial advantage. Despite this, if they are identified and proven damages arising from this research, you are assured the right to indemnity. You will have clarification on the study in any aspect you wish and will be free to participate or refuse to participate and at any time and without any damages. Your participation is voluntary, and your refusal to participate will not entail any penalty or modification in the way in which you are served by the researcher, who will treat your identity with professional standards of confidentiality. (A) Mr. (a) will not be identified (a) in any publication that may result.

Results and discussions

Data analysis using the IRAMUTEQ program allows the creation of a dendrogram of classes, joining statistical analysis and description of categories on the basis of discussions, in addition to applying factorial analysis by correspondence of the words or terms presented. in this specific case, 11,766 occurrences were observed in the research, with a corpus divided into 7 words classes with 328 elementary context units (ECU), using 92.99% of the corpus built by qualitative responses (305 ECU) matched by classification Hierarchical descending (CHD) of text segments of different sizes, identifying different degrees of similarity and significance, of content use, with those with $p<0.05$ having been transcribed, with a chi-square test greater than 3.80. The program allows applying factor analysis by matching the words or terms presented from a dendrogram of classes, joining statistical analysis and description of categories in the basis of discussions.

Topics raised by the medical team and by the people involved in the process of implementing palliative medicine associated with ethics.

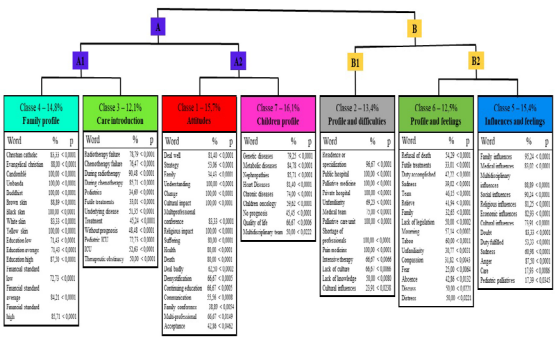


Figure 1: Dendrogram - total corpus.

From the Dendrogram we can observe the main topics raised by the medical team and by the people involved in the process of implementing palliative medicine associated with ethics.

In class 4, the Family Profile stands out for religion, where the influence of beliefs limits not only adherence but also the lack of interest in the foundations of palliative care. Religions such as Catholic, Evangelical, Candomblé, Umbanda and Buddhist have ingrained, sometimes extremist, thoughts about how to deal with care and loss, opting for behaviors that are in accordance with their beliefs. Race is also another point that draws attention, with black and brown skin colors being highlighted, which we can correlate with the precariousness of education and the low financial standard, which limits access to palliative care, as it is not a treatment for everyone still. Despite its importance, palliative therapy is still limited due to the lack of professionals and adherence to health centers, making it even more inaccessible for this population*(8,9)*.

In class 3 Introduction to Care, the treatments performed, such as chemotherapy, radiotherapy, futile treatments, inappropriate treatments, especially in palliative care in pediatrics, are the main focuses, questioning how far this type of conduct should be done. The professionals' lack of knowledge often leads to a therapeutic obstinacy that goes against the essence of palliative care, which is based on improving the quality of life, reducing the pain and suffering of the patient and family members[1].

In class 1 Attitudes, we have words that guide the real definition of palliative medicine, based on the family and multidisciplinary strategy, which has as its foundation care, dealing with adversities and cultural, religious impacts and demystifying what this type of treatment is really based on. Facing, accepting and understanding death in the lightest way is also a crucial point in adherence, knowing that it is the best thing for the patient[3].

In class 7, Profile of children, the diseases that are most repeated and that are indicated for palliative care are genetic diseases, metabolic diseases, nephropathies, heart disease, chronic diseases, childhood cancer, and other diseases with no prognosis. These comorbidities tend to compromise the quality of life of patients, and their treatments are not always effective, which reaffirms the need for a multidisciplinary care team, as there is physical and mental impairment of both the patient and their families*(10,11)*.

We observed in class 2 that professionals in both private and public hospitals do not have knowl-

edge about palliative care, nor are they encouraged to seek knowledge on the subject in both private and public colleges. The lack of residency and specialization in the area ends up limiting the behavior of professionals, also associated with their lack of training and adherence culture, especially in intensive care*(3,5)*.

The most difficulties in palliative care are represented below in five classes:

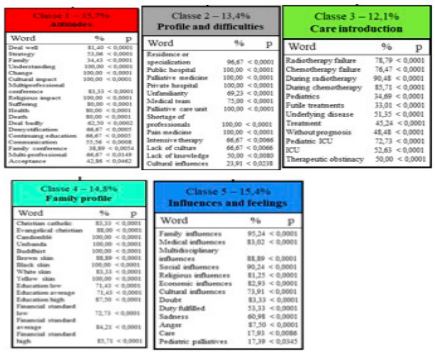


Figure 2: Five most important classes.

The most relevant questions for the interviewed professionals were selected and distributed into correlated classes using the chi-square test. Data indicate a higher prevalence of various influences, as well as the presence or absence of strategies to provide the best possibility of therapeutic choice for the patient, which encompasses ethical issues about the end of life6.

In class 5, social, medical, multidisciplinary, religious, economic, institutional and cultural influences stand out, which directly affect the adherence of palliative medicine, being necessary to give the necessary relevance to each family context*(7)*.

According to the study in question, we can observe that the word Northeast appears with greater incidence when compared to other regions of Brazil, which may suggest that regions with lower purchasing power have greater difficulty in maintaining palliative care, since the power acquisitiveness can directly influence education and, consequently, health*(12)*.

It can also be seen that cultural, social and religious influences are present during the disease process and during the period of mourning, directly influencing the way they will deal with the moment, as even today there is a lot of difficulty for the family to accept the process of terminality of life*(13,14)*.

Another point to be discussed concerns strategy, communication, information, welcoming and empathy, basic notions that the health professional team must have, to maintain a good performance. the course of the disease, associated with curative therapy, and not after its failure. Furthermore, with the improvement in the quality of medical care, patient survival has increased, as has the demand for palliative care*(2,5)*.

Ethical issues should be easily raised in patient care, thus, the attitude, posture, knowledge and communication skills of the medical team are extremely important, as they need to provide coherent guidance, sharing the prognosis and possibilities of therapy in the act of diagnosis, in a family conference, for the parents to understand the patient's condition and the therapeutic possibilities at an early stage, promoting a mourning process with better acceptance and less suffering. In view of this, there is a need for a multidisciplinary continuing education conference, with honest and comforting strategies that provide the necessary support for this process*(10)*.

It was observed in the research that most families deal badly with this moment, although death is an absolute truth, it is still a subject with little acceptance, which generates discomfort, leading to many changes in the pattern of family life, which still suffers from the cultural and religious impact of mourning. At this time, the longitudinal support provided by palliative care is essential, with a multidisciplinary team that promotes the demystification of death and helps families to deal well with the grieving process*(13,14)*.

Patients with chronic diseases, genetic and metabolic diseases, heart disease, nephropathy and with no prognosis need to be monitored with a multidisciplinary team that promotes a better quality of life, in a way that brings comfort and safety to their families, as the effect long-term

these diseases culminate in the physical and mental exhaustion of families and caregivers*(10,11)*.

It is worth emphasizing the importance of residency or specialization to work in palliative care, as seen in the dendrogram, in which the words are often cited by professionals. Although palliative medicine is not widespread in Brazil, most studies indicate that physicians express a lack of information on the topic, especially in intensive care medicine, which often plays an important role in the provision of care at the end of life, therefore, it is important receive additional training to work with palliative care and provide a better quality of life for patients*(15)*.

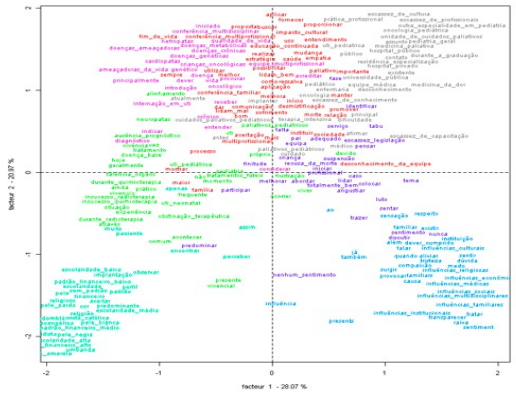


Figure 3: Factor analysis of the research.

From the factorial analysis of the graph, it is possible to observe the level of relevance and the relationship between the words. According to the survey, the medical team reports the main difficulties faced in starting palliative care, such as the family profile of those most adept at palliative therapy, indicated from the words highlighted in the figure, such as religiosity, or "Christian Catholic", "Evangelical Christian", "Candomblé", "Umbanda" or "Buddhist" which may or may not be a factor greater adherence to care, because in case of loss of the patient, it helps family members to overcome the grieving process8. However, religious beliefs can provide parents with hope for a distant cure for the child's condition, investing in futile treatments that can increase suffering and reduce the patient's quality of life*(16)*.

According to a publication produced in Africa, a continent with a predominantly black and low-income population, adherence to palliative care is also related to skin color – "brunette", "black, "white" or "yellow". According to the World Health Organization, most children and adults in need of palliative care live in low-income countries. Developing countries have as a priority the fight against hunger, thus, effective disease prevention programs or carrying out adequate work-up with the provision of diagnostic tests are not a priority. As a result, most patients will present the disease at an advanced stage at the time of diagnosis, requiring palliative care such as pain relief and human suffering in its terminal stage*(16)*.

With the analysis of the graph, it is possible to identify the proximity between the words "Radiotherapy failure", "Chemotherapy failure", "Futile treatments", "No prognosis", "Pediatric ICU (Intensive Care Unit)" and "Therapeutic obstinacy", which indicates that this therapy is implemented late in most cases, the reality to implement palliative therapy is complex, as it involves personal issues that must be demystified for the understanding of the method by family members, who, in addition to the taboos existing in society, face the sentimental barrier of non-acceptance of the death of a loved one as a natural process. So it is up to palliative care to provide, in addition to monitoring, information for patients and families about the benefits of palliative care and that they can be allied to treatment and not just a last alternative for terminal patients*(17)*.

Pediatric palliative care is performed in most cases in a hospital environment, whether public or private, in intensive care units, especially in children with threatening diseases, without a prognosis or in the terminal phase. However, due to the lack of knowledge of both family members and the medical team, the application of palliative therapy is still questionable*(18)*.

In addition, the relationship between physicians' attitudes to increase adherence to care is shown in the factor analysis graph by "Demystification", "Continuing education", "Communication", "Family conference" and "Multiprofessional", which indicates the importance health education, necessary for family members, who often carry cultural ideologies that can interfere with the inadequate decision of the patient's therapy, thus, it

is up to palliative medicine to provide adequate information to caregivers through family conferences with the multidisciplinary team*(10)*.

However, there is a shortage of specialized doctors in the area, in addition there are few publications on palliative care, especially in the field of pediatrics, with the lack of training to deal with and care for their patients, leads professionals to feelings such as insecurity in the midst of difficult situation with the patient*(10)*. Therefore, the purpose of the graph presented in this manuscript is to understand the influences related to the introduction of palliative care and the main difficulties presented during the treatment by the patient, family and medical staff*(1)*.

Dealing with the suffering of a terminally ill patient, especially pediatric patients, involves, in addition to ethical and moral issues, issues of family values. Palliative care aims to improve the quality of life of patients and their families, helping them to face the moment of pain and grief. Thus, according to the family profile, several variables can interfere in palliative care, and consequently in medical practice*(1)*.

In terms of ethical assessment, a series of multidisciplinary meetings and conversations are held involving family, health professionals and the ethics committee, aiming at the best decision on the implementation of the care plan for the patient, so as not to prolong suffering and promote its well-being*(18)*. However, from the study, it was observed that there are often divergences according to the family profile, with regard to religion, be it Catholic Christian, Evangelical Christian, Buddhist, Candomblé, Umbanda, or others that have different ideologies in relation at the end of life and care for the sick, insisting on futile treatments in the view of the medical team that cause greater suffering for the child*(8,9)*.

In a study it was found that 98% of children who need palliative care live in Africa, a region with low financial income, predominantly people with black and brown skin, medium to low education, where the sources of information are few or nonexistent, the which hinders the early introduction of palliative care for children. On the other hand, according to the survey, countries with medium and high financial standards, in which there is a predominance of high education and white skin, the dissemination of knowledge about the benefits of palliative care is favored*(16)*.

The introduction of palliative care in pediatrics must respect the appropriate starting time, based on the patient's underlying disease, the decision-making of the medical team must be ethical and fair to avoid futile treatments, leading to unnecessary hospitalizations in pediatric ICUs, and therapeutic obstinacy. In this context, it is noteworthy that the objective of palliative therapy is to provide better comfort to patients with no prognosis, avoiding unnecessary treatments*(17)*.

Thus, the dissemination of the concept of Palliative Care is ineffective, since there is a shortage of professionals trained to work in the area, due to the lack of residence or specialization of the health team, also due to the lack of knowledge about the concept of palliative medicine, limiting treatment to indiscriminate application of futile and invasive therapies that reduce the quality of life of patients*(3,5)*.

In addition to health professionals, family members find it difficult to deal with the behavior proposed by palliative care, by lack of knowledge and by putting their cultural, economic, religious, social and family influences on the agenda, which revolves around the entire taboo of refusal of death*(7)*.

Palliative medicine focuses on providing holistic care to patients, seeking to alleviate suffering, alleviate fear and sadness through compassionate care. The multidisciplinary and medical influence brings positive reflections on the joint results, in addition to ensuring that the right to dignity is respected throughout the process. However, the quality of palliative care initially depends on the ability of specialized professionals to identify and explain the ethical issues that lead to conflict or uncertainty, in addition to raising discussions with the family about medical, moral and legal issues surrounding the difficult situation*(3,19)*.

Thus, although jurisprudence and state regulations can be discussed in an ethics consultation, there are still several gaps in how to manage each

patient; the lack of applicable protocols, in addition to limiting the process, also ends up restricting the scope of work of professionals*(4)*.

Therefore, better communication, clarification of differences and available treatment options, and careful documentation of the decision process can reduce the potential for future legal actions and contribute to improving the patient's quality of life*(19)*.

Ethical challenges are constantly complex situations in which palliative physicians must relate legal concepts, knowledge and family values, which generally conflict, which harm patients and medical staff, due to inadequate decisions or reduced quality of treatment and care in daily clinical practice*(20)*.

Palliative care must be provided in accordance with the principles of universal health coverage, as issued by the WHO, where all people, regardless of income, type of illness or age, must have access to a set of nationally determined basic health services, including palliative care. Thus, the ethics of patient care is called into question, where the International Narcotics Control Board found that in 2018 79% of the world's population, mainly people in low- and middle-income countries, consumed only 13% of the total amount of morphine used to treat pain and suffering, or 1% of the 388 tons of morphine manufactured worldwide. Thus, the non-use of drugs that can alleviate the suffering of patients contradicts medical ethics, financial and social protection systems need to take into account the human right to palliative care for any population group, especially the poor and marginalized*(1)*.

To gain autonomy to make decisions and provide informed consent, patients must have access to information, understanding, freedom and willingness, with competence being a prerequisite for autonomy. Physicians often face patients who are not able to make decisions, however, there are less than half of these cases and the team often underestimates patients, especially in pediatrics, compromising the entire process of ethical conduct in medical practice*(10,16)*.

Faced with ethical challenges, the perinatal world approaches the treatment of two patients along the lines of decision-making and clinical management - the fetus and the pregnant woman. The potential of the newborn fetus is confused with the absolute considerations for the woman as an autonomous patient. Special needs and technology become questionable in the face of minute-to-hour survival charts. The ethical ramifications for prenatal diagnosis, clarification of parents' values and goals, birth plans, the fluidity of decision-making over time, are reinforced and clarified from palliative care, for greater optimization of choice of conduct and treatment*(10,21)*.

The field of pediatric palliative care frequently discusses ethical issues, including prenatal diagnosis, ineffective treatment of children with serious intractable illnesses, and medical negligence. In addition to providing the necessary information for the best treatment options, health professionals have the responsibility to provide patients with all possible treatment methods, however, the limitations of patients and their families must be respected, as the therapeutic choice depends the resources and socioeconomic status, religion and philosophy of patients and their families, as well as policies of related institutions and medical limitations*(8,16)*.

Summary

It is concluded from the study that there are divergences between the implementation of palliative medicine and ethics regarding the acceptance and management of the end of life of pediatric patients. Thus, it is up to the multidisciplinary team to provide a holistic approach, seeking to promote better patient care based on medical ethics, offering adequate support to the child and their families, based on adequate knowledge about the patient's condition, as well as the necessary communication with the family to provide greater security and fitness in choosing the best treatment. Therefore, palliative care provides a multidisciplinary and longitudinal follow-up, taking into account the particularity of each individual, which is necessary to alleviate suffering, provide quality of life and comfort.

Acknowledgments

We are also grateful at Faculty of Medicine of University of Porto.

Authors contributions

Anderson de Almeida Rocha doctoral researcher who conceived, designed, investigation, analyzed the data, formal analysis and wrote original draft and translated the article. Lurdiano Freitas student of medicine course and Business graduated contributed as statistics reviewer. Juliana Cesconetto, Lara Calhau Rebouças, Vitória Barreto Salomão, Students of Medicine course contributed regents, conceived, designed, analyzed the data and wrote the paper in Portuguese. Rui Manuel Lopes Nunes project administration, supervision, validation review, and guided the research and the guided the article.

Conflict of interest

The authors have declared that no competing interests exist.

Funding

The authors have no support or funding.

References

1. World Health Organization. *Palliative Care* [Internet]. Geneva: OMS; 2020 [cited 2021 July 3]. Available from: https://www.who.int/news-room/fact-sheets/detail/palliative-care
2. Dadalto L, Affonseca CA. Medical, ethical and legal considerations about end-of-life decisions in pediatric patients. Brasilia: *Bioethics Magazine* 2018; 26(1): 12-21.
3. Brazilian Society of Pediatrics. *Pediatric palliative care: what is it and why is it important? Taking care of the child at all times* [Internet]. São Paulo: Scientific Department of Pain Medicine and Palliative Care; 2017, 2020 [cited 2021 July 3]. Available from: https://www.sbp.com.br/fileadmin/user_upload/2017/03/Medicina-da-Dor-Cuidados-Paliativos.pdf
4. Federal Council of Medicine. *Code of Medical Ethics: CFM Resolution No. 2217, of September 27*, 2018 [Internet]. Brasilia: Federal Council of Medicine; 2019 [cited 2021 July 3]. Available from: https://portal.cfm.org.br/images/PDF/cem2019.pdf
5. Haines ER, Frost AC, Kane HL, Rokoske FS. Barriers to accessing palliative care for pediatric patients with cancer: A review of the literature. *Cancer* 2018; 124: 2278-2288.
6. Cheng BT, Rost M, De Clercq E, Arnold L, Elger BS, Wangmo T. Palliative care initiation in pediatric oncology patients: A systematic review. *Cancer Med*. 2019; 8(1): 3-12.
7. Lima SF, Lamy ZC, Motta VBR, Roma TM, Gomes CMRP, Souza TP, et al. *Dynamics of pediatric palliative care provision: a multiple case study*. São Luiz: Public Health Notebooks; 2020.
8. Seller L, Rasmussen LA. Integrating ethics and palliative care concepts into pediatric end of life care and decision-making: A changing landscape? *Paediatr Respir Rev*. 2019 Feb; 29: 1-2.
9. Silva EMB; Silva MJM; Silva DM. Health professionals' perception of neonatal palliative care. *Brazilian Journal of Nursing* 2019; 72: 1707-1714.
10. Marty CM, Carter BS. Ethics and palliative care in the perinatal world. *Semin Fetal Neonatal Med*. 2018 Feb; 23(1): 35-38.
11. Feudtner C, Nathanson PG. Pediatric palliative care and pediatric medical ethics: opportunities and challenges. *Pediatrics*. 2014 Feb; 133 Suppl 1: S1-7.
12. Freire MEM, Costa SFG, Lima RAG, Sawada NO. Qualidade de vida relacionada à saúde de pacientes com câncer em cuidados paliativos1. *Texto & Contexto-Enfermagem* 2018; 27.
13. Rosenberg AR, Wolfe J, Wiener L, Lyon M, Feudtner C. Ethics, Emotions, and the Skills of Talking About Progressing Disease With Terminally Ill Adolescents: A Review. *JAMA Pediatr*. 2016 Dec 1; 170(12): 1216-1223.
14. Middleton W, Raphael B, Burnett P, Martinek N. A longitudinal study comparing grief phenomena in newly bereaved spouses, adult children, and parents. *Aust NZJ Psychiatry* 1998; 32(2): 235-241.
15. Baylis J, Harris DR, Chen C, Ting DK, Clark K, Kwan A, et al. Palliative and end-of-life care education in Canadian emergency medicine residency programs: A national cross-sectional survey. *CJEM* 2019 Mar; 21(2): 219-225.
16. Sasaki H, Bouesseau MC, Marston J, Mori R. A scoping review of palliative care for children in low- and middle-income countries. *BMC Palliat Care* 2017; 16(1): 60.
17. Hoell JI, Warfsmann J, Gagnon G, et al. Palliative care for children with undiagnosed syndrome. *European Journal of Pediatrics*

October 2017; 176(10): 1319-1327.

18. Green SB, Markaki A. Interprofessional palliative care education for pediatric oncology clinicians: an evidence-based practice review. *BMC research notes* 2018; 11(1): 1-11.
19. Moon M; Committee on Bioethics. Institutional Ethics Committees. *Pediatrics* 2019 May; 143(5): e20190659.
20. Bruun H, Huniche L, Stenager E, Mogensen CB, Pedersen R. Hospital ethics reflection groups: a learning and development resource for clinical practice. *BMC Med Ethics* 2019 Oct 24; 20(1): 75.
21. Wool C, Catlin A. Perinatal bereavement and palliative care offered throughout the healthcare system. *Ann Palliat Med* 2019 Feb; 8(Suppl 1): S22-S29.

Received: September 26, 2022
Accepted: October 24, 2022