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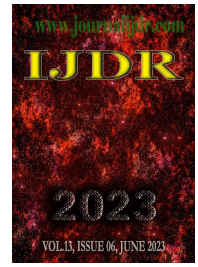
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RESEARCH ARTICLE

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## INFLUENCES THAT ARE CONNECTED TO THE BEGINNING AND CONDUCT OF PALLIATIVE CARE IN PEDIATRICS

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### ABSTRACT

Palliative care improves the quality of life for patients with life-threatening illnesses, their families and medical staff. They should be performed early in the process of disease evolution, always in conjunction with curative therapy. We investigated which influences are related to the conduct of palliative care in Brazilian children. Data were analyzed qualitatively by the software IRAMUTEQ (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires). The analysis performed by IRAMUTEQ selected words with  $p < 0.05$ . The process of pre-testing the questions was carried out with pediatricians from the institution where the researcher works, to analyze the perception of these professionals regarding the applicability of the questions and their objectives in relation to the various questions about pediatric palliative care found in the scientific literature. The instrument was validated and 236 questionnaires were subsequently sent to physicians from the National Academy of Palliative Care, between July 2018 and December 2019, who worked with this care in the Brazilian child population. 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. Ethical recommendations for research with human subjects were followed. In pediatrics, the understanding of palliative care is often mistaken or incomplete when it is assumed that it is only applied in the final stage of the disease. Health professionals must provide this care not only to patients, but also to family members, even after death, in a multidisciplinary and personalized way. There are difficulties in implementing palliative care. In Brazil. It was possible to observe that health professionals have difficulties, resulting from different influences, which make communication and care with the child and their family difficult in relation to death. There are several influences that make it difficult to conduct palliative care and that need to be worked on in their fields by the multiprofessional team, together with the family, with a tendency to create a new culture based on the true meaning of palliative care.

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## INTRODUCTION

With the development of Medicine and technologies to be used in the health area, there is a greater number of early diagnoses and treatments. However, this evolution also contributes to the increasing use of maneuvers for therapeutic obstinacy, with futile treatments that are not suspended by various conflicts.

On the other hand, there are palliative care that are not instituted at the right time by various influences, such as family, cultural, ideological and the feeling that it can only start when there is nothing more to be done (Dadalto, 2018). The World Health Organization (WHO) defines palliative care as an approach aimed at quality of life for both patients and family members in the face of problems associated with life-threatening diseases, with a view to relieving suffering, through accurate and judicious evaluation of the treatment

of symptoms, whether of a physical, psychosocial or spiritual nature. The WHO emphasizes that children, physical, psychological and social stress should be assessed, with a multidisciplinary approach that includes the family (Lima, 2020). The principles of action in palliative care defined by WHO include: the promotion of pain relief and other symptoms responsible for suffering; recognition of death as a natural process inherent in life, which occurs at a time outside human will, and should not be anticipated or postponed; the integration of psychological and spiritual aspects to care, with full support to the family, the health team and the patient, with a view to understanding and organizing grief, in the face of the disease process and the terminality of life, including palliative care in the early in the course of the disease's evolution, always adjuvant to curative treatment, and maintaining such care even after death, within the family, society and the professionals inserted in them; attention to the context of improving the quality of life and human dignity within palliative care with the best practices so that complications from clinical treatment do not cause suffering (Lima, 2020). Palliative care must be integrated with curative care from the diagnosis and continue parallel to the disease- modifying treatment until after the death process. Health professionals "facing children in life-limiting conditions must recognize the need for palliative care", but there are several influences such as the non- acceptance of pediatric death, parental acceptance, ignorance, the team's decision and preparation, health conditions hospital and the doctor-patient relationship that hinder this decision-making (Silva, 2019). Thus, in this context, the objective of this study was to reflect on the main influences that are directly and indirectly related to the conduct of pediatric palliative care by Brazilian doctors.

## METHODS

The study provides the analysis of the data in different spheres program was used for the qualitative data the software IRAMUTEQ, version 0.7 alpha 2\*, as an interface of the statistical program R capable of analyzing texts and questionnaires in a multidimensional way. 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-test process of the questions was carried out with pediatric doctors at the institution where the researcher works, to analyze the perception of these professionals regarding the applicability of the questions and their objectives in relation to the various questions regarding pediatric palliative care found in the scientific literature. The tool was validated and 236 questionnaires were subsequently sent to doctors on the list 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 database of Scielo, Lillacs, Cochrane and Pubmed, articles published until the year 2020, selected for their relevance in the scientific literature. The ethical recommendations proposed in resolution 466/12 of the National Health Council (Brazil, 2012), which prescribes ethics in research with human beings, were maintained. The research was approved by the Research Ethics Committee, under the number of the Certificate of Presentation for Ethical Appreciation (CAAE): 09142319.9.0000.0012. Opinion number 3,227,573, in Brazil, in addition to being approved by the opinion of the Scientific Committee of the Faculty of Medicine of Porto, in Portugal.

## RESULTS AND DISCUSSION

11,766 occurrences were observed in the research, with a corpus divided into 7 word classes with 328 elementary context units (ECU), with use of 92.99% of the corpus built by qualitative responses

(305 ECU) equated by descending hierarchical classification (CHD) of text segments of different sizes, identifying different degrees of similarity and significance, of using content, with those with  $p < 0.05$  being transcribed, with a chi-square test greater than 3.80. The program allows to apply factor analysis by correspondence of the words or terms presented from a class dendrogram, joining statistical analysis and description of categories in the basis of the discussions. (Figure 1). It is observed in class 5, all the influences and feelings reported during the research. It is noticed that 95% of those surveyed have family influences as important when choosing palliative care, in addition to medical, multidisciplinary, social, religious, economic, institutional and cultural influences (Figure 2). Medical influences are also observed (15%), often linked to the team's lack of knowledge, lack of preparation, lack of legislation to assist the physician in decision-making. There are many studies and protocols in the Portuguese language that address this topic. In addition, there is not much training and specialization for doctors in this area, being an obstacle and gap of resources's origin. Furthermore, the pediatric palliative care requires competences that will break down de barriers and serve effectively in the patients' caring (Sasaki, 2017; Alveno, 2018; Nilsson, 2019; Raman, 2021) (Figure 3). The main feelings experienced by doctors who have already indicated palliative care are: duty accomplished, relief, sadness, grief and anguish. These feelings permeate the professional's decision to introduce palliative care and the child's death situation. Less commonly, there will be a spoke of positive emotions. The factor analysis below corroborates all the results presented (Hubik, 2021) (Figure 4).

Pediatric palliative emerged as an extension of the hospice movement (Moresco, 1992) This practice care aims to alleviate suffering and improve the quality of life of children and their families, as they face serious illnesses, providing support to deal with the uncertainties and physical, psychological, social and spiritual burdens of the disease, which begin at diagnosis and extend to the period of mourning (Sasaki, 2017; Hoell, 2017; Snaman, 2018; Snaman, 2020; Hubik, 2021). Although they offer numerous benefits to supporters, according to research and data in the literature, it was observed that palliative care is often implemented late, leaving gaps in attendance, like thethe unhelpful communication patterns providing incomplete information, and deferring or omitting information which can lead to the provision of care incompatible with the most beneficial therapy for the patient's condition (Weaver, 2015; Haines, 2018; De Clercq, 2019; Moresco, 1995). According to the graphs presented in the study, among the information provided by the medical team on the profiles, attitudes, influences and difficulties related to the implementation of palliative care in pediatrics, including the family experience of illness, the relationships between topics can be observed and which are most frequently cited by health professionals as an obstacle to this approach. Thus, a relationship was found between the characteristics of the family profile of children who are submitted to palliative care, which, according to WHO data, mostly live in low-income countries and have a low level of education, which makes it difficult to access to information on the benefits of such care. In addition, they present religiosity as a common factor, which can help families of patients to overcome the experience of grief, however, religious beliefs can foster the "culture of hope", due to the difficulty of parents in accepting the child's prognosis, leading them to believe in a possible cure that is difficult to achieve, and insisting on futile and invasive treatments that reduce the child's quality of life. Furthermore, it's positive for the doctor when the patient had comfortable death (Sasaki, 2017; Snaman, 2018; De Clercq, 2019; Moresco, 2021; Hubik, 2021). The introduction of palliative care has a direct correlation with the family profile and its theme, justifying the insistence of family members to continue with invasive therapies, frequent hospitalizations, chemotherapy and other futile treatments for children with no prognosis, increasing their suffering. This point of view is connected to several challenges and barriers including organizational, social, political and the treatment-oriented to those barriers (Amroud, 2021). The beginning of palliative care does not exclude curative treatment, but, however, they are usually implemented in the late stage of the disease, due to the poor prognosis of the child or the significant decline in quality of life.

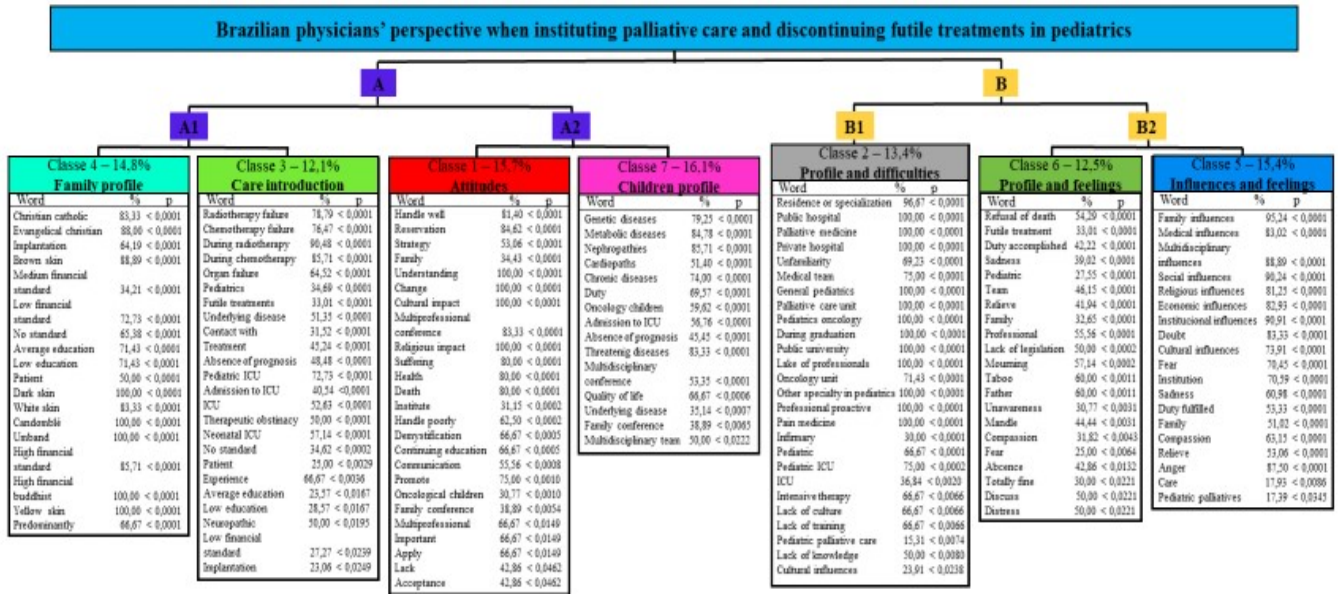


Figure 1. Dendrogram total corpus

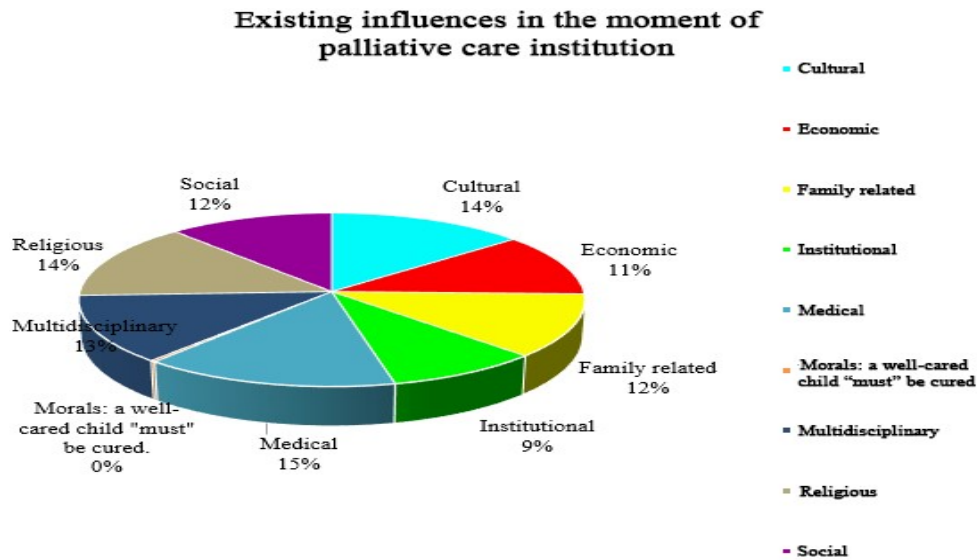


Figure 2. Existing influences in the moment of palliative care institution, perceived by Brazilian doctors

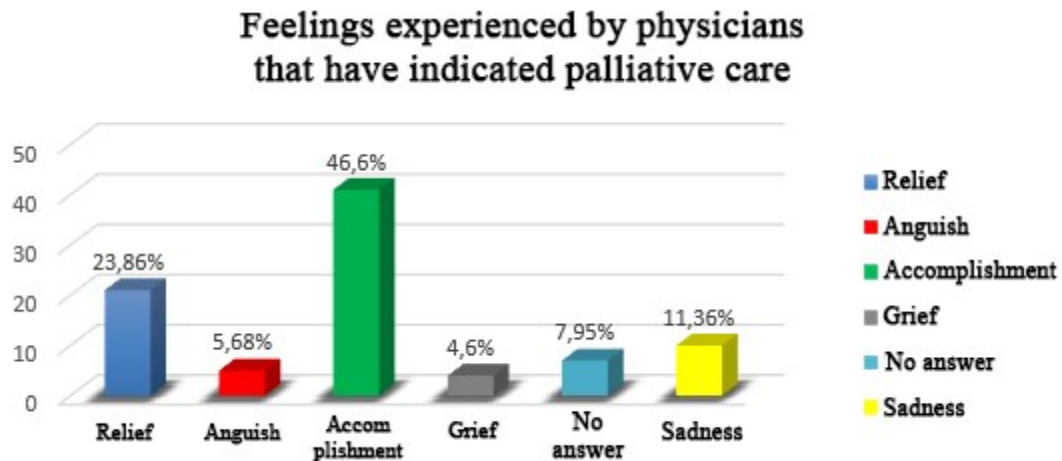


Figure 3. Feelings experienced by doctors that have indicated Palliative Care



These feelings also elucidated in the study graphs, are part of the daily routine of the medical team, who need to manage the anguish and impotence in the face of the patient's therapeutic failure. The reality for implementing palliative therapy is complex, as it involves personal issues that must be demystified for family members to understand the method, who, in addition to the existing taboos in society, face the sentimental barrier of not accepting the death of a loved one as a process natural (Lima, 2020; Silva, 2019). Prognostic understanding can empower families to revisit and reshape their priorities, treatment decisions and focus on ways to maximize quality time together.

Parents who involve their children in discussions about prognosis and demystify the concept of death generally do not regret doing so. However, most of the time, even if conversations about palliative care are not necessarily inserted in the final stage of diseases, the families of patients can perceive them as an indicator that the provider has given up curative treatments. As a pediatric palliative care teams work with the families directly and are often joined in their bereavement work by other professionals within a hospital. During active treatment, patients at an advanced stage and their families have access to psychosocial support, however, when their children do not survive the disease, the abrupt end of the relationship with the care team may seem like an additional loss for the family. Thus, the family is more likely to suffer a complicated grieving process and should be prioritized and cared for by the health team (Lima, 2020; Silva, 2019; Rocha, 2021). It is observed that such a process is more accepted by families that profess a religious belief, even the medical team can express diversity of opinions in decisions about life and death based on their religious experience. Thus, the influence of society is directly linked to the patient's reaction to the devastating situation experienced, so it is up to palliative medicine to provide an environment surrounded by dignity, humanism, compassion and free from physical suffering for the patient and his family. Providing a "good death" should be a demystified issue and considered a reason for satisfaction and fulfillment, something similar in some respects to saving lives (Hubik, 2021).

#### **ETHICAL APPROVAL AND CONSENT TO PARTICIPATE**

The ethical recommendations proposed in resolution 466/12 of the National Health Council (Brasil, 2012), which prescribes ethics in research with human beings, were maintained. The research was approved by the Research Ethics Committee (CAAE) number: 09142319.9.0000.0012. Opinion n°: 3,227,573, in Brazil, by the Research Ethics Committee of Faculdades Integradas Aparício Carvalho (FIMCA), on 03/27/2019 and approved by the Scientific Committee of the Faculty of Medicine of 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.

The authors declare that all methods have been carried out in accordance with the relevant guidelines and regulations as per the Declaration of Helsinki: "A physician shall act in the patient's best interest when providing medical care"; and "It is the duty of physicians who are involved in medical research to protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects. The responsibility for the protection of research subjects must always rest with the physician or other health care professionals and never with the research subjects, even though they have given consent"; and since "Physicians must consider the ethical, legal and regulatory norms and standards for research involving human subjects in their own countries as well as applicable international norms and standards. No national or international ethical, legal or regulatory requirement should reduce or eliminate any of the protections for research subjects set forth in this Declaration"; "Medical research involving human subjects must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, as appropriate, animal experimentation. The welfare of animals used for research must be respected".

#### **DECLARATIONS\*\***

The images do not identify personal or clinical details of the participants and do not compromise anonymity, there is no need for a declaration of consent for the patient's publication, as the research was carried out with physicians without them needing access to medical records and they did not need to interview or patients and nor family members. Therefore, the presentation of the patient's declaration of consent is not applicable.

#### **CONSENT FOR PUBLICATION**

Not applicable to patients as presented end following term. Free and informed consent form presented at clinicals. You are being invited as a volunteer to participate in the research "Perspective of Brazilian physicians when instituting palliative care and suspending futile treatments in pediatrics". We ask for your authorization for the collection of data, storage, use and disposal via survey questionnaire. The use of data is only linked to this research project or if you (a) agree on other futures. In this research we intend:

- Understand the difficulties in implementing palliative care in pediatrics as well how to suspend futile treatments.
- Reflect the perspectives of Brazilian physicians facing the challenge of care palliatives in pediatrics.
- Assess the financial impact of futile treatment in pediatrics.
- Map Brazilian pediatric palliative care services.
- Understand how pediatric palliative care is provided in Brazil.
- Knowing the application strategies of pediatric palliative care in Brazil and the profile of the institutions that apply them.
- Knowing the profile of families and pediatric patients who come into care palliatives.
- Understand the difficulties of suspending futile treatments in children.

For this research we will adopt semi-structured interviews with physicians who work with palliative care in Brazil through an internet tool, by email, with questions that become data that will allow reflections and statistical analyses. 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 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. You 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 for 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 linguistic 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 is not will entail any penalty or modification in the way in which you are served(a) 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. This consent form is printed in two original copies, one of which will be filed by the responsible researcher, in his possession or in file of the University of Porto, and the other will be provided to Mr. (a). The data, materials and instruments used in the research will be filed with the researcher responsible for a period of 5 (five) years in the room of the Department of Medicine of the Faculty of Medicine of the University of Porto and after that time they will be destroyed. Researchers will treat your identity with professional standards of secrecy, in compliance with Brazilian legislation (Resolutions No. 466/12; 441/11 and the Ordinance 2.201 of the National Health Council and its complementary), using the information for academic and scientific purposes only.

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## 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, Vitória Barreto Salomão, Ivy Letícia Brandião Costa, 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.

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## AVAILABILITY OF DATA AND MATERIALS\*\*

The datasets used and/or analyzed during this study are available from the corresponding author upon reasonable request. Full name of the Responsible Researcher: Anderson de Almeida Rocha Address: Rua Ervália, 99 Bela Vista CEP: 35160-188 /Ipatinga- MG/ Brazil Phones: +55 (31) 99966-6037 Email: anderson.forbaby@gmail.com

Listofabbreviations	
IRAMUTEQ	Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires.
WHO	The World Health Organization
CAAE	Presentation for Ethical Appreciation
ECU	elementary context units
CHD	descending hierarchical classification

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