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# BRAZILIAN PHYSICIANS' ATTITUDES AND FEELINGS TOWARDS PALLIATIVE CARE IN PEDIATRICS

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**Abstract**: The aim of the article is to evaluate and understand the feelings and attitudes of Brazilian physicians regarding the implementation of palliative care in pediatric patients.
Between July 2018 and December 2019, 236 questionnaires were sent to physicians on the National Academy of Palliative Care roster. The data collected through the planned questionnaires were analyzed using the IRAMUTEQ programs (Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires).
From the analysis performed by IRAMUTEQ, a dendrogram containing words with $p<0.05$ was obtained. Feelings of sadness, anguish, relief, regret and fulfillment were perceived as relevant. Attitudes such as understanding, communication, instructing, treating well, strategy, and multiprofessional conferences were also described. Thus, it was observed that these professionals experience different contradictory feelings and make use of different strategies so that they do not harm the treatment carried out, in addition to maintaining a good relationship with the patient's family.
In the present study, we demonstrate that there are intrinsic characteristics of pediatric palliative care that are a source of mixed feelings for medical professionals. In this context, challenges still exist and it is essential to conduct new studies that address this issue. Paying attention to these feelings promotes better management of palliative care in pediatrics.
**Keywords:** attitudes, palliative care, feelings, pediatrics, health care quality

**Actitudes y sentimientos de los médicos brasileños hacia los cuidados paliativos en pediatría**

**Resumen:** El objetivo del artículo es evaluar y comprender los sentimientos y actitudes de los médicos brasileños en relación con la implementación de los cuidados paliativos en pacientes pediátricos.
Entre julio de 2018 y diciembre de 2019, se enviaron 236 cuestionarios a los médicos de la lista de la Academia Nacional de Cuidados Paliativos. Los datos recogidos a través de los cuestionarios previstos se analizaron utilizando los programas IRAMUTEQ (Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires).
A partir del análisis realizado por el IRAMUTEQ, se obtuvo un dendrograma que contenía palabras con $p<0,05$. Sentimientos de tristeza, angustia, alivio, arrepentimiento y realización fueron percibidos como relevantes. También se describieron actitudes como comprensión, comunicación, instruir, tratar bien, estrategia y conferencias multiprofesionales. Así, se observó que estos profesionales experimentan diferentes sentimientos contradictorios y hacen uso de diferentes estrategias para que no perjudiquen el tratamiento realizado, además de mantener una buena relación con la familia del paciente.
Demostramos que existen características intrínsecas de los cuidados paliativos pediátricos que son fuente de sentimientos encontrados para los profesionales médicos. En este contexto, aún existen desafíos y es esencial realizar nuevos estudios que aborden este tema. La atención a estos sentimientos promueve una mejor gestión de los cuidados paliativos en pediatría.
**Palabras clave**: actitudes, cuidados paliativos, sentimientos, pediatría, calidad asistencial

**Atitudes e sentimentos de médicos brasileiros em relação a cuidados paliativos em pediatria**

**Resumo**: O objetivo desse artigo é avaliar e compreender os sentimentos e atitudes de médicos brasileiros no que diz respeito à implementação de cuidados paliativas em pacientes pediátricos.
Entre julho de 2018 e dezembro de 2019, foram enviados 236 questionários a médicos do rol da Academia Nacional de Cuidados Paliativos. Os dados coletados através dos questionários planejados foram analisados usando os programas IRAMUTEQ (Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires).
Da análise realizada pelo IRAMUTEQ, obteve-se um dendrograma contendo palavras com $p<0.05$. Sentimentos de tristeza, angústia, alívio, arrependimento e satisfação foram percebidos como relevantes. Atitudes como compreender, comunicar, educar, tratar bem, estratégia e conferências multiprofissionais também foram descritas. Assim, observou-se que esses profissionais experimentam sentimentos contraditórios diferentes e fazem uso de diferentes estratégias de forma a não prejudicar o tratamento realizado, além de manter uma boa relação com a família do paciente.
No presente estudo, demonstramos que há características intrínsecas de cuidados paliativos pediátricos que são fonte de sentimentos contraditórios para profissionais médicos. Nesse contexto, ainda existem desafios e é essencial conduzir novos estudos que abordem essa questão. Prestar atenção a esses sentimentos promove melhor manejo de cuidados paliativos em pediatria.

**Palavras-chave**: atitudes, cuidados paliativos, sentimentos, pediatria, qualidade de cuidados à saúde

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## Introduction

Palliative Care (CP) is defined by the World Health Organization (WHO) as a care network governed by principles, promoted by a multidisciplinary team, whose objective is to promote an improvement in the quality of life of patients with a disease that threatens the continuity of life and of their families. This care encompasses the various dimensions of the individual, so there is a concern not only with the physical symptoms resulting from the disease, but also with the psychosocial aspects inherent to the patient and their family*(1)*. Within the CP universe, pediatric palliative care is found when the feelings of the responsible team are evidenced, since the death of a child is seen as an unnatural occurrence, generating a great psychological impact on those responsible for treatment and monitoring. Therefore, it is relevant to highlight some of the principles established by the CP, as they guide the attitudes of the professionals involved. Some of the principles are: promoting pain relief and other symptoms through pharmacological and non-pharmacological methods, affirming life and thinking of death as a natural event in life, caring for the patient in a way that also integrates psychological and spiritual aspects, providing support to the patient and family members, to work with measures to prolong life (such as radiotherapy, chemotherapy), improve the quality of life with a multidisciplinary team*(1)*.

Within the universe of CP, there are pediatric palliative care, which should be started soon after diagnosis, as it does not exclude measures and treatments that aim to prolong life, always aiming at quality of life, and must be adapted to the level of each child's development. In Latin America, pediatric patients eligible for CP may be those who fall into one of four categories defined by the Pediatric Association for Palliative Care (ACT) and the Royal College of Pediatrics and Child Health (RCPCH) in the UK. The categories cover: conditions in which there is curative treatment but it may fail, conditions without great chances of cure but which can be prolonged in life, progressive diseases without much chance of cure and non-progressive diseases that are irreversible*(2)*.

In addition, within pediatric palliative care, it is known that there may be more difficulties in relation to drugs (which are often not available for children's doses) and bioethical issues. Also in relation to pediatric palliative care, the feelings of the responsible team are very evident in this context, since the death of a child is seen as an unnatural occurrence, generating a great psychological impact on those responsible for treatment and monitoring.

Thus, as care and treatment are generally longer and involve the care of patients with more debilitating diseases, there is an approximation between the team and the patient, which triggers different feelings in those involved. From this perspective, it is known that the purpose of CP is to bring relief from suffering, which contributes even more to this involvement. Given this relationship, the literature reports the frequency with which health professionals feel distressed and have depressive feelings in the face of a worsening of the patient's condition*(3)*.

Thus, a more detailed assessment of this topic is needed to understand the attitudes and feelings of Brazilian physicians regarding the implementation of palliative care in pediatric patients.

## Methods

The study performed the analysis of data in different spheres, for the quantitative, the Windows Excel 2016* program was used and for the qualitative, the IRAMUTEQ software, version 0.7 alpha 2*, an interface of the statistical program R capable of multidimensionally analyzing texts and questionnaires.

After the instrument validation, 236 questionnaires were subsequently sent to physicians 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.

The bibliographic material was obtained by searching the Scielo, Lilacs, and PubMed databases. Articles were published up to 2020, selected for their relevance in the scientific literature. 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 under 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, Portugal.

**Results and discussions**

A total of 11,766 occurrences were observed, with a corpus divided into seven word classes with 328 elementary context units (ECU), using 92.99% of the corpus built by qualitative responses (305 ECU) matched by descending hierarchical classification (CHD) of text segments of different sizes, identifying different degrees of similarity and significance, of content use, 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 the statistical analysis and description of categories on the basis of the discussions. From this analysis, dendrogram 1 was constructed below (Figure 1).

The main goal of pediatric palliative care is to continuously provide comprehensive and comprehensive medical care, involving emotional, physical, social and spiritual aspects, aiming to promote quality of life for patients, as well as help the family during treatment and grief*(4)*. Therefore, the doctors in charge of providing this care constantly suffer moral conflicts regarding the attitudes to be taken and their relationship with their own feelings.

In this context, common feelings were perceived by physicians who worked with palliative care. Among these different feelings, in Graph 1, duty fulfilled (46.6%), relief (23.86%), and sadness (11. 36%) stand out. In addition, feelings of grief and anguish were highlighted.

In dendrogram 1, it can be seen that class 6 had feelings and difficulties reported by the participants during the research. The most significant words were "refusal of death," "duty accomplished," "sadness," "grief," "relieve," "futile treatments," "pediatrics," "team," "family," "professional," "lack of legislation" and "taboo" (Figure 2).

In line with the feelings of sadness and grief, a study carried out with a multidisciplinary team

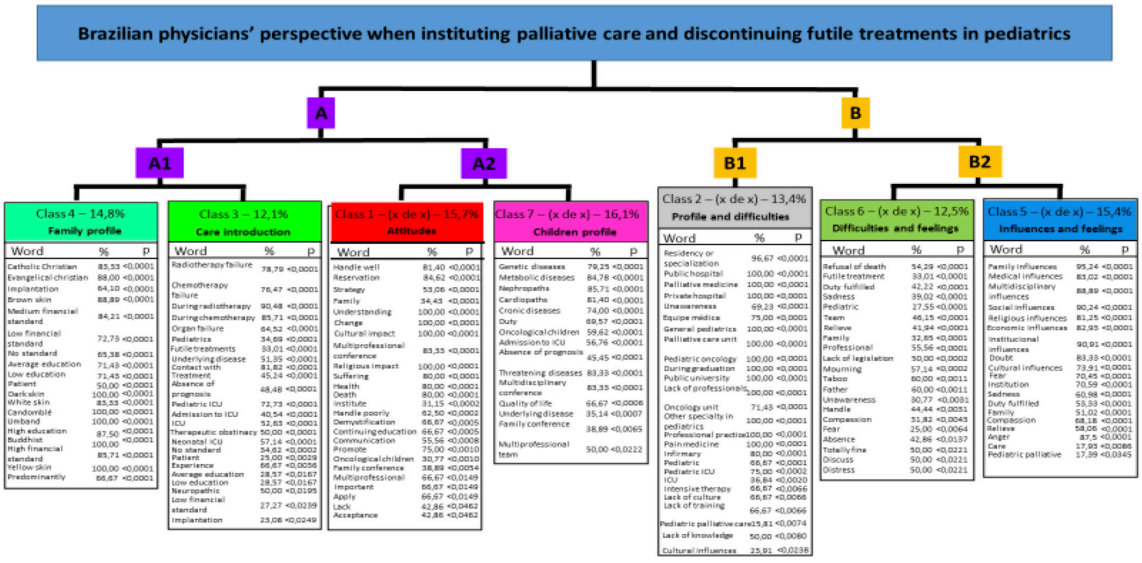



Figure 1: Dendrogram 1 - total corpus - Dendrogram 1: brasilian physichians' perspective when instituting palliative care and discontinuing futile treatements in paediatrics.

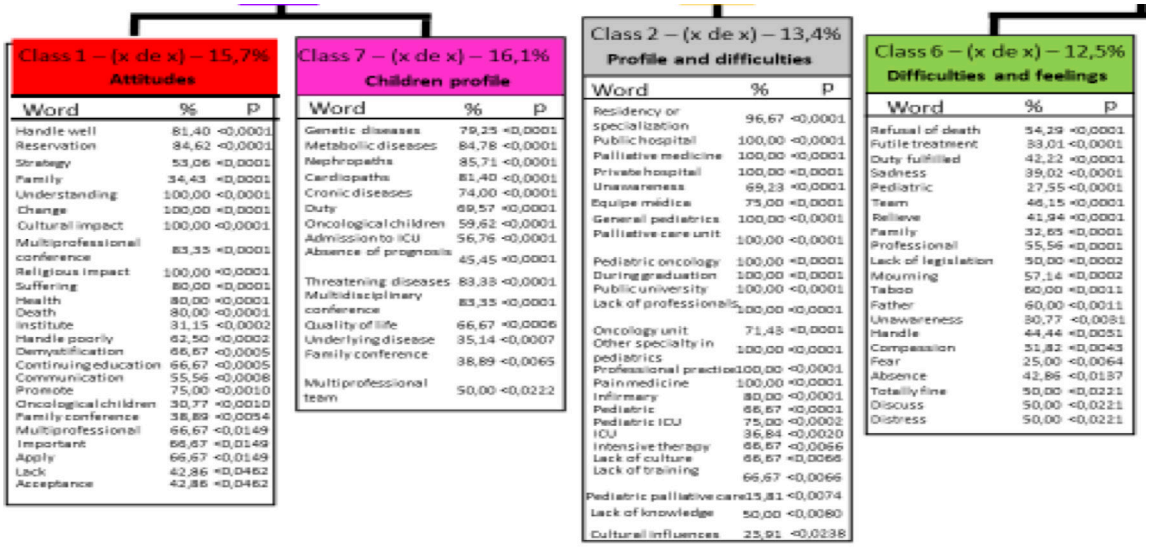



Figure 2: Dendrogram extract - Dendrogram extract: classes 1, 7, 2 and 6.

responsible for providing pediatric palliative care states that following the history of the cancer patient, for the health professional, can cause anguish and feelings of sadness. Such feelings may be a result of the hope of a cure since, from a cultural perspective, the process of death is not associated with a child, and therefore, such a condition is characterized as an unnatural situation that should be avoided*(5,6)*.

In addition, in the literature it is noticed that feelings of anguish and disappointment are quite frequent when the palliative care team feels they cannot meet the expectations created by the family regarding the patient's treatment*(4)*.

In this context, there is also the presence of contradictory feelings that manifest themselves in the team responsible for caring, mainly due to the emotional involvement generated by the bond with the patient and his family*(7)*. Thus, there are thoughts such as sadness/relief, wishing for life/wishing for death, feeling/not feeling, expressing/being silent and duty accomplished/frustration*(3)*.

Other feelings reported in the literature and present in class 6 of dendrogram 1 include anxiety, impotence (in view of the evolution of the condition or death of the child and the parents' grief), failure, fear*(3,8)*, duty fulfilled, pride and gratification to provide a better quality of life for patients and their families, are also frequently reported*(4,8)*.

For professionals involved with the patient, it is a difficult process to deal with the patient's death and suffering, as this situation leads them to reflect on their own losses and past and future conditions, making them think about their own finite condition. They also often report feelings of injustice and demand*(3)*.

Failure comes (added to other factors) from deficient academic training that leads professionals to avoid death at all costs and not consider it a natural process of life. Accordingly, it is reported in the literature that Brazilian physicians claim not to have received sufficient education and training to implement palliative care during training*(3,9)*. Positive feelings, on the other hand, are good sources of renewal and well-being for the team.

All these feelings and experiences in practice with palliative work were seen by some nurses as positive, since when faced with these situations, they start to reflect on their own personal attitudes. From that point on, they begin to value the feelings of others and the family more, leaving aside negative feelings such as selfishness*(10)*.

In class 1 of dendrogram 1, the attitudes undertaken by the professionals studied regarding the

need to implement pediatric palliative care are present. The most significant words reported in class 1 were "handle well," "qualification," "strategy," "communication," "understanding," "change"', "cultural impact," "multiprofessional conference," "religious impact," "health," "death" and "instruct."

Similar to what was perceived, it is reported in the literature that professionals often use different strategies to facilitate communication with patients and their families, as well as their understanding of the situation. Among such strategies, family education regarding palliative care stands out, as well as the holding of multiprofessional conferences, which facilitate the understanding of the case addressed, facilitate communication with the family, and promote better decision-making*(7)*.

Regarding the strategies adopted by professionals in the face of work and the emotions to which they are inherently exposed, there is the so-called Coping Strategy, which includes different ways to adapt to face a stressful situation. For this reason, a good relationship with family, friends, self-care, leisure activities greatly help professionals involved in pediatric palliative care, as they are always dealing with different feelings*(3)*. Another study also pointed out the practice of physical exercise as a positive strategy to deal with the emotions arising from work, and thus, the team sees this activity as an escape valve*(8)*.

Many professionals adopt "defensive" attitudes with the purpose of "protecting" attitudes to protect themselves from negative feelings in the face of distressing situations involving children as strategies. Thus, attitudes such as talking to colleagues about the topic or performing activities after work to ease the mind and separate the person's professional life were reported. In this context, the importance of having a good relationship between the professionals in the team is highlighted in order to avoid additional stressors*(4)*. In addition, there are strategies for emotional distancing from the patient and the search for spirituality, as well as a tendency to rationalize against to expose feelings in order to avoid grief*(5,8,10)*. In relation to spirituality, this can be defined as a form of resilience. to deal with issues related to the physical and psychic domain that helps the individual to recognize (in this context) death in a more natural way*(10)*. Thus, it is known that it is seen by many professionals in the context of palliative care as a very positive adaptation strategy to situations, as it generates, in a subjective way, meaning to the conditions experienced*(3)*.

When professionals do not adopt a strategy to deal with situations that generate emotional stress, they become vulnerable to the development of mental disorders, such as Bournout Syndrome which is widely reported in the literature within the medical profession. This condition can generate several symptoms and potentiate anxiety, stress, exhaustion, anguish and decreased personal fulfilment*(5)*.

The interviewed physicians claimed to have already experienced situations or practiced futile treatments to prolong the pediatric patient's life. One of the main causes of this phenomenon in the literature is formal medical education, which ends up conditioning future professionals to never give up on the disease, always in search of a cure, even to the detriment of the patient's quality of life. Thus, when graduating, many professionals find themselves making unnecessary approaches to incurable diseases*(9).*

Communication is a fundamental attitude within a CP, as it is necessary to establish a good relationship with the child's family*(9)*, to be effective and must include the conditions for understanding the family and the patient. For this, good teaching, clarity and patience on the part of the team are essential, so that decisions are taken in the best way. In addition, the professional responsible for communication must pay attention to other signs, as it is known that there is verbal and non-verbal languages that express a lot the listener's thoughts. Communicating bad news is a challenge within CP, and to help in this situation, professionals can use different approaches, such as the SPIKES protocol which covers six steps for conducting this dialogue*(2)*.

From this perspective, for parents, this communication when done well helps a lot in coping with grief and other anxieties*(11)*. Added to this, feelings of tranquility and satisfaction are reported in

the literature when the team manages to establish good communication with the patient and their family.

However, in many articles, communication is presented as a challenge for professionals, which directly influences the way of dealing with the entire palliation process*(6,12)*. Professionals do not feel prepared to communicate bad news because they do not have access to this education during their training*(6,13).* Furthermore, this issue is seen as a stressor for many people*(14)*.Within the results present in class 1 on attitudes, the words "communication" and "handle poorly" were exposed by about 50% and 60% of the participants respectively, being, therefore, relevant themes within this practice.

In addition, it is known that there is still a stereotype about palliation, as many see it as an approximation of death, but it must be inserted when the disease is diagnosed, as it offers comprehensive support to the patient and their family*(15).* For many professionals, the lack of an environment and time for dialogue about the feelings experienced is something negative, as this communication would even be a way of taking care of the team itself. Communication is still of paramount importance in the team for the prior definition, in adequate time, of when to place the patient in CP(4). In addition, as mentioned above, many health workers have academic training with a vision of cure like success and death just like failure and failure, which generates negative feelings. Thus, there needs to be more inclusion of this subject in the training of these professionals, as well as more training in the workplace. In addition, spaces can be created for dialogue between the team about aspects related to death in order to avoid misunderstandings and wrong attitudes about this process. Finally, it is essential that there is adequate psychological support in order to support emotional issues related to work in pediatric palliative care, as physicians must attend to the patient in a comprehensive manner, also aiming at the psychological aspects, therefore, the patient must be prepared for such performance*(4,12).*

**Summary**

Our results show that Pediatric Palliative Care is extremely important to improve the quality of life of children with different clinical conditions and quality of life their families. In this context and within the principles of palliative care, attention should be paid not only to the patients' physical symptoms, but also to their psychosocial domains. With this, the importance of addressing the feelings experienced by people is perceived. It is known that due to its intrinsic characteristics, the palliative work directed to children ends up being a source of contradictory feelings for the medical professional. Thus, it is clear that the emotional state of these professionals can affect the care and attitudes undertaken. In this context, feelings of sadness, frustration, anxiety, and pleasant feelings which are a source of renewal and pleasure in the work performed such as accomplishments and gratification have been reported. In addition, in the field of attitudes affirmed by professionals, rationalization strategies and emotional distancing from the patient are exposed to avoid anguish facing the loss of a pediatric patient or worsening of his condition. Communication is still a challenge, because academic training is still deficient in addressing the topic and there is a lack of emotional support resources for the care team and specific interventions are needed to make this practice calmer. Finally, broader and more detailed studies are needed to address the impact of these feelings on the professional behavior of physicians responsible for implementing palliative care in children, as there are few studies in the literature with the direct participation of physicians, with more studies being found with the multidisciplinary team and nurses.

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Conflict of interest

The authors have declared that no competing interests exist.

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Statement of non-duplication

During the Additional Information section of the submission process, all authors must certify that their manuscript is a unique submission and is not being considered for publication by any other source in any medium. Further, the manuscript has not been published, in part or in full, in any form. Work published or presented as an abstract at a professional meeting will be considered.

| **List of abbreviations** | |
|---|---|
| IRAMUTEQ | Interface de R pour les Analyzes Multidimensionnelles de Textes et de Questionnaires. |
| CAAE | Presentation for Ethical Appreciation |
| ECU | Elementary Context Units |
| CHD | Descending Hierarchical Classification |

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