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Ethical dilemmas for pediatricians administering palliative sedation to children in Brazil

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Abstract

This study aims to analyze the use of pediatric palliative sedation and understand how it is connected to medical training and the doctor-patient relationship in Brazil. This is a cross-sectional exploratory study using an online survey targeted at pediatricians working in Brazil to evaluate concepts of palliative sedation and aggressive symptom management. The lack of specific training, protocols, and institutionalized guidelines can create uncertainties in palliative care. This also contributes to the increased end-of-life suffering those children and their families face. Improving education in pediatric palliative care is an urgent and pressing need in Brazil.

Keywords: Critical care. Medical errors. Ethics. Pain. Palliative care.

Resumo

Dilemas éticos de pediatras ao administrar sedação paliativa em crianças no Brasil

Este artigo objetiva analisar o uso de sedação paliativa e entender como ela está ligada à formação médica e ao relacionamento médico-paciente no Brasil. Com base em pesquisa on-line focada em pediatras que trabalham no Brasil, este estudo transversal e exploratório buscou avaliar conceitos de sedação paliativa e tratamento de sintomas agressivos. A falta de treinamento específico, protocolos e diretrizes institucionalizadas pode gerar incertezas no cuidado paliativo. Isso também contribui para o aumento do sofrimento de fim da vida que essas crianças e suas famílias enfrentam. Melhorar a educação em cuidados paliativos pediátricos é uma necessidade urgente e imediata no Brasil.

Palavras-chave: Cuidados críticos. Erros médicos. Ética. Dor. Cuidados paliativos.

Resumen

Dilemas éticos de los pediatras al administrar sedación paliativa a niños en Brasil

Este artículo tiene como objetivo analizar el uso de la sedación paliativa y comprender cómo esta se vincula con la formación médica y la relación médico-paciente en Brasil. Basándose en una encuesta en línea con pediatras que trabajan en Brasil, este estudio transversal y exploratorio pretendió evaluar los conceptos de sedación paliativa y tratamiento de síntomas agresivos. La falta de formación específica, de protocolos y guías institucionalizadas puede generar incertidumbres en los cuidados paliativos. Esto también contribuye al aumento del sufrimiento que enfrenta estos niños al final de la vida y sus familias. Es imprescindible y urgente mejorar la educación en cuidados paliativos pediátricos en Brasil.

Palabras clave: Cuidados críticos. Errores médicos. Ética. Dolor. Cuidados paliativos.

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The death of a child represents a subversion of the natural order of life. Moreover, the act of caring for a child facing death has always presented limitations [1]. However, medicine still has a long way to go in improving the palliative care (PC) of children with terminal illnesses [2].

Palliative sedation (PS) is a form of aggressive symptomatic treatment during PC [3,4]. Authors define PS as a last resort treatment, initiated when all other methods of symptom control have failed [5]. PS is a highly specific therapy and thus it is crucial to identify both the continuous and persistent symptoms which are difficult to treat and bear by the patient [3,4]. It should be stressed, however, that it requires close monitoring and full cooperation between the family and hospital team [3,4]. PS, if carried out properly, is the intentional use of sedative medications to relieve intolerable suffering from refractory symptoms by reducing patients' awareness and consciousness with their consent or their legal representatives' and is incapable of accelerating death. Thus, it can also be defined as an aggressive form of symptomatic treatment [3,4].

The advancement of medicine and technologies with more effective treatments for previously incurable diseases, accompanied by the advent of pediatric intensive care units, has directly impacted the perception of pediatrics and its conduct [6]. However, it is still necessary for the various health services in different localities to be structured to enable more humanized support for pediatric patients and their families [7]. In Brazil, medical training in PC is rare [8,9].

If the use of PS in adults already faces complex ethical dilemmas and doubts, its use in children is even more complex. Its complexity lies not only in the difficult task of communicating with parents but also in the suffering caused by the potential death of the child. The prospect of violating ethical concerns with the deliberate decrease in patient consciousness is a big challenge for pediatricians [10] who, in general, feel uncomfortable practicing PS [11].

Studies in European countries have shown that PS occurs in between 2.5% and 16.5% of all adult deaths and has become more widespread in recent years. As a result, the publication of guidelines and recommendations to guide and help doctors deal with the clinical and ethical challenges of this practice with adults has increased in recent years [12]. On the other hand, while several studies suggest that PS is often used in end-of-life practices in children's guidelines [10,13,14], data on such practices remain rare. In the United States, recent studies have shown that the lack of research in the use of PS with children fails to reflect the frequency of its practice (which it is not rare) and the same scenario is a potential reality in Brazil. Additional in-depth research in Brazil is necessary so the literature can better understand how decisions are made and how PS relates to the explicit intent of reducing suffering in children with terminal illnesses [11,12,15,16].

Some studies in Latin America have explored different aspects of the practice of pediatric PS and the lack of knowledge in Brazilian pediatricians about PC options, as well as how ethical and legal care protocols can cause insecurity with parental decision making in the use of PS. As a result, guardians lack knowledge of the alternatives available to them and critically ill children may suffer unnecessary pain and discomfort [17-24].

Because of the limited data and absence of guidelines around pediatric PS in Brazil, it is thus crucial to survey pediatricians so as to understand their motivations and dilemmas for the practice of PS or lack of it in Brazil.

Method

This cross-sectional exploratory study used an online survey, targeting pediatricians working in Brazil, and followed STROBE guidelines. Respondents were invited to complete an online questionnaire and agreed to participate by signing an informed consent form. All procedures are in accordance with the Declaration of Helsinki (Code of Ethics of the World Medical Association) [25] and the Ethical Standards and Guidelines of CNS Resolution 466/2012 of the Ministry of Health [26]. The pediatricians in the sample were divided into two groups according to whether they had or not practiced PS.

The survey, now closed, conducted in the Portuguese language, was hosted online via Google Forms. Respondents were surveyed about the concepts of PS and Aggressive Symptom

Management (ASM). PS concept was presented as *the intentional use of sedative medications to relieve intolerable suffering of refractory symptoms by a reduction in patient awareness*[3], whereas *ASM is a procedure that produces sedation proportional to the anguish of symptoms, accepting unconsciousness as provided for unintentional side effect of this management*[11].

Then, two short vignettes were given to assess the kinds of decisions physicians might make regarding treatment and drug administration, as well as the individuals and factors which might influence those decisions when caring for pediatric patients at the end of their lives. The questionnaire was based and adapted from Henderson and collaborators, as they described it: *the survey assessed agreement with a definition of palliative sedation, as well as thoughts about its alignment with ASM*[11]. Respondents answered a total of 31 questions, ranging from objective and open-ended questions. It was structured around the following topics: PS concepts, the actual practices of pediatricians in the use of PS, perceptions regarding the institutionalization of PS in services around the country, and their knowledge of PC and PS in schools they attended. Duplicate responses were excluded from the analysis.

The minimum sample size was determined using a sample calculator (n=198). For open-ended answers, qualitative analysis by saturation was adopted, whereas demographic data were descriptively analyzed. *Rather than thinking of qualitative and quantitative strategies as incompatible, they should be seen as complementary. Although procedures for textual interpretation differ from those of statistical analysis, because of the different type of data used and questions to be answered, the underlying principles are much the same*[27]. In the search for correlations, inferential statistical analysis was performed. For the rejection of the null hypothesis, p<0.05 was adopted. SPSS 20.0 for Windows was used for analysis.

Results

The research sample included 202 participating pediatricians, of which 34% were general pediatricians; 30%, critical care physicians; 25%, neonatologists; 10%, palliative care physicians; 8%, hematologists or oncologists; and 35%, from other specialties. In total, 61% of our sample were aged between 25 and 44 years old, whereas 38% was aged above 45 years old.

The young women from Southeast Brazil (p=0.04) represented most pediatricians. The data showed that 50% of respondents had practiced PS in the last 12 months and that 86% of these lacked professional qualification in PC. Of the 10% respondents with professional qualification in PC, 74% had practiced PS in the last 12 months. In our sample, 90% of pediatricians received no training in PS during medical school. This was correlated with professional qualification in PC (p=0.04), with a higher error rate for those without any professional qualification in PC (rho=−0.729; p<0.00). The practice of PS was also related to the practice of a religion (p=0.04) (Table 1).

Table 1. Pediatricians' demographic and professional characteristics data. Brazil, 2019-2020

Palliative Sedation	Variables	Not Practiced n (%)	Practiced n (%)	Total n (%)
Gender	Men	20 (19.8)	16 (15.8)	36 (17.8)
	Women	81 (80.2)	85 (84.2)	166 (82.2)
Brazilian region*	Southeast	74 (73.3)	74 (73.3)	148 (73.3)
	South	6 (6.0)	11 (10.9)	17 (8.4)
	Northeast	13 (12.9)	11 (10.9)	24 (11.9)
	North	4 (4.0)	1 (1.0)	5 (2.5)
	Midwest	4 (4.0)	4 (4.0)	8 (4.0)

continues...

Table 1. Continuation

Palliative Sedation	Variables	Not Practiced n (%)	Practiced n (%)	Total n (%)
Religion*	Roman Catholic	45 (44.6)	42 (41.6)	87 (43.1)
	None (atheist/agnostic)	9 (8.9)	8 (7.9)	17 (8.4)
	Unaffiliated	20 (19.8)	14 (13.9)	34 (16.8)
	Other	27 (26.7)	37 (36.6)	64 (31.7)
Instances in the last year*	0	101 (100.0)	-	101 (50.0)
	1 and 5	-	83 (82.2)	83 (41.1)
	6 and 10	-	12 (11.9)	12 (6.0)
	11 and 15	-	-	-
	More than 15	-	6 (6.0)	6 (3.0)
Undergraduate training*	No	95 (94.0)	86 (85.2)	181 (89.6)
	Yes	6(6.0)	15 (14.9)	21 (10.4)

*$p<0.05$

Respondents had doubts about reducing patients' awareness and consciousness using PS. They were divided about their agreement with the adopted definition of PS (52% agreed versus 48% who disagreed), especially on the aspect of consciousness (36% pointed to an unnecessary reduction of consciousness). Otherwise, 52% of respondents believe that PS and ASM are equal and thus feel more comfortable with the term "ASM" than "PS," highlighting the importance of keeping patients conscious.

The main indicators for the use of PS in the study were pain (85%), dyspnea (42%), and delirium (23%). Pediatricians who choose the indicators which constitute total pain correctly were more inclined to use PS (rho=0.872; $p<0.00$). Inversely, the wrong indications are related to absence of total pain identification (rho=-0.459; $p=0.04$).

In this study, 65% of the respondents also indicated they were afraid to opt for PS out of fear of creating conflicts with the family. Of those who were palliative specialists, 68% showed the same behavior.

Additionally, more than 55% of pediatricians surveyed stated that their institutions lack a standard protocol to implement PS and 89% said they were unaware of legal regulations in Brazil around the practice.

Discussion

The teaching of end-of-life care in medical schools in Brazil receives little attention[9]. Approximately 90% of all respondents in this study reported a lack of education on PS in their medical training. The scarcity of medical curricula focused on palliative medicine in undergraduate courses causes an empirical reduction in the use of PS in Brazil. Thus, its practice is not based on knowledge and qualification, increasing the risk of medical errors and creating danger for patients. On the other hand, since PS is also practiced by physicians without professional qualification in PC, current medical training should also contemplate adding courses around the provision of end-of-life care in their curriculum to provide guidance for future medical professionals. This training will provide generalists with an integrated, theoretical, and practical foundation in palliative skills[9].

Among pediatricians with professional qualification in PC, 74% had practiced PS, suggesting that professionals with specific qualification are more likely to adopt appropriate measures to deal with end-of-life situations[11]. When analyzing the characteristics of the participants who practice SP, we found that several components may or may not influence it, such as religious practice. Non-Christian respondents practice it more than Christians, reflecting the multifactorial character of the practice.

Half of our respondents disagreed with the PS definition Wolf, Hinds and Sourkes adopted[3], especially on consciousness maintenance. Some point to the lack of reduction of consciousness or even indicate the importance of keeping the patient conscious, suggesting a lack of knowledge of the definition of PS and pointing to the ambiguities surrounding the practice[11].

In total, 52% of the respondents felt uncomfortable stating they are practicing PS but indicated that they are using aggressive symptom management (ASM), whereas half claimed that there was no difference between the two. It is extremely important to outline that there are no differences between PS and ASM. One reason that PS is not openly named, in addition to the question of the intention of maintaining consciousness (as discussed earlier), is that it might violate cultural beliefs of an ethical and/or religious character. The deliberate decrease in the patient's consciousness is seen to be close to the practice of euthanasia[28]. The international literature also corroborates our data, in which U.S. pediatricians also question the maintenance of consciousness and differences between PS and ASM[11]. Specifically, the practice of euthanasia, in addition to being unethical, is also considered a crime in Brazil (Brazilian Penal Code, Art. 121. Paragraph 1)[29]. The lack of knowledge arising from lack of training creates an internalized concept of PS that is fueled by fears and fantasies not only in relation to the legitimacy of the practice but also regarding the legal support to limit the provision of curative therapy in patients with terminal illnesses[5]. The Code of Medical Ethics[30] currently in force in Brazil makes explicit the need and ethical duty of the physician to provide PC for patients with terminal illnesses.

Regardless of the circumstances, pediatricians should be prepared to address symptoms as they manifest themselves in the death process[11]. Although pediatricians' motivations to use PS are influenced by the manifestation of pain and dyspnea, which are classic criteria for the use of PS, other symptoms – which are currently incompatible with the practice of PS, such as immobility, convulsion, sweating, pallor, tachycardia, nausea, fatigue, hypertension, crying, communication difficulties, epilepsy, bone disorders, headache, orthopedic deformities, cases of self-harm and suicide attempt – were also identified[31-34]. International studies advocate the need for guidelines clarifying what is considered acceptable practice and point to the role and importance of institutions in developing PS protocols which include criteria such as patient selection, choice of duration of therapy, as well as the necessary documentation for the protection of the doctor and the patient[16]. More than half (55%) of our respondents stated that their institutions lack a standard protocol to implement PS and 89% said they were unaware of legal regulations in Brazil about the practice[11]. The lack of guidelines in PS, the various barriers to the implementation of bioethics committees in Brazil, given their importance in advising decision-making and the dignity of the person[35], the lack of specific training, and the difficulty of communication with the family could increase the possibility of professional exhaustion and errors in the conduct of clinical practice and ethical management, creating greater risk to the provision of end-of-life care. However, to the best of our knowledge, no studies consider the rate of error of physicians' use of PS and its correlation to the absence of specific guidelines in PC. Most pediatricians feel they are helpless in decision-making and highlight the need for substantial materials explaining PS[4,9,11].

Although they were first implemented in the United States in the 1960s, bioethics committees remain optional in Brazilian health institutions and hospitals[36]. Hospital bioethics committees are multi- and transdisciplinary, assisting in decision-making and in issues of moral health conflicts[37,38] and offering support and protection to patients, their families, caregivers, and other health professionals. They are spaces for dialogue in hospitals and health institutions, helping and reinforcing the quality of services and decisions in health, guaranteeing respect for fundamental individual freedoms[39], and responsible for the educational and advisory challenge of fostering ethical awareness sustained in the autonomy and dignity of patients regarding decision-making[40,41].

In the absence of guidelines and protocols, the following questions could be used to generate greater confidence in pediatricians who consider the use of PS. They are as follows: have all efforts been made to identify and treat the causes producing reversible suffering? Have all non-pharmacological approaches been applied, such as relaxation and distraction techniques? Is sedation consensual[8]?

PS is a valuable option for children with terminal illnesses, although it presents additional complexities in pediatric practice, such as parental consent and understanding[11]. For fear of conflict with the family, 65% of respondents were afraid to use PS, and 68% of palliative specialists have the same fear. This suggests that the fear of conflict is not an exclusively key determinant of the use of PS[2]. Only after knowing the effective participation of the family in the end-of-life process can an appropriate strategy be defined to improve the quality of care for children hospitalized with terminal illnesses. In this context, it is essential to use preventive measures, using the ethical motivation of anticipatory virtue and the mitigation of conflicts, aiming to anticipate negative outcomes and enabling an individualized and studied planning for each patient, reconciling the desires of patients and family members and the performance of the health team[42]. Without the participation of the family in this decision, physicians may be engaging in practices that fail to meet the expectations, wishes, and values of patients with terminal illnesses and their parents[2], which could lead to undesired consequences.

Due to the absence of protocols and guidelines, the difficulty of managing the care of children with terminal illnesses and the lack of education around PC and PS in medical schools, increased by physicians self-sufficiently practicing PS, it is necessary to reflect on their possible impact, raising the idiosyncrasies distinctly from non-pediatrician physicians[5]. The internalized concept about PS in the absence of clear protocols and guidelines is formed by personal morals and beliefs, which are based on subjective experiences. This subjectivity is not based on medical training and will cause professionals to make incorrect decisions. Pediatricians who use PS without clear guidelines on patient eligibility raise the possibility of errors in practice. Physicians will also be engaging in unethical and negligent practice. This can prolong end-of-life suffering for patients and their families, generating dysthanasia and acting against the ethical principle of non-maleficence. On the other hand, if PS is used in an ineligible patient, another unethical practice will have been practiced, mysthanasia, which may cause suffering and hurt to patients and their families. The term comes from the Greek (*mys*=unhappy, *thanathos*=death, "unhappy death"); which means miserable, precocious, and avoidable death. Mysthanasia indicates that death is impinged by the maintenance of poverty, violence, drugs, and lack of infrastructure[8,29]. The systematic reduction of health financing; the indiscriminate opening of medical schools, the misuse of money available in the budget; the contempt and devaluation of physicians, eroded by corruption, incompetence, and inhumanity are facets of mysthanasia. It affects life and death, increasing the vulnerability of the patients in most need[2] and based on the concept of social responsibility and health — Article 14 of the Universal Declaration on Bioethics and Human Rights — health promotion is one of the central objectives of governments, which should cherish access to quality health care and eliminate marginalization without distinction or discrimination[39,43]. The concept of mysthanasia can also be applied to the education budget, an area which is directly interconnected with health since it offers the right conditions to medical training and practice and decrease idiosyncrasies. This is in fact, malpractice, in which such imprudent acts can lead to violation of the principle of dignity in death (Appendix).

The bioethical discussion thus arises to contribute to the search for balanced responses to current conflicts, essential in determining the forms of intervention to be scheduled and in prioritizing actions[46].

The generalizability of our results to the larger population of Brazilian pediatric physicians is threatened by the questionable accuracy of the list we used for our population. Some physicians within the population were likely excluded from the list and/or had incorrect e-mail addressed listed, and several other names on the list are probably now not a part of the population. Consequently, the likelihood of both under- and overcoverage must be considered as a study limitation.

Final considerations

In Brazil, the lack of guidelines on end-of-life care for the pediatric population is evident. Guidelines with this scope are of paramount importance as they enable the improvement of practice, deepen the discussion on indications, and guarantee the maintenance of ethics in decision-making. We need better training in pediatrics regarding end-of-life practices to increase patient safety, considering that pediatric palliative sedation is not only practiced by palliative care providers. Morally, the best practice will result in less suffering in the end-of-life process and guarantee the active participation of the family in the decision-making process. The improvement of education in pediatric palliative care is an urgent need in Brazil with the objective of making end-of-life care services increasingly refined and articulated in ethical principles.

Several spheres may be responsible for improving education in palliative care and developing professionals with the knowledge and ability to deal with end-of-life situations. From hospital managers improving the training aimed at palliative care in undergraduate and medical residencies with their teams, an growing number of hospital ethics committees promoting continuous training and assisting in decision-making and moral health conflicts, to professionals who must be aware that end-of-life processes are part of the practice of medicine and that the possession of this knowledge will impact the quality and offer good-quality medicine for their patients, actively seeking to develop this sphere of knowledge.

In conclusion, Brazilian pediatricians who practice PS are mostly young women who are not necessarily trained in PS and usually work in the developed areas of the country. Their main motivation to practice PS is to relieve patients' pain and dyspnea. However, there is concern around the family's role in the decision-making process of the use of PS. The lack of specific training, protocols, and institutionalized guidelines can create uncertainties over the conduct of PC with risks of misconduct in the practice of medicine, raising the possibility of increased end-of-life suffering of patients with terminal illnesses.

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Participation of the authors

Daniele Rodrigues and Denise Gonçalves Priolli conceived the idea of the study; Daniele Rodrigues and Djalma Lessa performed the experiment and collected the data; Denise Gonçalves Priolli supervised and guided the research. All authors discuss the results of this research and contributed to this final draft.

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