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MEDICAL ETHICS

Pediatric Palliative Care and bioethical reflections on COVID-19

Cuidados paliativos pediátricos e reflexões bioéticas na COVID-19

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Abstract

Introduction: COVID-19 has generated drastic changes in children's social life, as well as extreme changes in habits and care, especially in patients in pediatric palliative care, who have severe and life-threatening chronic diseases. In this context, the bioethical view becomes imperative, which aims to defend the best interest of the patient, the maintenance of his autonomy, as well as the desire of his family and caregivers, in addition to justice in the distribution of resources. **Discussion:** Ethical basis in health is essential in the current situation. Reflections on emergency decisions and support in pediatric palliative care are necessary, as well as autonomy and psychological aspects of isolation in pediatrics, so that assistance and protective measures can be at least sufficiently adequate for children and their families in this pandemic moment. **Conclusion:** Bioethical reflections among the interdisciplinary team working in pediatric palliative care have always been important, and the COVID-19 pandemic brought new questions and exacerbated other existing ones.

Palavras-chave:
Bioética,
Ética Médica,
Cuidados Paliativos,
Medicina Paliativa,
Pediatria,
Criança,
COVID-19.

Resumo

Introdução: A COVID-19 gerou mudanças drásticas na vida social das crianças, e também modificações extremas de hábitos e cuidados, especialmente em pacientes em cuidados paliativos pediátricos, que possuem doenças crônicas graves e ameaçadoras da vida. Nesse contexto, torna-se imperioso o olhar bioético, que visa defender o melhor interesse do paciente, a manutenção de sua autonomia, assim como o desejo de sua família e cuidadores, além da justiça na distribuição de recursos. **Discussão:** Embasamento ético na saúde é essencial na conjuntura atual. São necessárias reflexões acerca de decisões emergenciais e suporte em cuidados paliativos pediátricos, além de autonomia e aspectos psicológicos do isolamento em pediatria, para que a assistência e medidas protetivas possam ser, no mínimo, suficientemente adequadas às crianças e suas famílias neste momento de pandemia. **Conclusão:** Reflexões bioéticas entre a equipe interdisciplinar que atua em cuidados paliativos pediátricos sempre foram importantes, tendo a pandemia da COVID-19 trazido novas questões e exacerbado outras já existentes.

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INTRODUCTION

The profile of pediatric patients has been changing over the years and the need for assistance to children living with serious and life-threatening chronic diseases is increasing. In this context, pediatric palliative care has a primary role, since it prioritizes comprehensive care, for both patients and their families[1]. Considering the COVID-19 pandemic, it is necessary to ensure that healthcare is maintained, even if we need to make certain adaptations, so that all aspects related to health are covered[2].

Within a few months of this new disease, the literature on epidemiology, pathophysiology and clinical features of SARS-CoV-2 infection is growing exponentially. We are experiencing the learning curve, discovering and investigating the most effective treatment. Studies have shown that children do not appear to be affected on large scale, and approximately 90% of infected pediatric patients have mild/moderate symptoms or are asymptomatic[3].

In this context, it is important to emphasize that individuals within the "risk groups", that is, those who have important comorbidities, must be monitored in a different way, as they may present more severe forms of the disease[4]. At the same time, many patients who are assisted by pediatric palliative care have extra comorbidities, such as heart disease, for example, which leads us to have extra caution with this group[2].

In general, the pediatric population is an important transmission vector of COVID-19 to risk groups; therefore, children must obey the rules of social distancing, in order to restrict the progression of the epidemic[2], which caused a drastic change in children's social life, in addition to extreme changes in habits.

From this perspective, we seek to contribute to the equitable care of the population in which the individual's autonomy is widely respected, both for the pediatric patient and his/her family. For this purpose, the individual approach to healthcare and bioethics have never been so important. Bioethics is "the systematic study of human acts in the area of biological sciences and health, while these acts are analyzed from the perspective of moral values and principles", which investigates the conditions necessary for the responsible treatment of human beings, animals and the environment[5].

When we see a chaos in public health, or proximity to it, in which basic and advanced resources for the maintenance of life may be lacking, the bioethical principle of justice comes to mind, that is, the fair allocation of the existing resources. However, it is important to emphasize that, in order to make good decisions; we need to visit all the aspects concerning the principles of clinical bioethics. We need to stablish a balance, above all, between the principle of beneficence, that is to do good for the individual patient and the principle of justice, to distribute the existing resources equally. Pediatric bioethics (following the adult principles) aims to defend the patient's best interest, the maintenance of his/her autonomy, the desires of the family and caregivers as well as the fair allocation of resources[6].

Assistance to people vulnerable to this infection due to chronic diseases, disability or life-threat situations must have its protective measures reinforced and intense support from psychosocial services. During the COVID-19 pandemic, according to Ciruzzi et al., some essential ethical principles for the ideal care of patients must be respected, which are[7]:

- **Non-abandonment:** No one who needs medical care can be neglected or abandoned; everyone who needs palliative care must have access to it;
- **Respect for people:** patient protection, dignity and human rights, including the provision of private space for those at the end of their lives and their families;
- **Autonomy:** autonomy is restricted only for compelling public healthcare reasons;
- **Reciprocity:** protection of the people and the healthcare provider is a priority; appropriate infection control precautions must be available, respected and enforced;
- **Confidentiality:** patient confidentiality should be maintained in the absence of convincing public health concerns;
- **Caring for people:** follow up, spiritual support and grief support play key roles together with intensive care, medical treatment and symptom control;
- **Justice:** patients with similar health conditions should have equal access to treatment and healthcare (including protective measures) without discrimination based on ethnicity, religion, sex, age, disability, socioeconomic status or political affiliation.

DISCUSSION

Emergency decisions in pediatric palliative care patients

In this pandemic, we need to make healthcare decisions for children who need intensive care with a technical approach, always aiming at the child's and his/her family's best interests[8]. What we have seen so far is that, due to social distancing, contagious and infectious diseases are not occurring as frequently as in previous years, with no lack of pediatric care beds. However, with the growth in the number of adults in critical condition, beds for these patients are becoming scarce; thus, the pediatric sector may have to supply the demand of adult patients. Therefore, it is essential that, when making a decision while the demand for some resource is greater than the available supply, as it is in the COVID-19 pandemic, bioethics is a science to help us, as it is able to apply ethics in real clinical situations. The existing recommendations on how to allocate resources when they are scarce are mainly

based on the patients' chances of survival, as well as on the patient's wellbeing and life expectancy[9]. Bioethical principles guide decisions taking into account morally relevant factors, including saving as many lives as possible.

Emergency decisions are always complex because the physician does not have the necessary time for a moral deliberation. In pediatrics, it is even more complex, since decision-making also involves the child's parents. Thus, it is necessary to carry out prior therapeutic planning in order to guide the action of professionals in emergency situations[10].

Therapeutic planning should involve the patient, especially older children and adolescents, staff and parents, and it should always aim at the patient's best interest. Therefore, clarity about the disease, the natural history of it, possible complications and the adoption of appropriate measures in the face of these complications have to be the priority, all of that should be registered in medical records. This planning still needs to be revised and re-discussed as the disease progresses, always with the appropriate notes registered in medical records[10].

After the planning is defined, decisions on ventilation, resuscitation or use of any life-supporting measure in the pediatric patient with COVID-19 in Palliative Care, must follow prior therapeutic planning. In pediatrics, it is unfeasible to decide not to use invasive support when necessary. For this reason, pointless or disproportionate treatment, the one that does not bring benefits, offering possible harm, will be avoided, especially in the face of a pandemic. We should share clear information about the diagnosis and prognosis with the child's family members, in the presence of the assistance team[8].

However, the decisions made in the context of therapeutic planning cannot be mistaken by any decision made in the perspective of allocating scarce resources, because while the first must always be based on the patient's best interest, the latter analyzes equity in the distribution of resources. Therefore, healthcare professionals and institutions should pay extra attention to communication, which, in the context of the pandemic, needs to be even more assertive and empathetic, in order to prevent the patient and his/her family from feeling therapeutically abandoned in the face of an eventual decision not to perform a certain procedure. We must emphasize to the participants in the decision-making process that the determination must be based on the developed therapeutic plan and not on the scarcity of resources.

Child autonomy and guarantee of rights

Naturally, during pediatric treatment, healthcare teams often delegate all decision-making authority to parents. Patient involvement is not common, and their opinion ends up being secondary. During the COVID-19 pandemic this is no different[11].

When doctors draw the therapeutic plan, specially, in the context of support at the end of life, the child's best interest must be prioritized, seeking to combine the family's profile (beliefs, culture, and social situation) with the biological aspects. However, we know that pediatrics involves a wide-range age group, where autonomy must be analyzed individually, taking into account not only age, but also maturity[10]. In long-term treatments, autonomy should always be revised, since children's maturity is in constant progress, which can make them able to participate in decisions that they previously couldn't[1].

A patient who has the ability to understand information relevant to a treatment decision, and to consider the predictable consequences of a decision is considered capable of making choices, which requires the integrity of his mental abilities[12].

The Committee on Bioethics of The Council of Europe recently published an action plan on human rights and biomedical technologies, targeting the post-pandemic period. Which suggests the development of a guidebook, for healthcare professionals, about good practices for the participation of children in the decision-making process on issues associated with their health, recognizing the evolutionary nature of decision making in relation to the evolution of the children's ability to make decisions related to their own health [13].

Psychological aspects of isolation and the social role of the child

The global expansion of COVID-19 is promoting major life changes in families, with some specialties for children. Despite the low rate of hospitalization and mortality, children experience the damage caused by social distancing, specially, by not going to school, a place of protection and safety. Studies show that the time spent by children with computers has increased considerably, at the same time it is impossible for them to practice sports and attend school, which can lead to obesity, anxiety and worse ability to concentrate[14].

Children had their routine changed, which can get them confused, afraid of the possibility of infection and/or death, of themselves, family or friends, concerned about their parents' financial instability and distance from classmates and loved ones[11]. They had their sense of security, sociability and normalcy changed. Children with special healthcare needs and complex chronic conditions are even more vulnerable to illness as well as to the psychosocial and assistance problems created by the problems on healthcare services caused by the pandemic [15].

Schools are often a safe space for vulnerable children, and it usually plays a key role in protecting them, by detecting signs of abuse or neglect. The closure of schools was not associated with the creation of support networks for those in need. In addition, social services have also been suspended, leaving these children and their families even more vulnerable. Likewise, children with disabilities who need specialized support are deprived of this assistance. The lack of a support structure, social distancing, unemployment and physical health risks cause significant impacts on the emotional health

of children and their families. This situation also adds to the increase in domestic violence and abuse of children and adolescents[16].

Pediatric Palliative Care teams and families are faced with a great opportunity to develop their communication skills, promoting and stimulating the dialogue between parents and children about the coronavirus, the disease in their family, values, virtues, definitions and about inevitable losses. There is an urgent need to find a balance between empathy and honesty in these relationships[17].

In this context, good communication with children and their families requires honesty, trust, a sense of security and family unity, sensitivity to children's demands, affective relations, self-compassion from family members, emotional and spiritual support as methods to help coping with the situation, perception of death as a natural part of the life cycle as well as understand and practice the value of leaving a legacy in this life[15].

Support for children in Palliative Care and their families: what can be done?

It has never been so important to observe the patients' and their families' needs, assuming that the therapeutic plan must be flexible in order to adapt to changes in values and goals over time. Therefore, it is essential that healthcare professionals are always alert of the situation, looking for other possible options. The key to an adequate care plan may rely in the ability of finding different solutions that can be reached at a specific time, modifying this plan together with the team, the patient and his family whenever necessary[8].

There are recent case reports about patients who were followed up by Pediatric Palliative Care teams and entered the end of life process in the midst of the pandemic. Evans and colleagues reported a patient, whose care plan was centered in the hospital environment, and the resources in her city for symptom control and for other demands would not be sufficient. After pandemic containment measures were implemented in hospitals, such as changes made to the criteria for visits and companions, the patient and her family, together with the interdisciplinary group, decided that the plan would be modified and that the end of life process would be remodeled in order to happen at the patient's house[8].

We emphasize that the pandemic has also brought sanitary changes, and; therefore, it is possible that the end of life process occurs at home, as long as it is not associated with a COVID-19 infection. In this context, the connection between the service networks needs to be even better, so that the control of symptoms can be carried out impeccably, as well as assistance for the family. Strategies for families to deal with social distancing - which can bring an even greater sense of isolation and abandonment for the patient's family - giving them opportunities to think about what is really important for them, are also extremely significant[8].

We need to adapt, but also to recognize the limits of it. The team must act within the existing possibilities and make the best possible choices, with open, empathetic and honest communication with the child and their caregivers, these aspects of the conversation are extremely relevant. Children appreciate honesty and understand that bad news does not mean having no plans for the future or losing hope. The team must work creatively so that dreams are possible[8].

CONCLUSION

The COVID-19 pandemic highlighted the importance of clinical bioethics in healthcare, and aggravated the impacts caused by the insufficient use of these principles on decision-making process within healthcare. In Pediatric Palliative Care, the bioethical approach enables the construction of decision-making paths that meet the interests of the patient, family and the team, and should be a guideline in the formulation of care planning.

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