



The global impact of COVID-19 on pediatric palliative care

<https://doi.org/10.56238/homeIIsevenhealth-134>

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1 INTRODUCTION

The coronavirus emerged as a threat to Public Health in mid-2019, with the first confirmed case on December 12, in China (HABAS et al., 2020). In January 2020, the World Health Organization declared a state of Public Health Emergency (HUGELIUS; HARADA; MARUTANI, 2021). In view of this situation, in this research, it was decided to approach children in palliative care in order to understand the importance of this care and whether there were impacts caused by the coronavirus pandemic.

The pediatric palliative care process must be continuously guaranteed, highlighting its responsibility for the child's health and the well-being of family members. Child care occurs in an integral way and includes professionals from different areas, from the health area to the spiritual area, in order to direct specialized care (SILVA; ROCHA, 2021).

There are more than 8 million children who need palliative care (CONNOR; DOWNING; MARSTON, 2017). Therefore, it is extremely important to understand, especially in situations like these, whether the health of children in palliative care has been preserved, since they are exposed to greater risks.

This study aims to address COVID-19, Pediatric Palliative Care and the impact generated between Pediatric Palliative Care and the Pandemic. In addition, the study will address, from the perspective of children, families, health professionals and global data, demonstrating what the pandemic has meant in these groups.

2 OBJECTIVE

Assess the impact between pediatric palliative care and COVID-19 during the pandemic time.

3 METHODOLOGY

In the bibliographic review research, the PubMed, SciELO, World Health Organization, International Network for *Children's* Palliative Care, National Cancer Institute of Brazil, National



Academy of Palliative Care, United Nations Children's Fund, as well as documents and manuals that address the theme, will be used as a primary search source, being available in these databases between 2017 and 2023. The articles will be collected and from the data will be performed the fichamento of all, in order to perform a critical analysis of each article, elucidating the hypothesis of the author of this work. The keywords to be used are: Pediatric palliative care; COVID-19; Childhood cancer; Inclusion Criteria: The inclusion criteria of the research are to select articles that address the theme under study, between 2017 and 2023; Exclusion Criteria: materials that do not answer the research objectives.

4 DEVELOPMENT

COVID-19

On December 12, 2019, in Wuhan, China, the first case of the SARS-CoV-2 virus that severely devastated humanity was reported (HABAS et al., 2020). According to the Situation Report 51 of the World Health Organization (WHO), which was published in 2020, it was evidenced that the elderly (over 60 years old) and people with underlying medical conditions (such as cancer, respiratory diseases and cardiovascular diseases) are classified among the groups at greatest risk, and are therefore more vulnerable to COVID-19. With the spread of the virus, other countries have established social distancing and other restrictive measures in an attempt to contain transmission (BANERJEE; RAI, 2020). Still, according to the WHO, in March 2023, there were already more than 759 million confirmed cases and more than 6 million deaths.

PEDIATRIC PALLIATIVE CARE

In 1967, in England, St. Christopher's Hospice was founded, one of the leading hospitals in the world with services in Palliative Care and Palliative Medicine (PCPM). However, it is seen that according to the International *Children's Palliative Care Network* (ICPCN), more than 70% of countries provide little or no palliative care for children. There is also a difference in the importance of this care in each hospital, because while some consider it essential and perform it exclusively, others do not prioritize it as part of the care network (BUSTAMANTE et al., 2022). Despite the barriers to the global development of these services, places that offer this type of care bring great benefits to the lives of patients and their families (BENINI et al., 2022).

Pediatric palliative care (PPC) is a multidisciplinary approach that aims to improve quality of life, limit suffering and, in many cases, bring prolonged survival to the patient in a way that meets their physical, psychosocial and spiritual needs. In addition to welcoming families, preparing health professionals to deal with situations where it is necessary to give bad news about the patient's conduct (TEOLI, SCHOO, KALISH, 2022). In addition to providing assistance to family members during



treatment, after treatment and even in cases of patient death, given that bereaved parents and siblings are more likely to develop physical and psychological health problems (BUANG et al., 2022).

Inpatient palliative care is delivered through a variety of models, including dedicated home care units in larger general hospitals, palliative care consultation services, and coordinated models in which palliative care is integrated into emergency departments or ICUs (KAZAZIAN, DEANNA, SWALLOW, 2022).

According to the National Cancer Institute of Brazil (INCA), the palliative team is composed of doctors, nurses, physiotherapists, nutritionists, social workers, psychologists, speech therapists, pharmacists, chaplains and volunteers. This ratifies the importance of an interdisciplinary team to fully monitor the evolution of the health-disease process of these individuals (PINHO et al., 2020).

PEDIATRIC PALLIATIVE CARE AND THE PANDEMIC

Health professionals

With the emergence of the global coronavirus pandemic, there has been a major impact on palliative care provided to children, through reduced numbers of providers, decreased communication between staff and patients, and reduced dialogues between teams (MCNEIL et al., 2021).

Although adherence to telehealth has facilitated interaction between families and their loved ones (ELLIS et al., 2020), physical contact in care settings that previously favored the patient's condition has been affected (KELLEY et al.; MACKIE et al.; apud HUGELIUS; HARADA; MARUTANI, 2021). In addition, many healthcare providers reported a lack of adequate support in the application of telemedicine, such as various technical problems with mobile devices (MAYO et al., 2022). With these new changes, there was an overload of professionals, as many now needed to provide more detailed and more frequent information about the patient's general condition (CREUTZFELDT et al., 2020).

Virtual conferencing can promote "work scheduling" by extending work hours for palliative care providers who are already at their emotional limits. In addition, some patients/families may not have access to the technology that enables telehealth and be limited by poor internet connectivity or technical challenges in navigating telehealth systems (CHÁVARRI-GUERRA Y APUT KAZAZIAN ET. AL, 2022).

In a study conducted in 41 countries during the pandemic period with palliative care providers, it was reported that the suffering and tension experienced negatively impacted their workplace performance (GARCIA et al., 2022). Also in Singapore, where a study was conducted with health professionals from four tertiary hospitals, between March and August 2020, professionals reported increased stress and weariness in the workplace, anxiety and exhaustion due to working hours (TEO et al., 2021).



Child

The United Nations Children's Fund (UNICEF), created by WHO in 1946, aims to promote the rights and well-being of children and adolescents. In this regard, a report released in 2021, evidenced that COVID-19 was the biggest global crisis for children in UNICEF's 75-year history. Previously, there were about 1 billion children worldwide lacking health, education and housing, however, with the spread of the SARS-CoV-2 virus these problems became more aggravating.

Children with cancer undergoing palliation, had loss of chemotherapy sessions, lack of specialized care and reduced consultations (SCOTT et al., 2022). Due to the public health emergency, much of the attention was focused on patients infected with the SARS-CoV-2 virus (CHONG et al., 2020). It is now known that childhood cancer is the most prevalent disease in society and represents one of the leading causes of death (MAJEED et al., 2022). The impact has been so great that an additional 1.2 million children are expected to die globally due to limited access to medical care (ROBERTON et al., 2020).

Furthermore, the pandemic prevented children from having contact with grandparents, parents or any close family members before death. Due to these restrictions, many children went through a painful grieving process (HARROP et al., 2022). Based on a study done on pediatric patients in six public children's hospitals in Italy, 2020 to 2021, 68% presented depressive symptoms and 63% anxiety symptoms (CORREALE et al., 2022).

Families

It is also important to emphasize that, due to the new restrictions and orders generated by the crisis, many families were worried and distressed that their children would contract the new virus (SCOTT et al., 2022), that they would not receive good medical care (EKBERG et al., 2020) and that it would not be possible to always be present with the child in hospital environments (MOORE et al., 2020). In addition, many parents began to have impasses to reach consensus with professionals on the decision-making processes of their children's health status (HUGELIUS et al., apud CREUTZFELDT, MUNIRAMAN, PISCIELLO, 2021).

In accordance with a study conducted in the United Kingdom from 2019 to 2020 with professionals and family members of PPC, it was found that parents experienced a feeling of physical and psychological exhaustion due to the loss of the support network provided by friends and loved ones (SCOTT et al., 2022). In addition, before the pandemic, parents were already tired of the stressful routine of living in an environment of intense suffering due to their child's health status and giving up their personal chores and activities in favor of caring for the child (SILVA, ROCHA, apud ESPÍNDOLA et al., 2018).



5 FINAL CONSIDERATIONS

The implementation of Pediatric Palliative Care still remains resistant over the years. There is still the harm to the health of children and their families caused by the recent COVID-19 public health crisis. This was preceded by discontinuation of treatments, postponement of appointments and psychological problems for children, in addition to families feeling lonely and health professionals unprepared. In view of this, it is necessary to understand all the damage generated by COVID-19 in pediatric palliative care so that in future global health problems, the people involved in the health-disease process of this group are stronger and prepared to develop techniques that mitigate their impact as much as possible. It is extremely important that the health of children in palliative care is preserved, since they are exposed to greater risks. In addition, limitation in the palliative care of these children should be avoided, regardless of the health situation at the time.



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