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REVIEW ARTICLE

Quality of life of children hospitalized in the COVID-19 pandemic

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Abstract

Objectives: The COVID-19 pandemic led to sudden and challenging changes. In addition to new coronavirus hospitalizations, children continue to be hospitalized due to other causes, which demands enormous caution to reconcile preventive measures to reduce the spread of SARS-CoV-2 with actions to guarantee quality of life during hospitalization. **Methods:** Aiming to offer quality of life for children hospitalized in the current pandemic, a literature review was carried out, with subsequent critical analysis, using databases and relevant descriptors, such as "quality of life", "hospitalized child", and "coronavirus infections". **Results:** The themes found were communication, reception, attention to the families needs, playing in the hospital and playful stimulation and continuation of the schooling process. Communication is an essential skill to ensure humanized and qualified care practices, important for good adherence and response to treatment. As for the reception, the emotional, social, spiritual, and physical spheres must be considered. In order to provide comprehensive care, it is essential to know the child's family context. Play is one of the main occupations of the child's context, being a way for the development of various capacities of adaptation, interaction, and a source of physical and emotional stability for children. Maintaining the schooling process can mitigate the significant losses that hospital isolation brings. **Conclusion:** It is concluded that, in order to offer quality of life in the pediatric hospital context nowadays, one must have a holistic and interdisciplinary view.

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INTRODUCTION

As provided for in the International Health Regulations, the World Health Organization (WHO), considering the outbreak of the disease caused by the new coronavirus (COVID-19), declared on January 30, 2020 a state of public health emergency of international importance, classified in March of the same year as a pandemic¹.

Such a situation requires a rapid and coordinated international response, in addition to local measures. Like several countries in South America, Brazil has been facing difficulties in combating the pandemic, and it is now considered one of the epicenters of the disease².

Local government authorities have faced countless challenges in controlling its spread, which has an impact on the way in which the population understands all the security measures proposed by public healthcare agencies. Considering that the main transmission of COVID-19 occurs through droplets, among the essential recommended control measures are the intensification of hand and respiratory hygiene and social distance¹.

Society needed to adapt to the demands presented and some populations, such as children, have been experiencing the impacts of the pandemic in a particular way. Situations such as disruptions in school activities, limitations in playing in diverse spaces and reduced social and family relationships are some of the aspects that are directly affecting Brazilian children and, if not properly managed, can cause damage to neuropsychomotor and sociocultural development³.

Along with the changes, life moves on and children continue to be hospitalized for several causes, other than COVID-19. Thus, more than ever, caution is needed to reconcile preventive measures against the spread of the virus with choices that guarantee respect for the general needs of children⁴, as well as quality of life during hospitalization.

According to the WHO Quality of Life Group⁵, quality of life is the individual's perception of their position in life, in the cultural context and in the value system in which they live, and in relation to their goals, concerns and expectations. In relation to these concepts, associated with the subjectivity of the topic, the literature adds dimensions that involve the offer of public policies and society's organization⁶.

In this aspect, among the public healthcare policies, the National Humanization Policy (PNH)⁷ stands out, which, with premises such as the pursuit of the guarantee of users' rights, respect for their dignity and the promotion of their physical, mental and spiritual health, tends to contribute to the well-being of hospitalized children, reducing costs and the length of hospital stay⁸.

It is of utmost importance to have the principles and guidelines outlined in the PNH⁷ as the foundation, with the clinic expanded, welcoming and acknowledging healthcare workers, the ambience, the user's right, transversality, among others - highlights that cannot be forgotten in the midst of to

the pandemic, since this policy is the "guiding thread" of all care actions that must make up the practices of healthcare teams, as well as managers and, above all, patients - these being understood as key players in their health-disease process.

Humanization in pediatric hospitals⁹ is highlighted by revisiting the way children and their families are cared for, and come to be understood as subjects with desires, who deserve understanding in view of the singularities of life and the changes imposed by hospitalization.

Contributing to a more humanized hospitalization favors the improvement in quality of life in the face of the negative impacts that hospitalization can cause on children and family members. Therefore, this paper intends to discuss the challenges of guaranteeing quality of life during pediatric hospitalization, from the perspective of humanization during the COVID-19 pandemic.

METHOD AND RESULTS

This is a theoretical study, based on a critical review of the literature, answering the question: how to offer quality of life for hospitalized children in the midst of the COVID-19 pandemic?

Since this paper intends to reflect on the Brazilian reality, the SciELO database was first used, with two keywords, being "Quality of life" and "Hospitalized child". We also decided to restrict papers from 2000 onwards, seeking updated scientific content.

We searched for "Quality of life and hospitalized child", resulting in four articles. These were read in full, with content analysis, looking for triggers that could answer the main question "how to offer quality of life for hospitalized children?", to guide the second phase of the searches.

The following themes stood out: communication¹⁰, welcoming¹⁰, playing in the hospital¹¹ and playful stimulation¹⁰, maintenance of the schooling process^{12,13} and attention to the needs of the families¹⁰.

The research was now linked to COVID-19. Since it is a recent disease and still constantly updated, we needed to expand the search to beyond the Scielo database, including the Pubmed and Lilacs databases, using the same previous keywords, in Portuguese and English, and associations with the "COVID-19" keyword, in addition to the Portuguese terms for "Coronavirus Infections" or "Pandemics", as well as the English terms "Coronavirus Infections" or "Pandemics".

We used the following new searches "Quality of life and hospitalized children and COVID-19", "Quality of life and hospitalized children and coronavirus infections", "Quality of life and hospitalized children and pandemic", "Quality of life and hospitalized children and COVID- 19", "Quality of life and Hospitalized Children and Coronavirus Infections" and "Quality of life and Hospitalized Children and Pandemics", but they did not yield results.

Thus, based on the themes initially found, the present paper continued to associate these approaches to the adaptations and reflections necessary for the current moment.

DISCUSSION

Based on the findings, we see that actions such as effective communication, welcoming, family support, maintaining the playing and studying and are basis for providing qualified pediatric hospital care, even in the middle of a pandemic.

Communication

Communication is an essential skill to ensure humanized and qualified care practices¹⁴, and when we think of children, it is important to consider that the information must involve the child-family binomial.

When communication involves difficult news, the dialogue becomes complex regardless of the age group and, when the situation involves children, whether they are key players or have a supporting role, it becomes even more challenging. In the current context, to the usual difficulties, we add the fact that the insecurity of parents and caregivers, in addition to that of the health professionals themselves, intensified, since many factors must be taken into account, such as age, stage of development, environment where they live, among others. Such a task, although arduous, is extremely important for good compliance and response to treatment¹⁵.

Essential points of an efficient communication are "speaking the truth" and adapting the language for each age group, since children, regardless of age, perceive that something "out of the ordinary" is happening. We should always consider aspects related to the choice of the environment and non-verbal communication, such as maintaining eye contact with the child and not diverting attention when the news is being communicated¹⁵.

It is very important for children to have an active participation in these choices, within their reach, and they must have room to express themselves (whether through speech, gestures, writing, drawings, crying), continuously maintaining the necessary support from the multiprofessional team¹⁶.

Feelings of guilt, fear or even anger are common occurrences, but which, with proper communication, understandable explanation, active listening and support from a reference adult, can be positively understood by the children¹⁵.

Welcoming

Cecily Saunders¹⁷ addressed the concept of "Total Pain", based on the emotional, social, spiritual and physical spheres. Suffering, in this sense, appears fitting the complexity of all these aspects, associated with a set of negative situations in the life of human beings. In the midst of the pandemic, the four spheres may be compromised, since there are different triggers to generate discomfort, such as fear, hopelessness, loss of social role, questions about the meaning of life, in addition

to the physical pain itself, which can manifest themselves in different ways in any life cycle.

Based on this understanding, embracement, as a guideline from PNH, favors the identification of the patient's demands, since it consists of an ethical posture that involves constructions that enable the formation of bonds and relationships of trust through active listening and sharing knowledge, enabling referrals to solve problems¹⁸.

Relating these theories applied to childhood, it is still possible to find actions that do not consider the child as a complete being and in training, which can interfere with the quality of care. Understanding the individual in a broader way is a premise and, in this sense, children are also part of this view and must be welcomed as such.

There are tools that help healthcare professionals to deal with the uniqueness of the child at each stage of development, enabling him/her to be able to identify his/her pains and needs.

Physical pain can be identified and measured with pain scales. These scales can be uni or multidimensional, depending on the need, the specific environment and the training of the team, as well as the validated scale and the child's age must be taken into account¹⁹.

Another little explored resource in the children's scenario is spirituality as an intrinsic part of healthcare. Regarding the instruments for addressing spirituality in children, studies are still scarce, that is, there is no rule. It is important to carry out this approach in a calm and natural way, understanding the child's language, respecting the beliefs involved and broadening the view on him/her and his/her family. There is a validated rating scale of hope for children between 8 and 16 years of age (Children's Hope Scale), related to spirituality, but open questions expressed by children with serious illnesses, such as "does it hurt to die?" or "what did I do to deserve this?", are already described in the literature as opportune "triggers" to address possible spiritual suffering in children²⁰.

Concerning other spheres, that is, social and emotional, in addition to the psychological support that must always be present, care with communication and with the family are aspects that are also relevant¹⁰ and are being addressed separately, with more details, in other topics in this paper.

Attention to the needs of the families

To fully care for a child, it is necessary for the healthcare professional to know the family context in which he/she is inserted²¹. Multidimensional suffering factors are also involved and directly linked to care; therefore, assistance and welcoming the person in charge should be routine in care practice. Identifying social, emotional, environmental and cultural factors, as well as formal and informal support networks, is fundamental in guaranteeing the quality of family care²¹.

Since visits are prohibited, meetings and conversations via digital platforms on mobile devices, for example, are new formats for children to keep in touch with important figures of affection⁴.

Considering the scenario of restrictions imposed by COVID-19, hospitalization was severely modified. Changes in the routine of visitors and companions have brought important impacts, both for the children and for the family member who becomes the main and, in this case, the only caregiver during hospitalization⁴, with this aspect being relevant in the provision of care by the caregiver.

Playful stimulation and playing in the hospital

Playing is one of the main occupations in the children's context, being a way for the development of various capacities, for adaptation and interaction and a beacon source of children's physical and emotional stability²².

Thus, activities guided by professionals, as well as free play are strategies that should always be encouraged in the hospital. However, due to the pandemic, socialization spaces such as playrooms and the like, cannot be used¹¹, requiring institutions to redesign strategies to ensure recreational and therapeutic activities in the child's own room and/or bed, such as, for example, making exclusive materials and non-transferable painting, reading, as well as games and toys made with recyclable materials that can be discarded at the child's discharge.

Storytelling is also a powerful recreational resource. Research on the practice points out beneficial data such as favoring joy, increasing interaction and acceptance of medical procedures, as well as helping with pain control²³. Stories also stimulate the imagination, contributing to educate and increase vocabulary, enabling expression, can favor the understanding of unpleasant situations and help in creating identities²⁴. This activity can be adapted to hospitalization in the setting of COVID-19, through remote channels such as video calls in which friends and family tell stories chosen by them or by the children themselves.

Maintenance of the schooling process

The relocation of school activities is not new for children who experience long periods of hospitalization¹³; but, in the pandemic setting, it gains specific characteristics.

School activities, as a whole, were adapted to the requirements of the moment, being offered remotely. For children who are hospitalized, there is the possibility of remaining connected to the school routine in the midst of the hospitalization routines. This conduct tends to mitigate the significant losses that hospital isolation itself already brings¹³.

In this way, adapting for the moment, guidance on the possibility of using digital equipment, preferably from the hospital itself, such as cell phones, computers or tablets, contributes to hospital stay to follow a certain social and educational normality.

CONCLUSION

Considering the COVID-19 pandemic and all the socio-cultural changes that have occurred in our environment, the

care of hospitalized children must be redoubled. The quality of life in pediatrics, based on humanization, must be remodeled in all settings, taking into account current health issues, but also based on our cultural context.

In order for all spheres of care to be considered, adaptations can and should be made concerning the main themes, such as changes in play and school activities, communicating in different formats, expanding the look at total pain, welcoming patients and family.

Therefore, in order to offer quality of life, currently in the pediatric hospital context, one must have a holistic and multidisciplinary approach.

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