

Experience Report

Occupational therapy in a pediatric cardiological clinic during the COVID-19 pandemic: experience report of a resident

Terapia ocupacional em uma clínica pediátrica cardiológica durante a pandemia de COVID-19: relato da experiência de uma residente

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Abstract

Hospital treatment of children with congenital heart disease during the SARS-CoV-2 pandemic restricts their daily activities such as bathing, eating, studying, and leisure. The protocols of patient safety and hospital biosafety that aim to improve the care quality actions and infection control tend to generate a reality of anonymity, depersonalization, which exacerbates the presence of fear related to pain and the threat of death in patients and their families. In this context, the environments that symbolized essential care for life now come to be understood by the population, as a place of the great possibility of infection by the new coronavirus. This set of factors can affect the lives of children with heart disease, given the urgency of hospital therapy, negatively influencing the acceptance of interventions performed in this context. To reflect on these aspects, this study describes the professional experiences that occurred during the COVID-19 pandemic in 2020 provided by a Cardiovascular Health Care Residency program. It is a descriptive and qualitative study of professional experience reports. In this, it was observed that the interaction of children and companions became restricted to individuals who shared the same ward environment and with the team members during the interventions. Because of this, the occupational therapist is the qualified professional to identify disruptions in daily life, reflect and intervene in new ways to meet occupational demands, develop resources and adaptations that corresponded to the needs of each patient.

Keywords: Heart Defects, Congenital, Child Hospitalized, Professional Training, Occupational Therapy, Pandemics, COVID-19.

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Resumo

O tratamento hospitalar das crianças com cardiopatias produz cerceamento das suas atividades rotineiras como banho, alimentação, escolarização e ludicidade; tal cerceamento se agravou durante a pandemia da COVID-19. Os protocolos de segurança do paciente e de biossegurança hospitalares que objetivam melhoria da qualidade das ações do cuidado e controle de infecção tendem a gerar uma realidade de anonimato, despersonalização, o que pode exacerbar a presença do temor relativo à dor e à ameaça de morte nos usuários e seus familiares. Os ambientes deste contexto que simbolizavam cuidados essenciais à vida agora passam a ser compreendidos, por parte da população, como o local de maior possibilidade de infecção pelo novo coronavírus. Este conjunto de fatores pode afetar a vida da criança cardiopata, diante da urgência da terapêutica hospitalar, influenciando negativamente na aceitação das intervenções realizadas neste contexto. Este artigo descreve a vivência sobre a atuação de uma residente de terapia ocupacional no programa em Atenção à Saúde Cardiovascular no contexto hospitalar durante a pandemia COVID-19, sobretudo no ano de 2020, em uma enfermaria pediátrica cardiológica. Trata-se de um estudo de caráter descritivo e cunho qualitativo do tipo relato de experiência profissional. Foi observado que a assistência e o cuidado às crianças e acompanhantes se tornaram restritos aos indivíduos que compartilhavam do mesmo ambiente de enfermaria e com os integrantes da equipe durante as intervenções. Diante disso, o terapeuta ocupacional se apresentou como o profissional habilitado para identificar rupturas no cotidiano, refletir e intervir em novas formas de atender às demandas ocupacionais e desenvolver recursos e adaptações que correspondessem às necessidades de cada usuário.

Palavras-chave: Cardiopatias Congênitas, Criança Hospitalizada, Formação Profissional, Terapia Ocupacional, Pandemias, COVID-19.

Introduction

Care for the maintenance of the quality of life in children with heart disease has evolved over the last 60 years. Even in the most complex cases, a better life prognosis is possible. Thus, therapeutic approaches have been aimed at comprehensive care for the long-term evolution of the individual (Aita & Souza, 2016).

In the list of possibilities of professional interventions, the comprehensive care of the people addressed and especially in the hospital context includes the occupational therapy professionals. Their interventions are intended to promote the adequate neuropsychomotor development of the hospitalized child, especially through the occupation of playing and the Activities of Daily Living (ADL's) (Amaral et al., 2019).

Hospitalization in different age groups can cause anxiety and abrupt loss of control over life, resulting in a reality of anonymity and depersonalization. However, the hospital environment also provides other possibilities of care in which the child and family can better know about the health-disease process, body functioning, favoring the child's development, pain, and symptom management (Menezes & Moré, 2019; Marcolino et al., 2017).

During the COVID-19 pandemic, experiencing hospitalization became more complex. The hospital context that symbolized an environment of essential care for life is now understood by the part of the population as a place of the greater possibility of infection

by the new Coronavirus (SARS-CoV-2) (Silva et al., 2020). We know that the transmission of SARS-CoV-2 happens through droplets of saliva from the infected person and contact with the mucous membranes of the uninfected individual, especially in closed and poorly ventilated places such as hospitals, which can be environments that facilitate this transmissibility (Medeiros, 2020).

Facing this reality of fear of contamination by the new virus in the hospital context, Falcão et al. (2020) highlight that there was a decrease in the search for cardiac emergency care in a hospital in Fortaleza-CE. This may be the result of the difficulty in recognizing symptoms of a cardiac emergency, little access to care in this specialty, and the fear of infection by COVID-19, generating postponement of the demand for assistance from health services.

However, not only the general population has been affected by the changes brought by the COVID-19 pandemic but also health professionals in the workplace. This is because there has been an increase in exposure to cases of large-scale deaths, recommendations not to interact with each other in a physically close way, high risk of virus infection, a longer time for clothing, and removal of individual protection equipment. These factors can trigger or increase symptoms of anxiety, depression, and stress (Zhang et al., 2020; Bao et al., 2020).

In this sense, this article aims to describe the experience of an occupational therapy resident in the Cardiovascular Health Care program in the hospital context, in a pediatric cardiology ward during the COVID-19 pandemic period, in 2020.

Outlining the Methodological Path

This is a descriptive study of a qualitative approach. It is a professional experience report type to describe the professional experiences obtained during the COVID-19 pandemic in 2020 offered by a Residency program in Cardiovascular Health Care.

Among the various practice scenarios provided by the residency program, we decided to delimit the analysis to what is experienced exclusively in the pediatric cardiology environments of a public hospital of reference in the Amazon region. This is because its relevance for professional training and the provision of care present in the uniqueness of these occupational therapy service patients affected by congenital heart disease and with COVID-19, with separation of wards according to the classification of confirmed, the confirmation process, and non-confirmed COVID-19.

The experiences in the pediatric ward were recorded in a field diary and the reflections found theoretical support in a literature review with scientific publications in Portuguese in the last 5 years, using the same keywords in all databases in Portuguese: *Terapia Ocupacional, Pandemia, Cardiopatias Congênitas e SARS-CoV-2* (Occupational Therapy, Pandemic, Congenital Heart Diseases, and SARS-CoV-2). The search was carried out in the databases of the *Biblioteca Virtual de Saúde* (BVS) and CAPES Journals and in the *Revista Interinstitucional Brasileira de Terapia Ocupacional* (REVISBRATO). We chose them because when we consulted them, they are the platforms that presented results.

Understanding the patient and the practice setting

The residency program that enabled the personal experience per hour reported here has a reference hospital specialized in cardiovascular health care as a practice setting. It receives patients from the metropolitan region of Belém, as well as from 144 municipalities in the

State of Pará. Most of the time, they are rural or riverside people with a family economic base in agriculture and/or fishing. The age of the children admitted to the pediatric clinic is between 1 month and 12 years old. They are patients with different Congenital Heart Diseases (HD), admitted for elective or urgent procedures, who remain hospitalized for an average of two months, while they receive medications, numerous diagnostic and therapeutic procedures (Fundação Pública Hospital de Clínicas Gaspar Vianna, 2021). The hospitalization process has several stressors related to this environment. Also, there was the intensification of COVID-19's biosafety measures in the hospital context, an element that registered and negatively enhanced the restrictions during the performance of Activities of Daily Living (AVD) and Instrumental Activities of Daily Living (IADL), exacerbating the aforementioned emotional and behavioral aspects, and intensifying the fear of death in children and their families, sometimes causing them to forget the severity of the heart disease.

Issues about Children's Daily Life in the Hospital, Occupational Therapy, and Pandemic

Dimensions affected by the pandemic

According to Andrade & Pacheco (2016), children from 144 municipalities in Pará are usually part of the daily routine of direct interaction with the environment, using toys made from local raw materials, interaction with a social group, bathing in the river, and playing in free environments. Thus, by understanding the culture of this population, it is possible to access the occupational dimensions, patterns, and meanings of each occupation (Pereira et al., 2018).

This reality is confronted with the common characteristics of congenital heart disease, which generate several restrictions, mostly motor, due to clinical signs of tachycardia, dyspnea, tiredness, and hypoxia crisis. These signs and symptoms can lead to changes in routine, care, medications, and long hospital stays (Mari, 2015).

Kudo et al. (2018) state that chronic disease in childhood is accompanied by numerous drug intakes, occupational and functionality restrictions, daily changes, asthenia, and hospitalization that leads to social withdrawal, fear, exams, and painful stimuli, with altered mood and reactive to the presence of the health professional identified by the white gown.

Added to these conditions, we need to highlight the changes that have occurred in the pediatric ward scenario. In the period before the pandemic, the inpatient sector had a physical area consisting of 20 beds and isolation for clinical and/or cardiac surgical treatment. The wards offered an air-conditioned environment, with 2 to 3 beds, individual seats for companions, and a toilet. Patients and companions had free access to the common area, with television and chairs. It had a Lecture Room, in which occupational therapy groups took place in the morning, and also a Hospital Class to continue teaching during hospitalization, with classes in the afternoon for school-age patients, a right that is guaranteed by Resolution No. 41/95 (Brasil, 1995). There was also a hospital playroom with various resources and materials available from eight-thirty to seventeen; this is recommended by Law 11, 104/05 and Ordinance 2,261/GM of 2005 as mandatory in pediatric hospitalization institutions, being a playful space, consisting of educational games and toys, aiming to encourage the child and companion to play, favoring the bond, affection among themselves and with their environment (Brasil, 2005a; Brasil, 2005b).

Once a month, a movie session for children and their companions was offered in the institution's auditorium.

In this nursing setting, occupational therapy interventions could use the toy library or Lecture Room, with no restrictions on the number of participants and individually, in the bed or the living area. There was a wide possibility of resources such as a puzzle, memory game, cutting and pasting resources, books, plastic toys that referred to kitchen utensils, dolls, bowling, balls, among others. They aimed to favor individual skills, playfulness, social interaction, surveillance, and stimulation of Neuropsychomotor Development (NPMD) in the hospital context.

We observed that, during interventions in pediatric hospitalization, the objectives were often health promotion, encouraging independence, social participation, and a redefinition of the daily routine in the hospital. When proposing an intervention, the occupational therapist needs to consider the life history, culture, values, preferences, and potentials adapted to the hospital context, as well as the patient's physical limitations and clinical restrictions, in individual and/or group interventions, played in bed, playrooms, among other environments (Kudo et al., 2018).

In this pandemic period, they had to readjust the pediatric environment, in which two wards started to be used as pediatric Intensive Care Units (ICUs). This distribution resulted in a reduction in the number of beds for admission to the sector. Such modifications resulted in 7 beds available for children/adolescents from the cardiology clinic affected by COVID-19 and 3 beds for children from the cardiology clinic whose virus was not detected. There was also a need to make use of an infirmary, transforming it into an exclusive nursing station for professionals who attended COVID-19 infirmaries. Due to this new scenario, all hospitalized children and their caregivers were restricted, and they were not allowed to leave the wards, aiming to prevent the spread of the virus between patients and caregivers. Also, the Hospital Infection Control Commission (HICC) determined the closing of the toy library, the interruption of school activities in the hospital class, the suspension of occupational therapy groups with family members, and cinema activities.

Therefore, the interaction between children and caregivers became restricted to individuals who shared the same ward and with team members during the interventions. The past reality in which children played freely in their homes interacted with their environment and their families. Since then, it has become particularly distant in the environment of cardiology and COVID-19 infection, which imposed isolation within the hospital confinement for these adult and child patients. In other words, this reconfiguration of the physical area restricted the exploration of the environment, reduced access to stimuli and playfulness, a naturally facilitating element of child development.

The literature reveals that the removal of the child from the family environment, from their objects, from friends, and the school present in the hospitalization process tends to cause a rupture in the patient's daily life. In this sense, there will be a need to adapt to a routine that is sometimes dissonant from the family culture to new people and environments, and the hospital routine (Simonato & Mitre, 2017; Folha & Della Barba, 2020).

Also, the social distance recommended by the Ministry of Health as a preventive measure against the contamination of the new coronavirus can generate stress and discomfort. However, even in social isolation, it is important to remain engaged in alternative and meaningful occupations that can be performed in this context that favor the discovery of new skills, minimize stress, anxiety, and discomfort (De-Carlo et al., 2020).

Occupational therapy is a profession capable of identifying disruptions in daily life, reflecting and intervening in new ways to meet occupational demands, in addition to developing resources and adaptations that correspond to the needs of each patient in this pandemic time. Thus, it is expected that occupational therapy professionals act to ensure the child's right and opportunity to play. This is their main occupation and also a primary object in occupational therapy care with these people, with playing as a space in which the child identifies himself as the subject of the action, interacts with the environment, has exchanges in the interpersonal relationship, and brings his daily life closer to the hospital context (Silva et al., 2020).

This may have been the main intervention challenge since the variety of playful resources was directly affected in the hospital context, further limiting the materials to be used during care, considered as a risk of contamination, and the possibility of contagion vectors. This required more refinement in the clinical reasoning for human occupations, when thinking about the activity, the environment, the resources, materials and with the practice based on the occupation, meeting the patient's demands, the reality imposed by the virus, and biosafety.

In addition to material resources, the therapeutic relationship was negatively impacted several times, an essential element for good practices in occupational therapy. The restricted physical contact in the COVID-19 context becomes the central focus of the setting, together with various individual protection equipment, which makes it difficult to express affections in the interaction produced and in the intended bonding. The therapeutic relationship is influenced by the environment, context, and psychological aspects in which it is inserted. The bond is established by the dynamic relationship of interpersonal experience, face observation, contact, the quality of attention, presence, the identification process that occurs (which is expressed when the individual imitates facial expressions), gestures, and what is susceptible to an emotional connection with the other (Castro, 2007).

Promoting the therapist-patient bond with the child has still been a complex task in the context of cardiology diseased by COVID-19, in which the tone of voice, the look, and the body expressions stand out in the process. However, when this relationship is established, the child can feel safe to express doubts, anxieties, concerns regarding the surgery, and fear of death, as well as the possibility of infection by COVID-19 and its health problems. For this reason, in addition to promoting engagement in activities appropriate for their age group, which provide the possibility of independence and encourage development, occupational therapists also seek to encourage the expression of content such as fear, anxiety, doubts, allowing children to externalize concerns and with answers in an age-appropriate manner (Simonato & Mitre, 2019).

These aspects were addressed by Silva et al. (2019) when reporting that, during the child's isolation, the action of the multidisciplinary team trained to promote qualified listening is essential, helping them and their families to face this experience with less possible suffering and harm. Thus, the occupational therapist as a professional working in coping with contact isolation, having resources to favor the processes of resignification of this experience and encourage treatment adherence.

Reinventing “doings”: theirs, mine, ours...

Difficulties were faced when thinking about resources that satisfactorily met the patient's demands in this context since the resources available for the use of the

occupational therapist were mostly porous materials, making hygiene impossible. Furthermore, the options for permanent and high-cost resources had to be discarded as they did not meet the exclusivity criterion for their use, making them inaccessible.

Reflecting on these difficulties as a health professional and the urgency to solve the new challenges of the practice context, managing concerns and resource limitations sometimes caused uncertainties that seemed to be insurmountable, generating a lot of anguish at this stage of professional training. However, they had the challenge and, in it, the pressing need to rethink occupational therapy, our doing, restructuring the way of planning actions, accepting the demands of patients and families, revisiting a known/strange context of in-service training practice, the hospital. Among the challenges, there was the interaction with the multidisciplinary team that, in the various categories during the months, presented infection with COVID-19 and also the resident. At this point, the fortuitous became reality and showed once again, under a new perspective, what he had captured from the experience with patients with chronic diseases, in the academic path: that death is part of the natural cycle of life. Its presence brings restlessness, suffering, curiosity, transformation, and life relief. Certainly, sharing this “place” with patients aroused reflections on ways of taking care of occupational therapy not yet considered. This thinking about the professional practice was consistent with those who defended the work in the wards and ICUs, readjusting their practices to the reality experienced (Silva et al., 2020).

I highlight here the contribution of the occupational therapist in dealing with the pandemic. In early April, the Federal Government, through Ordinance 639, provides for the strategy “*O Brasil Conta Comigo - Profissionais da Saúde*”, which aimed to provide training to professionals to deal with COVID-19, including occupational therapy in listed categories (Brasil, 2020). Recognizing the role of the occupational therapist at that time, the World Federation of Occupational Therapy (2020) highlighted the actions of the profession working with the individual, family, community, in social and environmental adaptation as in the use of infection control measures, in the maintenance of mental health, well-being and the engagement of occupations.

In the context described in this experience report, the urgency of adapting to the circumstances, facing and overcoming limitations emerged for reflection, in addition to transforming the way of acting, following professional ethics as indispensable in facing the COVID-19 pandemic and its repercussions in all dimensions involving the child with heart disease in the face of the pandemic.

Rethinking intervention materials

Adapting to the more restrictive biosafety standards, while still looking at these children as occupational human beings that they are, analyzing the change processes that influence the transformation of children's occupations, allows the offer of interventions centered on occupation with a view to the child's participation in family life, in educational spaces, in community activities and other spaces frequented by it such as the hospital environment (Humphry & Wakeford, 2006; Mandich & Rodger, 2006). This balance between the adaptation to the new norms and meeting the occupational demands expressed by the children and their families proved to be an intense, exhausting, costly, and provocative process.

To meet these biosafety demands, disposable resources were used, such as printed drawings. This material was given by the hospital upon request. After being received by

the occupational therapy service, the material was stored in plastic bags for more than 72 hours to ensure non-contamination by Sars-Cov-2. The material was handled with sanitized hands, chosen according to the child's preferences and age, and delivered together with the colored pencil box, which became its exclusive use for future disposal at the time of hospital discharge.

Regarding this strategy, Silva et al. (2020) reinforce the importance of the occupational therapy service having a collection with toys and stationery materials, which can be discarded. Thus, children hospitalized and infected with SARS-CoV-2 cannot have access to recreational resources. De-Carlo et al. (2020) add that the occupational therapist's biosafety care should include the cleaning of resources, equipment used, and the environment, prioritizing materials that can be disinfected and, when not possible, discarded, configuring an essential criterion during the acting in the hospital context, especially in the pandemic period.

With these aspects, playful resources were developed (Figure 1 and 2), printed and laminated, enabling cleaning with 70° alcohol before and after use. It was also invested in services with singing games and storytelling, both strategies aiming to meet the needs of infection prevention, as well as to promote playfulness, health education, cognitive stimulation, global motricity, in addition to favoring the confrontation of social isolation and encouraging the redefinition of the hospitalization process. It is evident in the specialized literature that the occupational therapist, when using playful activities common to childhood, favors the adaptation of the routine and the environment, making them less frightening for the child, configuring a powerful approach for intervention. It is also a promoter of social, emotional, and intellectual development and occupational engagement (Vieira & Cazeiro, 2017; Pelosi et al., 2020).

In this way, the occupational therapist can develop materials that help in health guidelines, minimize resistance to the use of medications, encourage treatment adherence, and can ensure engagement in playing, in the company or not of the occupational therapist, adjusting their professional practice to the reality in which they work (Silva et al., 2020; Fonsêca & Silva, 2015).

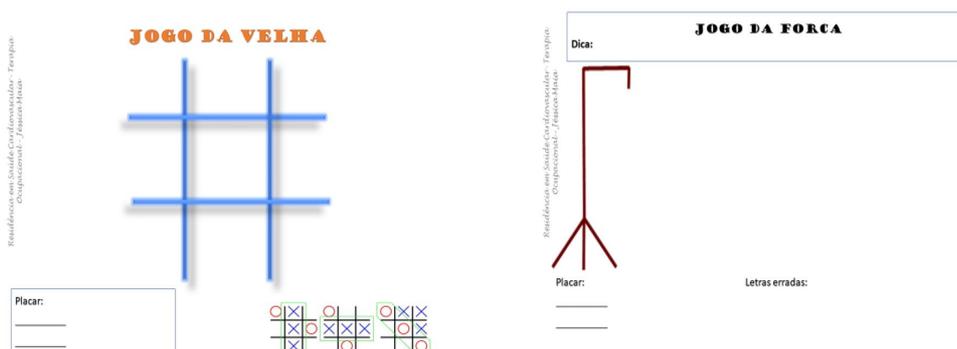


Figure 1. Tic-Tip and Hangman file to laminate. Personal Archive (2020).

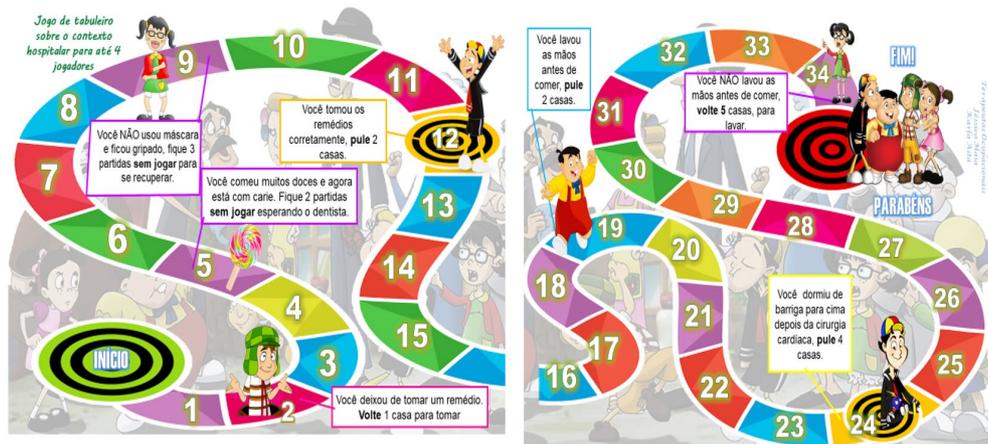


Figure 2. Chaves Board game. Personal Archive (2020).

The playful resources were developed to introduce an interactive dynamic that would favor the receptivity of children to interventions, the therapist-patient relationship and the engagement in the therapeutic process and children's occupations carried out in the hospital context.

Hospital biosafety, family and occupational therapy

The burden on the family in this process is an important issue to highlight. The exchange of companions, in this context, changed and were limited to reduce the risk of infection brought from the external environment to the ward's environment, as well as visits were suspended, increasing the length of stay of the same companion in the hospital and reducing contact with other family members.

Camelo Júnior (2020) says that, despite the importance of restructuring the hospital routine, some actions have become generators of stress and problems related to mental health such as the suspension of visits and restriction of companions for children. During this period, fathers and mothers are distancing from their occupational functions and roles due to the need to stay in the hospital, demanding to seek their support network (Souza, 2019).

Also, tiredness, physical, mental and emotional exhaustion are recurrent in the companions of hospitalized patients. The hospital can represent a place of sadness, loneliness, missing friends and family (Frizzo & Corrêa, 2018). The lack of closer contact between caregivers and other family members due to restrictions, physical and emotional exhaustion for a long period in the hospital, and concern about the occupations left to dedicate to care in the hospital context are situations that drew attention in this context, highlighting the occupational repercussions.

Thus, this period required a more delicate look at the demands of these family members due to their challenges, amplified by the recommended restrictions. The health education actions, in addition to emphasizing developmental surveillance in which the child's potential and acquisitions are valued above all, tend to positively support interventions against COVID-19 and the yearning for hospital discharge. However, it is necessary to question whether the experience of the companion who is profoundly impacted by the child's illness will result in marks on the individual that will not always be visible but may

be perceived. To offer humanized care and to deconstruct the fears that are generally presented by this segment in the hospital context, they must be open to accepting doubts, providing guidance on the hospitalization flow, and offering occupational therapeutic listening to the caregivers of the assisted children (Menezes & Moré, 2019; Rodrigues et al., 2020).

Final Considerations

When describing the daily life experienced in the practice of residency that took place in the pediatric cardiac clinic during the COVID-19 pandemic, we observed the vulnerability and impotence were capitalized and crossed clinical reasoning, the eligibility of material resources, occupations, as well as the therapeutic relationship with patients and family members.

Being hospitalized in this period not only caused occupational ruptures, distance from daily life, culture, and the family context but also reduced the possibilities of interaction within the hospital context, narrowed the hospitalization coping strategies, and amplified the suffering inherent to the imposed clinical treatment by heart disease.

These changes also impacted health professionals. Acting as a resident occupational therapist in this pandemic period sometimes raised fears, anxieties, insecurities, and doubts related to hospital practice and the possibility of contamination. However, these feelings were overcome by the satisfaction and accomplishment of intervening in the occupational changes and demands evidenced by the hospitalized children.

Occupational therapists should and can promote engagement in meaningful occupations and adaptation of environments and develop with the multidisciplinary team, together with children and families, strategies for coping with hospitalization and Covid-19. The experience in the exercise of occupational therapy during this period enabled us to revive the belief in mine, theirs, and our ability to reinvent ourselves and overcome challenges.

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