

Experience Report/Case Study

# Telemonitoring as a strategy for the intervention of occupational therapy of children and adolescents with autistic spectrum disorders in the pandemic context

*O telemonitoramento como estratégia de intervenção da terapia ocupacional com crianças e adolescentes com transtorno do espectro autista no contexto pandêmico*

Amanda Dourado Souza Akahosi Fernandes<sup>a</sup> , Aline Zacchi Farias<sup>a</sup> , Isabela Aureliano<sup>a</sup> ,  
Letícia Migliatti Polli<sup>a</sup> 

<sup>a</sup>Universidade Federal de São Carlos – UFSCar, São Carlos, SP, Brasil.

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## Abstract

**Introduction:** Occupational Therapy has acted from the perspective of the subjects' daily lives and their ways of living, given the transformations, impacts, and consequences generated by the pandemic of COVID-19. Among the possibilities of work of the occupational therapist, there is telemonitoring. **Objective:** To report an experience of a university extension project regarding the telemonitoring of children and adolescents with Autistic Spectrum Disorder (ASD) and their families. **Method:** The project team is composed of a teacher from Occupational Therapy Department, and graduate and undergraduate students. A survey of the demands and interests of the families was carried out, and thirteen children and two teenagers were subsequently selected for telemonitoring actions. **Results:** The interventions are aimed at an organization of daily life, routine, and family orientation. It is pointed out that the care offered was not restricted to the family nucleus, so regular monitoring and support for school teams were also carried out. **Conclusion:** Telemonitoring enabled the continuity of care, as well as support for the care network, promoting a welcoming, qualified listening and guidance, based on what has been proposed by the care guidelines and public policies.

**Keywords:** Occupational Therapy, Autism Spectrum Disorder, Telemonitoring, Coronavirus infections.

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### **Resumo**

**Introdução:** A terapia ocupacional tem atuado na perspectiva do cotidiano dos sujeitos e de seus modos de viver, tendo em vista as transformações, impactos e consequências geradas pela pandemia da COVID-19. Dentre as possibilidades de atuação do terapeuta ocupacional, tem-se o telemonitoramento. **Objetivo:** Relatar a experiência de um projeto de extensão universitária no que tange ao telemonitoramento de crianças e adolescentes com Transtorno do Espectro Autista (TEA) e suas famílias. **Método:** A equipe do projeto é composta por uma docente do departamento de terapia ocupacional e alunas de pós-graduação e graduação. Foi realizado um levantamento das demandas e interesses das famílias, sendo posteriormente selecionados treze crianças e dois adolescentes para as ações de telemonitoramento. **Resultados:** As intervenções visaram à organização do cotidiano, rotina e orientação familiar. Aponta-se que o cuidado ofertado não se restringiu ao núcleo familiar, de forma que também foi realizado acompanhamento regular e apoio às equipes escolares. **Conclusão:** O telemonitoramento possibilitou a continuidade do cuidado, promovendo o acolhimento, escuta qualificada e orientação, com base no que tem sido proposto pelas diretrizes de cuidado e políticas públicas.

**Palavras-chave:** Terapia Ocupacional, Transtorno do Espectro Autista, Telemonitoramento, Infecções por coronavírus.

## **Introduction**

The year 2020 was highlighted by the emergence and spread of COVID-19, an infectious disease caused by a virus of the coronavirus family (SARS-CoV-2), which was first detected on December 31, 2019, in Wuhan, China. Since then, the world has started to face changes in different spheres due to the need to control the spread of the virus (Organización Mundial de la Salud, 2021).

Some social groups have been more impacted by COVID-19 due to their vulnerability, the difficulty in accessing health equipment, and social inequality (Rodrigues et al., 2020; Lima et al., 2020; Demenech et al., 2020). In this context, there are children and adolescents with Autism Spectrum Disorder (ASD) and their families, who were severely affected by the pandemic and the control and safety measures adopted by governments (Fernandes et al., 2021).

We know that people with ASD have difficulties in dealing with changes in routine and the lack of predictability tends to intensify during a pandemic scenario and the measures adopted, generating stress, insecurity, and anxiety. The characteristics of this picture may sometimes limit the understanding of the current moment and the measures adopted, which may be an obstacle to adapting to this new reality (Machado, 2019).

Recent studies have focused on investigating the reality experienced by this population and the possibilities of care during the COVID-19 pandemic (Rodríguez & Cordero, 2020; Echavarría-Ramírez et al., 2020; Fernandes et al., 2021; Narzisi, 2020; Yahya & Khawaja, 2020; Colizzi et al., 2020).

Through a literature review research, Rodríguez & Cordero (2020) revealed the existence of possible changes in the mental health of children with ASD in this period, translated into behavioral changes such as aggression, irritability, sleep changes, and intensification of stereotypies. Based on these findings, the authors suggest some care possibilities, such as maintaining a healthy diet respecting the child's preferences, having an established sleep schedule, carrying out a schedule of physical activities and games, and professional support.

In the Italian research by Colizzi et al. (2020) carried out with 527 families in a remote meeting, the results showed that 93.9% of the participants consider this period as something challenging. Family members also reported difficulty in managing issues related to Activities of Daily Living (ADL), and greater severity and frequency of behavior problems in individuals with ASD. The survey also showed that 47% of participating family members claimed a lack of support from health services during the pandemic.

The literature has also shown that mental health care is underestimated and the scarcity of services makes coping with this reality even more complex and stressful (Duan & Zhu, 2020). Duan & Zhu (2020), Ornell et al. (2020) and Lima et al. (2020) reveal the lack of investment and preparation in the face of global health crises and how much it is still necessary to rethink mental health practices in services. With the unpredictability of some events, such as the case of the COVID-19 pandemic, services and professionals are not prepared in terms of human and structural resources to respond to emerging demands (Duan & Zhu, 2020).

Thus, with the need to create strategies to face COVID-19, different professional categories have given their opinion to reaffirm and reflect on the possible contributions in this scenario. Occupational therapy has acted from the perspective of the individuals' daily lives and their ways of living, given the transformations, impacts, and consequences generated by the pandemic (Malfitano et al., 2020). Galheigo (2020) understands everyday life based on the socio-historical construction that enables us to know the conditions of existence of both individuals and collectives. Thus, everyday life is a "[...] space-time in which the person, individual or collective, immediately and not always consciously, accesses opportunities and resources, faces adversities and limits, makes decisions, adopts mechanisms of resistance, and invents new ways of being, living and doing" (Galheigo, 2020, p. 15).

Among the possibilities for the occupational therapist's performance, there are remote services - consultation, consulting, or monitoring (Brasil, 2020) - or telehealth, as defined by the American Occupational Therapy Association (AOTA), to regulate services through technology (American Occupational Therapy Association, 2018).

According to the *Conselho Federal de Fisioterapia e Terapia Ocupacional*, (Brasil, 2020) teleconsultation consists of the clinical consultation registered and carried out by the physical therapist or occupational therapist at a distance and teleconsulting is the communication recorded and carried out between professionals, managers and other professionals in the health area. On the other hand, telemonitoring, the focus of this study, would be the distance monitoring, through technological devices, of a patient previously treated in person. In this modality, the physical therapist or occupational therapist can use synchronous and asynchronous methods, as well as for deciding on the need for face-to-face meetings for reassessment, whenever necessary.

In Brazil, regulated by COFFITO, remote services have enabled the total non-interruption of care provided to the assisted population groups (Brasil, 2020), as one of the few existing strategies that allow the maintenance of the care, even in a remote meeting.

Because it is a care modality recently adopted by professionals in the current context, there is a scarcity of studies available in the literature that focus on investigating its strengths and limitations. Based on a brief literature review, only two studies were found that address the remote services strategy involving occupational therapists during the COVID-19 pandemic with children and adolescents with ASD (Pereira et al., 2020; Priyadharsini & Chiang, 2020).

Based on an experience report, Pereira et al. (2020) described the experience of telemonitoring with 17 families of children who had psychological distress and who were previously treated at a child mental health clinic in the Federal District. The authors point out that the contact of health professionals with patients through telemonitoring enabled the continuity of care through listening, guidance, and information, aiming at mitigating psychic suffering.

The study by Priyadharsini & Chiang (2020) developed in Singapore, even pointing out the benefits of remote service and the potency for occupational therapy, shows some challenges during this process. Among them, they highlighted the parents' distraction during the remote service, the ineffectiveness in training the children's motor skills, and the economic/social issue, since many families did not have access to the internet and, consequently, were unable to participate in the remote services.

Given this context, we considered it relevant to reflect on the care of children and adolescents with ASD in this pandemic period, since the impacts generated by routine interruptions and treatments have intensified the suffering of this population and affected the entire family composition.

Despite the weaknesses found, the authors have affirmed the potency of actions of this nature, and further studies are essential to advance the possibilities of the occupational therapist's performance. We believe that, due to the extent of the pandemic and future uncertainties, telemonitoring can be adopted as a possibility for long-term care.

Therefore, this study aims to report the experience of a university outreach project regarding the telemonitoring of children and adolescents with ASD and their families, who were undergoing occupational therapy care before the pandemic.

## **Method**

This is the experience report of an outreach project linked to an outpatient clinic of medium complexity (specialized care) in a medium-sized municipality in the interior of the State of São Paulo. The outpatient clinic is considered a Multidisciplinary Academic Unit of a Federal University, which aims to train people through interprofessional health care, based on the inseparability of teaching, research, and outreach, for a humanization and comprehensive care. The assistance takes place via the primary care referral and from all points of the health, social assistance, and education network.

The participants of this outreach study were 13 children and 2 adolescents and their families who had already a follow-up care by the occupational therapy sector at the

outpatient clinic. We selected for participation those who were interested in telemonitoring, who had time availability, since most of the meetings would be with their families, and who had technological /equipment resources such as a computer/cell phone and internet.

The project team was composed of a professor of the occupational therapy course, twelve undergraduates, and one graduate student, and the actions were developed through synchronous or asynchronous telemonitoring and weekly clinical supervision, between August and December of 2020. Thus, the students carried out weekly telemonitoring with the families on a previously established day and time; later. There was a four-hour remote collective meeting with the entire project team, in which the cases attended were presented and discussed through clinical supervision carried out by the professor responsible for the project.

Before starting the activities, an online instrument (Google Forms) was applied to the families to collect information about the child/adolescent, family and demands presented. Through a descriptive analysis of the information collected, we discussed and elaborated the intervention plan with the families, which was based on three axes, as will be presented and detailed in the results: 1) Daily life as the central axis/background of the care; 2) Family participation and the need for support and care for them; and 3) The importance of the intersectoral network: the articulation between health and education. The intervention plan was systematically reviewed, according to the results achieved, difficulties faced, and the emergence of new demands.

Aiming at a better understanding of the entire process, the stages adopted to initiate the actions are presented below:

- STAGE 1: We identified 13 children and 2 adolescents and selected to be monitored by telemonitoring, considering the interest and availability of the families;
- STAGE 2: Collection of information about the child/adolescent, family, and demands submitted through Google Forms;
- STAGE 3: The intervention proposal was agreed upon with the families, as well as the frequency of meetings, the communication tools, and equipment to be used;
- STAGE 4: Start of telemonitoring with children, adolescents, families and the care network.

We should say that this project, in the mental health area, is based on the theoretical-methodological framework of Psychosocial Care (Yasui, 2009; Costa-Rosa, 2013), based on some pillars of support for psychosocial care as opposed to asylum, such as intersectoral networking, the exercise of citizenship, encouragement of autonomy, respect for subjectivity, comprehensive care, the inclusion of family members in the care process, among others (Yasui, 2009; Costa-Rosa, 2013).

Added to Psychosocial Care, we considered that the actions reported, based on the core of occupational therapy, are based on the perspective of everyday life (Galheigo et al., 2018). In Psychosocial Care, we expect that practices are transversal to the life stories and daily lives of people in mental health services (Fernandes, 2014).

## **Results and Discussion**

The results will be presented through 3 thematic axes, given the focus of the actions developed. Thus, it is intended to point out the strengths, weaknesses, and perspectives identified.

### **Daily life as the central axis/background of care**

Through the form used to survey the demands, we identified that most of the difficulties and weaknesses were about daily life, triggered by the change in routine in the face of the security measures adopted in the pandemic. In this sense, in the first contact with the family, we observed difficulties related to the child's sleep, bathing, feeding, carrying out school activities, and playing.

In general, through the reports of family members and the online form applied, the physical distance from activities carried out daily, such as school, social projects, private classes, visiting relatives, weekend trips, and therapies, significantly impacted the development of the child/adolescent, and some returns were also reported in terms of independence, autonomy, relationships, and social participation.

As an example, the child who already showed greater independence in activities of daily living (eating, bathing) began to demand more from family members in the execution of these activities, as well as began to use less verbal language to communicate in the home context, hindering also social interaction with siblings and parents. The families also pointed out that some clinical characteristics of the condition were intensified, making it difficult to perform some daily activities such as increased sensory changes, low tolerance to changes in routine, greater food selectivity, and restricted behaviors and interests.

Through the telemonitoring experience report by Pereira et al. (2020), we observed the same care demands found in this present study, so the authors suggest the organization of routine as an important tool to contribute to the construction of a more structured daily life, aiming to offer greater security to children and their families.

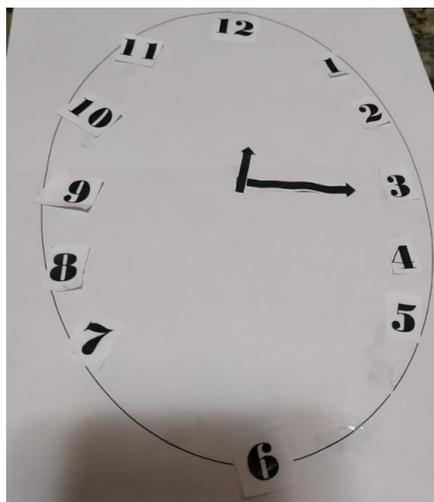
Through the identification of these demands, the interventions were organized to promote the reception of families, qualified listening and the development of actions aimed at coping with difficulties, child's development, structuring and resignification of daily life, exercise citizenship and social inclusion - pillars of support for psychosocial care for children and adolescents (Fernandes et al., 2020).

Thus, families were instructed on how to facilitate the performance of some activities through the provision of a routine chart, sheets for visual support and communication, and environmental adaptations. These resources were elaborated respecting the individualized subjectivity of the patients in a way that not only made sense in everyday life but also that it encouraged the active participation of the child/adolescent and their family in the proposition of such routines, as has been foreseen by psychosocial care (Costa Rosa, 2006; Argiles et al., 2017; Fernandes et al., 2021).

The routine charts were made with images of the child performing the activities and their particular interests. The visual support sheets were designed according to specific demands, as indicated by the families, as shown in Figures 1 and 2.



**Figure 1.** Visual support sheets.



**Figure 2.** Clock activity for the routine organization.

It is important to point out that the necessary guidelines for the use of these resources were carried out, as well as the remote weekly monitoring to solve possible doubts and difficulties. In addition, we discussed activity tips and guidelines for their performance with family members through the development of personalized illustrative e-books with resources already available at home, aiming to favor functional and symbolic play in children. In the case of very agitated children with sensory changes, an individual assessment was carried out and a routine of activities was established through a sensory

diet. For some disruptive behaviors, such as intense tantrums, behavioral strategies for handling situations were provided.

Through the strategies presented, we identified that occupational therapy is a profession that enables care in everyday life through activity, so that daily life can be seen as a background in which occupational therapy can be guided (Castro et al., 2001; Fernandes, 2014).

The concept of everyday life has become an interest in occupational therapy since the 21st century, as it is based on its construction that the person establishes a way of doing and relating to life (Castro et al., 2001). Thus, it is relevant for the occupational therapist to understand what and how people do, how they enjoy their time, and how the social context interferes in their lives. Therefore, the professional uses daily life as an instrument of attention, construction, and transformation of life, knowing that its rupture directly interferes with physical and mental health (Salles & Matsukura, 2013).

From this perspective, everyday life is shown as the guiding basis of emancipatory practice in our professional performance to give new meaning to the look at the demands and obstacles that we encounter with the assisted subjects (Galheigo et al., 2018). Therefore, in the work with the children and adolescents accompanied in this extension project, we sought to broaden horizons and bring emancipation in everyday life, by developing resources, guidelines, and activities, which, according to Galheigo et al. (2018), encourage and allow the production of social participation and autonomy, as well as favoring the development of skills and creativity, to achieve a daily life driven by protagonism and spontaneity, elements so dear to psychosocial care (Costa-Rosa, 2013).

Although we could identify the power of actions of this nature, we observed that they were mediated by the family, since the greatest difficulty in this type of care was the child's understanding of this type of intervention. The children had difficulty stopping in front of the screen, recognizing the therapist, and focusing on the activities being proposed and on the therapist's speech. We observed that this has also been one of the greatest difficulties reported in the few studies found in the literature on this topic (Barbosa & Fernandes, 2017; Pereira et al., 2020; Priyadharsini & Chiang, 2020).

### **Family participation and the need for support and care**

Because of the difficulties of remote monitoring with children and adolescents, it was necessary to adopt strategies aimed at families through guidance and social support, also considering that the family is part of the social network involved in the processes of psychosocial care.

It is pointed out that it was necessary to adapt the telemonitoring synchronously and asynchronously, as well as its frequency, to use different online tools and to evaluate internet access. As some authors point out, these initial agreements and the management of telemonitoring have been fundamental for their effectiveness (Barbosa & Fernandes, 2017; Pereira et al., 2020; Priyadharsini & Chiang, 2020).

After the initial agreement, the need for care for the caregiver was identified, since there was overload, anguish, and anxiety in the face of so many uncertainties in the current scenario. In this way, the family was able to find in the service space of reception and understanding of their difficulties. According to Minatel & Matsukura (2014),

caring for families is essential to expand new perspectives for their diagnosis, help prioritize demands/needs and mediate new networks, whether affective, relational, or social.

Studies indicate that difficulties in dealing with the child's behavior significantly influenced the lives of family members in different spheres (Minatel & Matsukura, 2014; Pinto et al., 2016), as evidenced in the results of this experience. During telemonitoring, family members stated stress and impotence in the face of daily challenges, strongly aggravated by the pandemic and social isolation measures. In this direction, some strategies were also proposed to assist family members in managing these moments and difficulties. As an example, in the particularity of situations, we guide families to anticipate some everyday events (parents return to work after the initial quarantine and resumption of school), so that the child or adolescent could understand and prepare, avoiding a crisis.

Within the scope of psychosocial care, the inclusion of family members in the care process for children and adolescents with ASD is one of the principles and guidelines of care, aimed at supporting families to promote their health (Brasil, 2015; Oliveira et al., 2017). Thus, at the end of the project, the families thanked them for their availability, and affection and for the possibility of sharing the daily delicacies that crossed them.

These feedbacks show that, despite the limits in the remote approach, the actions were significant for the families and supported them regarding the difficulties faced. This was anchored in actions that valued transparency in challenges and openness to inventive and affective ways to reduce distances and increase presence (even if not physically), contributing to the strengthening of bonds and possible and assertive interventions during the pandemic.

### **The importance of the intersectoral network: the articulation between health and education**

Based on remote services, we also identified the need for articulation with the network, especially in the school environment, with the main objective of expanding care and improving its effectiveness. Intersectorality in psychosocial care is the relationship built between one or several sectors and their parts to achieve a result that would not be possible only through the work of a single service (Silva & Rodrigues, 2010). Also, intersectoral actions are extremely relevant to the integrality of care insofar as they envision attention to the subject within their social context (Oliveira & Castanharo, 2008; Cardoso & Matsukura, 2012).

Thus, the actions aimed at overcoming and facing the existing difficulties such as the articulation and joint elaboration of actions for the (re)approximation with families and children who were weakened by the lack of possibility of face-to-face school experiences, by the challenge for children with ASD to interact in remote meetings, added to the wear and tear about the new way of life.

Among the actions with the school, synchronous meetings were held with teachers every two weeks to exchange about the planned activities, then converging on common projects, elaboration of activities that contributed to meeting the demands and providing support for them, in addition to re-signifying the role from school to families in this scenario. According to Cid & Gasparini (2016) and Fernandes et al. (2019), the

performance of health professionals such as occupational therapists in the school context aims to develop actions to prevent and promote mental health and specialized care, mediating the child's interaction with peers, educators, and family members. In other words, the occupational therapist's practice at school is not clinical, but it is an intersectoral practice, through the collaborative construction of care, aiming to guarantee access and inclusion.

It is important to emphasize the practice of occupational therapy concerning networking, as it enhances the articulation with the territory and creates a passage for the dialogue of different actions and specificities of each device of attention to the care of these families (Lourenço, 2020). Based on intersectoral discussions and meetings, we could foster spaces for exchanges, continued education, and convergence for the comprehensive care of children and their caregivers.

## **Conclusion**

The objective of reporting the experience of a university outreach project regarding the telemonitoring of children and adolescents with ASD and their families was achieved. As the weaknesses and daily difficulties were revealed, we planned and developed, together with the families, care strategies that aimed to mitigate the impacts of the pandemic on their daily lives. In addition, the care offered was not restricted to the family nucleus, so that regular monitoring and support was also carried out for the school teams to which the children and adolescents were linked.

The importance of actions of this nature that contribute to the development of children and adolescents with ASD is highlighted since much of the assistance to this population was in the background during the pandemic. Also, the urgency of care and support for the families, which are often overloaded, is highlighted. Telemonitoring enabled the continuity of care for this population, promoting reception, qualified listening, and guidance, through what has been proposed by care guidelines and public policies.

We found some limitations in the study. As it is a modality of remote care recently regulated in Brazil, greater dedication and efforts were necessary for its effectiveness, making it impossible to include more families in the project, due to the time of dedication and planning required.

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### **Corresponding author**

All authors contributed to the design, writing, and review of the text. All authors approved the final version of the text.

Corresponding author

Letícia Migliatti Polli

e-mail: [le\\_mp@hotmail.com](mailto:le_mp@hotmail.com)

Section editor

Prof. Dr. Beatriz Prado Pereira