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Original Article

On the occupations of parents of children with Autistic Spectrum Disorder

Sobre as ocupações de pais de crianças com Transtorno do Espectro Autista

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Abstract

Introduction: Autism Spectrum Disorder (ASD) is understood as a complex condition with multiple and variable impacts, characterized by behavioral changes that may occur from early childhood. It requires parents to develop strategies in response to new demands, leading to challenges in managing and engaging in occupations. **Objective:** To understand how the occupations of parents of children with ASD were presented. **Method:** Descriptive qualitative research. Eight parents of children with ASD participated in semi-structured interviews. The interviews were recorded and transcribed, and the responses were assessed through content analysis. **Results:** The results revealed that parents face difficulties in reorganizing their everyday lives, adapting to tasks, and reconciling their children's occupations. This demonstrates a certain dependence of parents' occupations on those of their children, as they often dedicate themselves to or prioritize the occupational needs of the children. Changes in leisure activities and attempts to adapt them to the children's demands were also noted. **Conclusion:** The research aimed to understand the occupations of parents of children with ASD and their repercussions. Additionally, it sought to build scientific knowledge about the participants' occupations, enhancing the discussion on the occupational dimension and its specificities. This study provides resources for individuals to analyze and understand their occupational development.

Keywords: Autistic Disorder, Parents, Daily Activities.

Resumo

Introdução: O Transtorno do Espectro Autista (TEA) é compreendido como uma condição complexa, com impacto múltiplo e variável, identificada por mudanças de comportamento que podem ocorrer a partir da primeira infância, e requer que os pais desenvolvam estratégias diante das novas demandas, levando a desafios no gerenciamento e engajamento de suas ocupações. **Objetivo:** Compreender como se

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apresentavam as ocupações de pais de crianças com TEA. **Método:** Pesquisa qualitativa descritiva. Participaram oito pais de crianças com TEA por meio de entrevistas com perguntas semiestruturadas. As entrevistas foram gravadas e transcritas, e as respostas foram tratadas por meio da análise de conteúdo. **Resultados:** Os resultados revelaram que os pais enfrentam dificuldades ao reorganizar seu cotidiano, adaptar-se aos afazeres e conciliar as ocupações das crianças. Isso demonstra uma certa dependência das ocupações dos pais em relação às das crianças, visto que os primeiros frequentemente se dedicam ou priorizam as necessidades ocupacionais dos últimos. Destaca-se, também, mudanças nas formas de lazer dos pais e tentativas de adequá-las às demandas das crianças. **Conclusão:** A pesquisa visou compreender as ocupações dos pais de crianças com TEA e suas repercussões. Além disso, buscou construir conhecimento científico sobre as ocupações dos participantes, incrementando a discussão sobre a dimensão ocupacional e suas especificidades. Este estudo oferece subsídios para que os indivíduos analisem e compreendam seu desenvolvimento ocupacional.

Palavras-chave: Transtorno Autístico, Pais, Atividades Cotidianas.

Introduction

The objective of this research was to understand the occupations of parents of children with Autism Spectrum Disorder (ASD). Since 1943, with the initial description by Leo Kanner and advancements in scientific studies, the term “autism” has been studied and disseminated by various authors who have helped differentiate this neurodevelopmental disorder from others like childhood schizophrenia and psychosis. In the past, autism was considered within the category of “pervasive developmental disorders” (Brasil, 2014; Whitman, 2019; Fernandes et al., 2020).

Currently, according to the Diagnostic and Statistical Manual of Mental Disorders – 5th edition (DSM-5), autism is referred to as Autism Spectrum Disorder (ASD), as it has distinct characteristics regarding the diagnoses in the International Classification of Diseases – 11th revision (ICD-11) (American Psychiatric Association, 2014). Both the DSM-5 and ICD-11 present the following main characteristics of ASD: deficits in communication and social interaction, along with restrictive and repetitive behavior patterns. Based on this, it is understood that ASD is a complex condition, approached as a spectrum, highlighting its multiple and variable impacts. The variability of the disorder’s manifestations, where brain functions do not develop as they should, is identified in behavioral changes that are noticed from early childhood (Gaiato, 2018; Volkmar & Wiesner, 2018; Riccioppo & Bellini, 2021; Organização Mundial da Saúde, 2022).

These manifestations can occur immediately after birth but are more noticeable within the first 12 months of life and are generally identified by parents before the child is three years old (Silva & Mulick, 2009). Common behavioral variations include deficits in social interaction and impairment of functional language, which present when the child shows little interest in maintaining reciprocal social relationships, with minimal eye contact, poor understanding of non-verbal language, and/or low social awareness of the use of their behaviors according to the social context. There is also the presence of persistent behavior patterns in which the child has a restricted interest in objects or engages in echolalic speech, stereotyped movements like hand-flapping, and behavioral rigidity when disrupted from routine (Brasil, 2015; Reis et al., 2016; Organização Mundial da Saúde, 2022), and Sensory Integration Disorders (SIDs).

A child with disorganized adaptive responses tends to present SIDs, which, according to Furtuoso & Mori (2022), can be divided into three main subtypes: sensory modulation disorder, sensory discrimination disorder, and sensory-based motor disorder. When there is this inefficiency in the neurological process, the child may present deficits in the development of gross and fine motor skills, food selectivity, learning difficulties, among others.

When considering ASD and the impacts of its diagnosis on the child's family, it can be observed that the caring for this child may be performed by more than one person, and this role is most often conducted by only one person – who, in both cases, are usually women (Moreira et al., 2020). In this context, caregiving is presented as a social role to assist the dependent or partially dependent person in performing their Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and maintaining their well-being and quality of life. However, what is expressed as affection, protection, and gratuity can also be taken as a overload motivated by social patterns that impact family dynamics and, especially, the everyday life of the primary caregiver (Misquiatti et al., 2015; Pinto et al., 2016; Silva et al., 2020).

The development of a child during early childhood is carefully monitored by the parents. This period is also marked by idealizations that, for the most part, are consolidated in the concept of social normality. Additionally, parents project their dreams and expectations during this phase. However, it is common for expectations to be disrupted when development shows delays or limitations, potentially leading to frustration and emotional instability until parents adapt (Costa, 2012; Lima et al., 2022; Maia et al., 2016).

Thus, with the loss of the idealized child, parents of children with ASD may experience a grieving process upon receiving the diagnosis. The first stage of this grief includes initial reactions such as shock, crying, helplessness, and fear of the future – challenges to be faced. The second stage involves the feeling of denial of the child's clinical condition and the new challenges imposed by it. Subsequently, anger and guilt are emotions that lead parents to question their beliefs and consider themselves the main causes of the disorder, seeking explanations and solutions to justify the situation. The final stage, according to Maia et al. (2016), is reorganization, when parents begin to accept reality and, although still under great stress, seek to understand ASD and recognize their child (Costa, 2012; Gaiato, 2018; Lima et al., 2022).

After acceptance, during the reorganization phase, parents may face an additional difficulty, with emotional and occupational repercussions, such as managing the child's demands, which can lead to feelings of helplessness and anxiety due to their inability to handle the symptoms, mainly because of the child's deficits in social interaction and communication.

The family reorganization following the child's diagnosis can be abrupt and directly interfere with the parents' everyday lives. Silva et al. (2023) report that the limitation of daily tasks depends directly on the level of support the child needs. This influences various aspects of everyday life, as the overload of tasks requires greater family attention.

Thus, social, professional, and family support becomes essential for proper adaptation, enabling the family to gradually resume their routine.

Ribeiro (2012) reports that this difficulty arises because, most of the time, parents cannot understand what the child wants to express, generating feelings of anguish. In the same study, mothers reported the following issues in caregiving: physical and emotional overload, due to little family support; occupational deprivation, especially of work, which they had to give up because of ASD; detriments from these factors, such as constant stress crises, anxiety, and depression (Muller, 2014; Gaia, 2016; Fávero & Santos, 2005). In this sense, other deprivations can be inferred, such as the roles of daughter and son, wife and husband, home caregiver, among others.

Effective caregiving may necessitate that parents spend a long time in therapy institutions, and most of their day is directed to assisting the child – living their child's everyday life rather than their own, as reported by Monteiro et al. (2008). In that study, mothers reported that their everyday life is the same as their child's, and that in the little time left, they dedicate themselves to household chores. In this context, parents lose their identity and social role. It is also observed that caregiving often requires abandoning their occupations, such as leisure, work, and self-care (Segeren & Françozo, 2014; Duarte, 2019; Moreira et al., 2020; Smeha & Cezar, 2011; Roiz & Figueiredo, 2023).

Another issue that brings emotional and occupational repercussions is the social stigma surrounding ASD. As mentioned earlier, a child with ASD exhibits a range of clinical manifestations—stereotypies, psychomotor agitation, low social interaction, and in more severe cases, self- and hetero-injury—that are unfamiliar to society (Faro et al., 2019). As a result, parents may have to cope with discriminatory and prejudiced looks, which can cause embarrassment and lead them to avoid social spaces, reflecting in an abrupt disruption of their routine and social activities, such as visiting relatives and friends (Constantinidis et al., 2018; Nobre & Souza, 2018).

Thus, the new scenario can be full of stressful and significant events, requiring parents to face the loss of the idealized child and develop strategies to meet new demands. Some of these parents do not receive instructions on how to proceed after the ASD diagnosis, and the impact caused by the loss of the idealized child, combined with the child's neuroatypical demands and changes in the parents' routines, can lead to overload and alterations in the family routine, presenting challenges in managing and engaging in new occupations. All these changes can impact the physical, psychological, social, and socioeconomic aspects of the parents, often leading to health conditions that may entirely deprive them of their occupations and affect their quality of life (Matsukura & Menechelli, 2011; Riccioppo & Bellini, 2021).

The changes in these parents' occupations are a relevant aspect to be studied, as humans are occupational beings throughout our entire lives, involving interpersonal relationships with others and self-care (Townsend & Marval, 2013). For occupational therapy, a profession that can anchor its practice in the science of occupation, occupations are fundamental to humans, based on the concept that they structure everyday life and contribute to well-being and health. These activities comprise human needs, such as self-care, entertainment, and participation in society (Carleto et al., 2010). According to Schiliebener-Tobar (2021), the meaning of occupation lies in how individuals construct their sense of life, and with each occupation performed, people can know and affirm themselves through it, guiding individual issues. Thus, a person can engage in ADLs or IADLs; however, if these activities are characterized as unsatisfactory or meaningless, they are not defined as occupations, as human occupation expresses what people want, need, or are expected to do – it is laden with meaning and intrinsically linked to temporal, cultural, environmental, spiritual, and social contexts (Benetton, 2003; Dickie, 2011).

Occupations can contribute to a stable and fully functional lifestyle; however, some occupations meaningful to the individual can be harmful, and negatively affect their health, well-being, and quality of life (American Occupational Therapy Association, 2020). The overload of parents of children with ASD, generated in the attempt of the first to meet the demands of the latter, reflects how caregiving, which contributes to the well-being of others, can compromise the health and satisfaction of the caregiver. According to Silva & Oliveira (2017), parents are frequently overwhelmed, which negatively impacts their rest, sleep, leisure, professional life, and other areas in which they are directly and indirectly involved (Matsukura & Menechelli, 2011; Riccioppo & Bellini, 2021).

Therefore, it is understood that the relationship between people and what they do is not simple. Engaging in occupations means building a personal identity, meaning everything people do and how they do it establishes who they are, including what people need, want, and expect to do, whether physical, mental, social, sexual, political, or spiritual, including sleep and rest, i.e., meaningful occupations (Taylor & Kay, 2015).

Given this, being a parent of a child with ASD can significantly impact occupations. It is worth noting that the factor contributing to the better quality of life and well-being of those involved is related to how the family organizes itself to deal with new challenges (Chaim et al., 2019). In this context, this study aimed to understand the occupations of parents of children with ASD.

Method

Type of study

The study was conducted using a qualitative descriptive research method, which is employed in various fields of knowledge. Based on personal opinions, this approach delves into individual and/or collective perceptions and has evolved with rigor, demonstrating potential for producing evidence. Qualitative research can be used to study occurrences involving individuals and their social relationships in various environments. Its objective is to offer possible answers and it refers to a broad set of approaches and modalities that seek to understand, interpret, and describe problematic situations that, for some reason, spark investigative interest (Taquette & Borges, 2021).

Study location

This study was conducted at a private clinic located in a municipality in the North Region of Brazil. This clinic is a reference for treating children, youth, and adults with some form of SID – among the main causes of these dysfunctions are children with ASD. Currently, the clinic has professionals in the areas of occupational therapy, psychology, nutrition, and music therapy. Because this is a private clinic, its clientele consists of individuals from the middle and upper classes. The significant role of occupational therapists in assisting with SIDs is highlighted.

Participants

Eight parents of children diagnosed with ASD of both sexes participated in the research.

Inclusion criteria

Parents of children with ASD of both sexes aged ≥18 years whose children were undergoing sessions at the selected clinic and whose data were duly recorded in medical records.

Exclusion criteria

Individuals who did not agree to participate in the study and those whose children discontinued treatment at the clinic during the data collection period.

Data collection and analysis

After the project was approved by the Research Ethics Committee (CEP), an Informed Consent Form (ICF) was read to the participants, who authorized their participation by signing it. Data were collected through semi-structured interviews containing the following questions: "1. Do you agree to talk about your occupations? If so, what were your main occupations before your child's birth?"; "2. Can you describe your occupations currently? Which occupations can you not stop doing?" The purpose of these first two questions was to understand the occupations of each participant; "3. What is the meaning of the occupations you have described to me?"; "4. What do these occupations mean to you?" aiming to understand their significance; "5. Regarding the occupations we discussed, is there anything you would like to highlight? If so, please comment. Is there anything else you would like to mention?"

The data were collected through recorded interviews, authorized by the participants. Subsequently, the content was transcribed independently by two researchers, keeping the information provided by the participants confidential. The transcriptions were validated by the researchers, each responsible for reviewing the other's transcriptions to verify the fidelity of the transcribed data. Subsequently, Bardin's (2011) content analysis was applied – a method by which the researcher aims to understand the meaning and significance of the data through systematic procedures (Godoy, 1995).

In content analysis, the object of study is the record, which can be present in a text, document, audio, or video; thus, it can be used to analyze different sources (verbal or non-verbal) of content. Silva & Fossá (2015) emphasize that its application must involve methodological care, which requires a systematic research practice. Content analysis is characterized by two extremes: the rigor of objectivity and the richness of subjectivity. Therefore, it requires the analyst to be rigorous, ethical, intuitive, imaginative, and creative, with particular importance placed on defining the categories of analysis (Freitas et al., 1997).

Ethical issues

This study was approved by the Ethics and Research Committee of the Institute of Health Sciences of the Federal University of Pará (CEP/ICS/UFPA) under protocol CAEE no. 59235622.3.0000.0018 and opinion no. 5.504.233, and followed the recommendations of the National Research Ethics Council (CONEP), according to Resolution 466/12 and Resolution 510/16. The procedures and the intention of the study were verbally explained to the participants, who signed an ICF before the commencement of data collection. The participants were referred to as P1, P2, P3, P4, P5, P6, P7, and P8 to preserve their identities.

Results

Eight parents of children diagnosed with ASD participated in this study. There was no predominance of sex. The ages of the participants ranged from 32 to 53 years. Regarding marital status, all were married. In terms of profession, only two mothers did not engage in paid work. The other participants highlighted the importance of remunerated work to cover the expenses associated with their children's treatment.

Table 1 presents the sociodemographic information of the study participants at the time of data collection.

Table 1. Sociodemographic data of the participants. Belém, Brazil, 2022.

Name	Sex	Age (years)	Marital status	Occupation
P1	Female	53	Married	Retiree
P2	Male	39	Married	Businessperson
P3	Male	41	Married	Attorney
P4	Female	38	Married	Bank officer
P5	Female	33	Married	Dentist
P6	Male	32	Married	Physical educator
P7	Female	41	Married	Housewife
P8	Male	38	Married	Bank officer

Source: Field research.

From the content analysis, the results were divided into the two categories most frequently mentioned by parents concerning their occupations in the conducted interviews: 1) Occupations of parents of children with ASD; 2) Leisure occupations of parents of children with ASD.

On the occupations of parents of children with ASD

When asked about their occupations, some participants reported changes, mainly regarding the need and difficulty of reorganizing their everyday lives after the ASD diagnosis. An example is the following account, in which a father describes his experience following the diagnosis:

> *Receiving the diagnosis of autism was a life change, it was a life change, it was a fear, a fear of what the future holds* [...] (P5).

In another account, it was observed that even years after receiving the ASD diagnosis, the family still struggles to adapt to daily tasks and reconcile their occupations with those of their child:

> *Since we got, you know, the diagnosis, we've been living in a rush and had to readjust our life, but we still haven't found much time* (P4).
>
> [...], *my wife and I used to go out twice a week, and nowadays we limit that a lot because of the children, so life has changed* [...] (P6).

The difficulties reported by the parents were also observed during the interviews as they waited for their children in the clinic's reception area. One parent was working remotely and expressed: "*I bring my laptop to get some work done*". Another couple was eating while their child was being attended, requesting to pause the interview to finish their meal, stating: "*Let us just eat a little, in this rush, we haven't eaten anything*".

From these accounts, it is evident that the parents' occupations are conditioned by their children's needs, with the tasks of the first being dependent on the demands of the latter. As illustrated in the following account, parents start or end their daily activities according to their child's schedule:

> *I tried to schedule E.'s therapies after my work hours, most of them are after work* (P2).
>
> *After the birth and consequently the ASD diagnosis of my son, my routine became very centered around work, my professional life* [...], *and also around his care, right? With A., especially because I am the one who takes him to therapies, I accompany his daily routine, also at school* [...], *I drop him off, pick him up from school, usually when I'm not traveling for work, right?* [...]. *So my routine is basically about work and taking care of A.* [...]. *For example, on Mondays, I drop him off at school, go to work, attend hearings, do my assignments, and always trying to organize my time so I'm free by noon to pick him up at school* (P3).

According to the accounts, the parents' occupations became secondary to accommodate their children's occupational priorities. Interferences were observed in some occupations, such as rest, sleep, leisure, and work, as indicated in the following accounts:

> *Yes, a lot, I sleep less now. Before it was harder because his sleep was very irregular, very, very irregular, and I slept very little, I was always on edge, wondering if he was awake or not. So that also affected me because I feel more tired* [...] (P4).
>
> *When M. fell asleep yesterday and woke up at eleven o'clock* [...], *he only went back to sleep now, around eleven, almost noon. So, he stayed up all night* [...], *stayed up all night, right?* [...] *Ah! I slept, woke up: at 1:00 AM, 2:00 AM, 3:00 AM, 4:00 AM, and 5:00 AM with the noise of him moving things around, destroying things. Then I really woke up, right?* [...] (P1).

> *In the routine, it was that before I had much more time for my work, my studies, and my leisure, and today I don't, right? Today, my time* [...], *my work and leisure time is limited* (P3).

Some accounts show the need to express feelings and a certain physical and emotional exhaustion with the current routine:

> [...], *there are days when we are stressed, and then there are days when you are depressed because, like, at the beginning, when you find out your child has autism, it's a big impact, right? It's an impact because, you know, there are many steps* [...], *I'm not saying that every day I have that energy, there are days when you wake up with cramps, stressed, tired, but what I can do best for him* [...] (P7).

In other accounts, an occupational imbalance is noticeable, in which parents mention how the physical and emotional aspects affect them and consequently alter their engagement in occupations, as the time previously available for leisure or self-care is now mostly dedicated to their children:

> *Oh yes, of course, there were changes* [...], *for example, time* [...], *time that my wife and I* [...], *were at home resting, right? Now, we have to rush to therapies or deal with traffic jams to get to therapy places, return home, leave home for therapies, and so on, which is very, very exhausting, this issue of the time we spend in traffic* (P8).
>
> *Sometimes, when we get very tired in this routine, we end up not going out much for* [...], *for fun* (P4).

Social class was another observable point, this time as a facilitator for the parents in conducting their occupations, since the social condition of the participants falls within the upper-middle and upper classes, with professional profiles including retirees, self-employed, and freelancers. This configuration provides them with the opportunity to adjust their schedules according to their children's demands, as in the following account:

> *I am self-employed, and I make my schedule, so it's a bit more flexible for me to organize my time to be present at L.'s therapies* (P5).

It is also noteworthy that financial condition is an important element for these parents, as it allows them to afford specialized therapies and provide assistance in caring for their children:

> *E. has a nanny* [...], *and he has a substitute nanny who also knows his routines, habits, and medication schedules. So, whenever we need to go to an event or something, one of them stays with him while we are out, you know* (P2).
>
> *Yes. So I managed to assemble a team of three professionals: a supervisor who organizes the routine to be worked on, and passes it to the therapists who apply it, they are already trained. They do it four times a week, two days each. They go on Monday, Tuesday, Wednesday, and Friday* (P5).

On the leisure occupations of parents of children with ASD

As for the leisure occupations of these parents, it was noted that there were changes, with some situations in which they adjusted their leisure activities to align with their children's needs:

> *We try to take some time on the weekends, right?* [...], *that's when the therapy routines, our work life routines* [...], *we get a break, and we take them to the pool* (P6).
>
> *So usually we try to* [...], *establish a time for us to have some time with them and for them to get out of the house, besides just therapy or just therapy in his case* (P6).

According to the reports of some participants in this study, there can be a sacrifice of the parents' leisure for the well-being of the family, leading to changes in the meanings of these occupations and generating a certain contentment with the current situation due to the children's demands, which already have a routine pattern.

> *A little bit of leisure, once in a while a movie or dinner with my wife, birthdays, and we reduced trips a lot because of him, right?* [...], *he doesn't accept much change* (P3).
>
> *As for my leisure, it ends up taking a back seat, right? It only happens at very specific moments, mainly because he doesn't accept much change, so trips become a bit rare* [...] (P3).

The reports emphasized the importance of leisure in the parents' routines; however, changes in leisure activities were reported, impacting their interpersonal relationships and how occupations were conducted before their children's diagnoses:

> *He doesn't like it when there are too many people, so it keeps me away from him, I have a very large family, so it's not every time we go, and my other daughter has problems with noise, so we don't go to noisy, crowded places, we try to go during off-peak times to some places, so they can have enjoyable leisure* (P6).
>
> *When it comes to leisure, like* [...], *I have things I do when my son and F. go to sleep, like, my leisure, that's my time, so usually, what I consider my leisure nowadays, I watch YouTube videos* [...], *take courses on cryptocurrencies because I'm interested in the topic, and I also like sports betting sites where I have fun with football, I have fun with football and play on those sports betting sites, so that's what I consider my leisure nowadays* (P8).

It was noticeable that occupations changed compared to the period before the diagnosis. Additionally, it is important to highlight the mental health of these parents, who make various attempts to adjust their leisure routines to their children's demands, potentially leading to stressful situations.

> *For yoga, forcefully, because I have to do something, yoga* [...]. *And the meaning of yoga is to relax so I can take care of him, right? Also the psychologist. To be well for him.* [...], *it's important for me because I stabilize. Yoga calms me down* (P2).

> *And sometimes, just to de-stress, we go out as a sort of escape, you know? We need it, because otherwise* [...], *you end up going crazy. So today, to be more precise, the reason we go out is a kind of escape, a de-stress, a social care* (P2).

Finally, based on the participants' reports, it was possible to observe the presence of occupational changes in the context they are in, showing a limited occupational repertoire, as they had to give up or adapt their daily and leisure occupations, leading to repercussions in the physical, emotional, and social spheres.

Discussion

Modifications were observed in the daily and leisure occupations of parents of children with ASD following the diagnosis. Daily activities such as eating, resting, sleeping, self-care, and work were the most affected because of the prioritization of their children's needs. Before the diagnosis, these activities were essential and occupied a significant part of the participants' time, also serving as a form of personal affirmation.

According to the definition proposed by Álvarez et al. (2007), occupations are activities that hold meaning for the people who perform them daily, can be named through culture, and possess significance. Muñoz Espinosa & Salgado Gómez (2006) state that daily activities are considered by Occupational Science as occupations in which people engage and attribute distinct characteristics: form, referring to the observable aspects of doing; function, related to the influence of doing on personal development; and meaning, which involves the personal values in occupations. In adulthood, these activities are purposeful and aimed at work obligations and personal and family care. Adults also engage in social activities, such as group meetings, or their absence, solitary activities like reading, watching television, among others. These activities are mainly characterized by being self-initiated, with intentions and purposes for those who perform them, contributing to self-development and personal growth, as through them the individual demonstrates their social skills (Costa et al., 2017).

The execution of daily activities is significant for the individual because through them they can express emotions, feelings, and desires. Thus, modifications in occupations become noticeable for the individual, potentially leading to changes in feelings, personal satisfaction, and engagement in occupations, reflecting on their well-being and quality of life (Echeverría Ruiz-Tagle et al., 2009).

The participants' reports highlight the need for engagement in occupations. They describe how, before the ASD diagnosis, they were involved in certain occupations that provided them with pleasure and well-being. Participants also reported difficulties in organizing their time during the study period. For example, they mentioned the difficulty of balancing self-care with their children's daily demands or facing work interruptions due to the time spent commuting to take their children to therapy sessions, waiting for them in reception areas, and caring for them daily. Participants reported having an exhausting occupational routine and shared the difficulty of engaging satisfactorily in other occupations.

These findings corroborate those of Roiz & Figueiredo's (2023) research, which observed changes in the occupations of mothers of children with ASD after the diagnosis. Concerning work, some mothers had to stop working, others started performing some type of income-generating work at home, and those who still managed to work outside reported lower satisfaction. In terms of self-care, they reported difficulties in performing activities such as going to the beauty salon and taking a bath. All these changes resulted from the need to meet their children's demands (Roiz & Figueiredo, 2023).

The parents' reports also showed the need for readaptation. Some reported giving up meaningful activities, such as going out on weekends or sleeping regularly. On the other hand, some parents could not adapt to the new circumstances, did not engage in new occupations, and lamented the loss of old ones, thus failing to find new meaning in their everyday lives.

Daily occupations can be directly related to the construction and maintenance of a person's identity, as it is through them that individuals express their identity (Drápela et al., 2008; Flores et al., 2015; Menegat et al., 2021). Therefore, an occupational imbalance concerning daily occupations can lead to the loss of occupational identity for parents of children with ASD, resulting in the absence of meaning in these activities. Certain conditions may make parents feel incompetent in performing their roles within their family or community, leading to severe existential crises (Gómez Lillo, 2003). Caparroz & Santos Soldera (2022) highlight how the ASD diagnosis impacts the family, including the initial difficulties faced by relatives, grief, the increased responsibilities of mothers, social isolation experienced in everyday life, lack of social support, limited access to healthcare services, and the sacrifice of professional life.

Another difficulty expressed by parents in their reports—affecting the full development of their occupations and resulting from occupational imbalance following the ASD diagnosis—is physical and emotional exhaustion. This results in distancing or abandonment of previous occupations or low engagement in new ones. Sprovieri & Assumpção Júnior (2001) identified that ASD permanently impacts the family, compromising the emotional health of its members. This impact manifests in difficulties related to family roles, communication, leadership, expressions of aggression, and physical affection.

Children with ASD face obstacles in performing their daily activities according to each stage of their development. However, pathological characteristics intensify the demand for greater care and, consequently, a higher degree of parental dependency. This context has been seen as a stressful environment for caregivers, indicating higher stress levels due to the overload resulting from their children's demands, care, and tasks, potentially leading to a higher risk of developing chronic stress, depression, and anxiety (Christmann et al., 2017).

Changes in daily activities can expose parents to functional damages that hinder their full involvement in their occupations. Piškur et al. (2002) conducted a study in which participants revealed that engaging in their occupations led to well-being; however, as they faced occupational imbalances, their health and well-being were negatively affected.

Therefore, it can be inferred that occupation is how humans attribute meaning to their actions, influenced by physical, social, and cultural circumstances, as well as by beliefs, capacities, abilities, and symbols. This demonstrates how the full exercise of an occupation is associated with the biopsychosocial sphere, and that the suppression of daily occupations significantly impacts human activities (Gómez Lillo, 2003).

In contrast, some parents were able to attribute new meanings to their current situation, engaging in new occupations or finding strategies to maintain previous ones. However, for this to happen, they relied on the support of other important people to share responsibilities and thus manage to take on new roles and maintain their occupational identities.

Aguiar & Pondé (2020), in their narrative approach to parents of children with ASD, identified categories to address areas altered after the child's birth. Parents' occupations were one of the factors modified after the ASD diagnosis. The reports indicate that the lack of a support network to assist the caregivers with daily demands led to their overload.

According to Smeha & Cezar (2011), this social network, which includes family, community, and professionals, is significant for individuals, as they receive social, emotional, cognitive, and even financial support through it. Additionally, the social network is a source of assistance and information in the face of adversities experienced by parents because of their children's limiting conditions.

Thus, having a support network is crucial for the effective participation of parents in their daily occupations, as it is through this support that they can feel secure, knowing they have someone to rely on for help with trips to therapy sessions or their children's ADLs, allowing them more time and dedication to daily tasks. Socioeconomic conditions facilitate a less stressful adaptation and consequently result in fewer occupational changes. Sprovieri & Assumpção Júnior (2001) analyzed 15 profiles of caregivers of neurotypical children and found that they belong to the upper and middle classes of society. The availability of financial resources is a factor that influences the quality of life and family stress (Konstantareas, 1991; Koegel et al., 1996; Jones et al., 2017). Given this context, it is important to highlight the need for additional support services for families, such as schools, projects, community support networks, among others.

Based on the parents' reports and the aforementioned statements, it can be inferred that the availability of financial resources in the families of children with ASD is a determining factor for these families to fully engage in human occupations, as it ensures that parents have favorable conditions to secure care services for their children, reducing overload and increasing the time they can dedicate to their occupations. At the same time, it is worth highlighting the occupational situation of thousands of parents with reduced socioeconomic conditions and social support.

The collected reports show changes in parents' leisure occupations, both individually and in groups, as after the ASD diagnosis, they often sacrifice their interests and needs in favor of those of their children. Other studies have also pointed out changes in the leisure activities of parents of children with ASD, such as difficulty in reading, traveling, visiting friends, and engaging in physical activities (Roiz & Figueiredo, 2023); lower satisfaction with leisure (Walton, 2019); and compromised quality of life (Davy et al., 2022).

Walton (2019) suggests that many families of children with ASD struggle to engage in satisfying family leisure activities and that these difficulties may be related to poorer family functioning and lower satisfaction with family life. That author emphasizes that interventions aimed at family leisure should focus not necessarily on the quantity of leisure time but on the quality of these family moments.

Acácio et al. (2021) consider leisure not just as "free time" from work but also as other activities; thus, any time could be considered leisure as long as it provides personal satisfaction.

In this context, the individuals' involvement in their leisure-related occupations significantly contributes to their health and well-being, as daily occupations are extremely important for the client's identity because of their particular meaning. The way individuals enjoy their leisure time favors their ideological, physical, social, cultural, and economic performance within their contexts (Guedes, 2015).

It was also observed that there is an overload in the routine of these parents due to having to take their children to therapy sessions. In this context, these parents seek leisure as a form of refuge to balance their routine, which is commonly dedicated to their children. Leisure can serve as a tool or means of occupation; however, few recognize and understand its value as a stimulus for personal development. Providing these parents with a personal activity that they can perform according to their will generates personal fulfillment and internal convictions, in addition to playing an important role in decision-making, leading to a happier life (Martinelli, 2011).

Therefore, the practice of leisure provides parents with a sense of well-being, independence, and autonomy over their life history. There is a lack of understanding in our society about the occupation of time with leisure; hence, it is necessary to break the labels that associate leisure with an unimportant activity. It is essential to understand human development as a whole, assimilating human beings to their specificities.

According to the aforementioned statements, involvement in occupations is associated with increased well-being and quality of life, and these tasks should meet basic, social, and personal needs, bringing satisfaction to the individual's needs and desires. Thus, the reports from the participants in this study allowed us to understand various factors that influence the human occupation of parents of children with ASD, and hence to know how changes impact personal and social life.

Therefore, the occupational therapist is the professional responsible for investigating and analyzing activities, facilitating the client's adaptation and reorganization concerning daily occupations. It is worth emphasizing the fundamental importance of the occupational therapist, who works with occupations considering each specificity presented, guiding the parents of children with ASD to adapt to their new reality after the diagnosis (Almohalha Lucieny & Pereira, 2020).

Final Remarks

This study provided a more comprehensive understanding of the occupations of parents of children with ASD and the repercussions of these activities on their everyday lives. Significant changes in occupations were observed, and how they impact the health, well-being, and quality of life of the participants. The main contributions of this research for the participants include understanding how occupational issues can be altered in response to the demands of caring for their children. It was also possible to observe the importance of daily occupations in the situations contextualized in this study.

In the participants' reports, demands related to daily occupations were identified. Some reports indicated feelings of guilt from parents for not always being able to perform occupations as planned. Occupational life after a child's ASD diagnosis can initially bring doubts, anguish, and frustration. Nevertheless, there can also be opportunities to discover new occupations. Both situations can impact the social participation of these individuals.

Research on ASD is quite diversified, and the results of this study can have important implications in both clinical and public health studies, given that there has been an increase in research and diagnoses in this field in recent decades.

This study proved relevant from an occupational perspective, highlighting the scarcity of investigations aimed at understanding human occupation, especially among parents of children with ASD. It also contributes to broadening the discussion on the occupational dimension and its specificities, providing subsidies for individuals to understand and analyze their occupational development, and highlighting the importance of occupational therapists in these cases.

For the researchers, this study allowed for an approximation with the context of the interviewees, enabling an in-depth look into the life factors of each one, observing and listening to their fears, everyday difficulties, anguish, desires, and expectations, which are peculiar to the experiences of parents of children with ASD. Above all, it enabled a more comprehensive understanding of a field that has repercussions on human activity and underscored the importance of addressing the occupational issues of all involved in these situations.

Limitations of this study include the difficulty in finding theoretical references on the chosen theme, especially when approached from the occupational dimension, compared to other contexts. It is also noted that, although limited by a small sample, this research, through the adopted methodological paths, managed to obtain reports highlighting important occupational situations that need attention. In this sense, the study aims to contribute to the academic community by providing scientific data that can support new research on this theme.

It is suggested that future studies with the same objective include parents from various socioeconomic classes, as well as children of different ages and varying levels of autism.

Finally, this study contributed to enhancing the knowledge about the occupations of parents of children with ASD, emphasizing the importance of occupational therapy in this context. Thus, it is possible to provide occupational therapeutic assistance anchored and attentive to the occupational demands resulting from the process of caring for a child with ASD. From a broad health perspective, this research seeks to understand the biopsychosocial and occupational aspects of the human being in a family-centered approach. It also highlights the need to invest in public support networks for parents of different socioeconomic levels, including daycare centers and specialized services, aiming to provide greater support and parental guidance.

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