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Original Article

Adaptation process and occupational performance of mothers of children with autism spectrum disorders

O processo de adaptação e desempenho ocupacional de mães de crianças no transtorno do espectro autista

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Abstract

Introduction: Adapting to a child with Autism Spectrum Disorder (ASD) can impact the occupational performance of mothers because of the care they demand, which can lead to difficulties in carrying out their occupations. **Objective:** To investigate the occupational performance and adaptation of mothers to their children with ASD. **Method:** Cross-sectional, descriptive, quantitative and qualitative study conducted with 11 mothers of children with ASD aged 2-9 years. Data were collected using the Parental Disability Adaptation Scale (EPAD) and the Canadian Occupational Performance Measure (COPM). EPAD data were analyzed by adding the scores of each participant and calculating the general average, whereas COPM data were analyzed from the values assigned to performance and satisfaction. **Results:** The mothers were well adapted to their children; however, they evaluated the presence of functional problems for occupational performance after their birth. Functional problems in the productivity category, specifically in work performance due to the demands of caring for the children, were mentioned by most mothers. In the self-care category, some mothers reported problems related to going to the salon and taking a shower. In the leisure category, some mothers indicated problems with reading, physical activity, traveling and/or visiting friends. **Conclusion:** The mothers in this study reported that adapting to their children with ASD involves factors such as transmission of the diagnosis, information, children characteristics, socioeconomic conditions, resilience, and personal beliefs and expectations. In conclusion, the mothers of children with ASD investigated presented functional problems regarding their occupational performance after the birth of these children.

Keywords: Psychological Adaptation; Role Playing; Mothers; Autism.

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Resumo

Introdução: A adaptação a um filho no Transtorno do Espectro do Autismo (TEA) pode impactar o desempenho ocupacional das mães em razão dos cuidados demandados, que podem dificultar a realização das suas ocupações. **Objetivo:** Investigar a adaptação e o desempenho ocupacional das mães de filhos com TEA. **Método:** Estudo descritivo transversal de abordagem quantiqualitativa com 11 mães de filhos no TEA com idade entre 2 e 9 anos. Os dados foram coletados por meio da Escala Parental de Adaptação à Deficiência (EPAD) e da Medida Canadense de Desempenho Ocupacional (COPM). Os dados da EPAD foram analisados pela soma dos escores de cada participante e cálculo da média geral e os da COPM a partir dos valores atribuídos para o desempenho e satisfação. **Resultados:** As mães estavam em adaptadas a seus filhos; entretanto, avaliaram a presença de problemas funcionais para o desempenho ocupacional após o nascimento deles. Problemas na categoria produtividade, especificamente para trabalhar, por conta das demandas de cuidados com o filho, foram referidos pela maioria das mães. Na categoria autocuidado, algumas mães referiram problemas para ir ao salão de beleza e tomar banho. Na categoria lazer, algumas mães indicaram problemas para realizar leitura, atividade física, viajar e/ou visitar amigos. **Conclusão:** As mães deste estudo demostraram que a adaptação a seus filhos envolve fatores como transmissão do diagnóstico, informação, características dos filhos, condições socioeconômicas, resiliência, crenças e expectativas pessoais. Conclui-se que as mães de filhos no TEA investigadas apresentaram problemas funcionais para o desempenho ocupacional após o nascimento desses filhos.

Palavras-chave: Adaptação Psicológica, Desempenho de Papéis, Mães, Autismo.

Introduction

The family is the first social group into which we are inserted at birth. The birth of a child with Autism Spectrum Disorder (ASD) requires changes from mothers and/or fathers to adjust and reorganize to the new context (Figueiredo et al., 2020). In addition, the expectations generated about a perfect child break down and give way to feelings such as failure, guilt and sadness (Dantas et al., 2019).

ASD is classified as a neurodevelopmental disorder, with impairments in the ability to initiate and sustain communication and social interaction, which promotes restricted interests and stereotyped behaviors that become excessive for the person and their sociocultural context (World Health Organization, 2021). The experience of having a child with ASD is unique for any family, considering that each member has their own history, beliefs, skills to face new situations, socioeconomic status and support network (Figueiredo et al., 2020). ASD often changes the routine and family dynamics. As a result, family relationships are shaken, as attention is completely focused on this child (Machado et al., 2018).

The adaptation of mothers and fathers to children with a disability and/or neurodevelopmental disorder, according to the Adaptation and Development Process Model by Franco & Apolónio (2002), consists of a process composed of a variety of factors and phases, constituting a journey that begins before the diagnosis until the resumption of the personal development of each mother and father.

Even before birth, a child is already born in the imagination of each mother and father as perfect, which favors the bond between them. The perfect baby is idealized from three dimensions: aesthetics, competence and future. The aesthetic dimension is composed of preconceived ideas for a perfect baby, such as chubby, pink, active and smiling. The competence dimension refers to the qualities and lifestyle expected for the child and which correspond to those of the mothers and/or fathers. The dimension of the future is the image that the mother and/or father create of a perfect future for the child, such as good studies and good professional skills (Franco, 2009).

The news of a diagnosis emotionally impacts each mother, causing a rupture with that imaginary child, which can affect the bond between them. These mothers can experience feelings of depression, guilt, anger and denial, affecting the course of their own development. Therefore, the adaptation of mothers to this unwanted fact involves a grieving process for the elaboration of the loss of the idealized baby as perfect and the re-idealization of the child based on reality. When this grief is not processed, such mothers and/or fathers can be dominated by the action of caring for the child, becoming functional and having difficulties relating emotionally to them (Franco, 2009, 2016a).

How to cope with this grieving process depends on personal factors of each mother and/or father, such as their stories, personality, beliefs, understanding of their own feelings and attitudes about the diagnosis. It will also depend on contextual factors that act as a support network, such as family members, friends, professionals and services. In this way, the re-idealization of the child will depend on the ability of the parents and/or mothers to see beauty in their children even with the disability and/or disorder (aesthetic dimension), the potentialities and abilities even with the consequent limitations of the disability and/or the disorder (competence dimension), a positive future even in the face of difficulties faced (future dimension) (Franco, 2009).

According to Trindade et al. (2021), in an integrative review, identified that the support of grandmothers to mothers of children with disabilities contributes to stress relief, helps in the search for strategies, information and services to deal with children and is always ready to listen to parents and thus provide emotional support.

Historically and culturally, mothers dominate the care of their children, and this is no different when you have a child with some type of disability and/or neurodevelopmental disorder (Rosa et al., 2010), which requires time and effort from the mother, resulting in losses in their occupational performance (Estanieski & Guarany, 2015) and emotional and physical health (Figueiredo, 2009).

Occupational performance, according to the Canadian Model of Occupational Performance and Engagement (COPM-E) is defined by the person's ability to carry out their occupations and fulfill the occupational roles specific to their stage of development, resulting from the interaction between the person, environment and occupancy. For the COPM-E each person is constituted by physical, affective, cognitive and spiritual aspects. The environment can be physical, social, cultural and institutional (Polatajko et al., 2013). Occupation is understood as a basic human need that gives meaning to life, being defined as "[...] everything people do [...], including taking care of themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric (productivity) (Polatajko et al., 2013, p.17). Thus, occupational performance is unique to each person and may vary according to personal characteristics, such as age, capabilities, limitations and/or favorable or unfavorable environmental conditions for performance, among others (Magalhães et al., 2009).

Feitosa (2020) reports that mothers of children with ASD in the process of adaptation sought to understand what the parental role was in the face of the demands arising from ASD and how to deal with their own expectations regarding their child's development.

Estanieski & Guarany (2015) found that mothers of children with ASD had an accumulation of tasks and occupational roles that overloaded them on a daily basis and impaired their occupational performance due to the need to adapt to the demands of their children.

Ribeiro et al. (2018) reaffirm that mothers of children with disabilities and/or neurodevelopmental disorders undergo occupational changes to meet the demands, which directly affect their own health and well-being.

Therefore, the literature indicates that becoming a mother of a child with ASD requires an internal movement of overcoming, accepting and adapting for the development of healthy parenting. In addition, such children have unexpected and differentiated demands, which the family, especially the mother, will have to adapt. Such facts may compromise the occupational performance of these mothers. However, despite the existence of significant literature on mothers of children with ASD, no national literature was found that related the adaptation process of these mothers with their occupational performance after the birth of these children.

In this context, the present study aimed to investigate the adaptation and occupational performance of mothers of children with ASD. Therefore, answers were sought to the following research questions: Are mothers of children with ASD adapted to their children? What assessment do mothers make about their occupational performance in terms of degree perfomance and satisfaction with the occupations they want, need or are expected to perform?

Method

This is a descriptive and cross-sectional study with a quantitative approach. Its descriptive design makes it possible to know how one or more characteristics, whether individual or collective are distributed in the population (Medronho et al., 2008). Thus, this method aims to describe the characteristics of a given population or phenomenon and/or establish relationships between variables through standardized data collection techniques (Gil, 2002). On the other hand, its transversal design refers to the analysis of a situation or phenomenon at a given moment, that is, "[...] it is presented as a photograph or instantaneous section that is made in a population through a sampling, examining in the members of the casuistry or sample, the presence or absence of exposure and the presence or absence of the effect [...]" investigated (Hochman et al., 2005, p. 3).

Participants

The sample consisted of mothers of children with ASD. The following inclusion criteria were adopted: mothers aged over 18 years, of any marital status and educational and socioeconomic level, with children aged between 6 months and 12 years with a diagnostic report confirming ASD. Mothers who had a disability and/or disease and children with ASD associated with other diagnoses were excluded from the study.

Procedures for data collection and instruments

The research began after approval by the Research and Ethics Committee of the Federal University of São Carlos (CAAE 33549720.6.0000.5504).

First, the researcher presented the project for public and private services for children with ASD located in the cities of Ribeirão Preto/SP and São Carlos/SP. Upon expression of interest by the service leader, the researcher's contact was made available to mothers who met the inclusion criteria and expressed interest in participating in the study. The researcher, in person or virtually, explained the objectives, risks and benefits of the research and, after accepting and signing the Free and Informed Consent Form, applied the data collection instruments. The collection took place both online and in person at the child care service, by prior appointment according to the availability of the participants.

Furthermore, the survey was publicized on social network, which allowed mothers to voluntarily express interest and, if they met the inclusion criteria, compose the sample. Data were collected between October 2020 and March 2021. Due to the COVID-19 pandemic, some collections took place remotely.

The instruments used were the Parental Adaptation to Disability Scale (EPAD) Franco (2016b) and the Canadian Occupational Performance Measure (COPM) Law et al. (1990).

EPAD was developed by Franco (2016b) for the Portuguese population to be used both in scientific research and in clinical practice. Londero (2019) validated it for the Brazilian population; however, EPAD is an individual assessment instrument, divided into 10 dimensions, each with 6 questions, within two subscales: Development and Non-Adaptation. The Development subscale identifies aspects of the parents' resumption of their development path and, consequently, the process of adapting to the disability, being divided into re-idealization and support, called factors. Each factor is composed of 30 items, and the result is obtained by adding the two factors considering a minimum value of 30 and a total of 180. In the re-idealization factor, we have the aesthetic, capacity and future dimensions, and in the support factor, the resilience and social support dimensions. The Non-Adaptation subscale consists of 5 dimensions: idealization, diagnosis, depression, guilt and functionality. These dimensions assess the obstacles formed for the adaptation and resumption of the personal development of the fathers and/or mothers/caregivers through the negative aspects. To answer the questionnaires, fathers and/or mothers must consider how they feel at the moment, answering within the scale: (1) completely disagree, (2) disagree, (3) neither agree nor disagree, (4) agree, (5) completely agree (Franco, 2016b). The analysis of the EPAD data is carried out from the sum of the scores of each participant in the existing dimensions within the subscales of Development and Non-Adaptation, in which it is desirable that the value obtained from the development factors be higher than that of the factors that become obstacles. Based on the individual scores, the overall average of the investigated participants is calculated and the results are expressed in a graphic scale.

The COPM was created with the purpose of investigating people's self-perception of their occupational performance and, therefore, is used as an outcome measure, that is, of results to support the elaboration and implementation of an occupational therapy intervention program (Magalhães et al., 2009). In this way, the COPM is used to

> [...] identify problem areas in occupational performance; quantify the client's occupational performance priorities; evaluate performance and satisfaction

> related to problem areas; measuring changes in the client's perception of their occupational performance throughout the occupational therapy intervention program (Magalhães et al., 2009, p. 13).

As an individualized measure, carried out through a semi-structured interview, the therapist encourages the person to think about the occupations they want to do, need or are expected to do based on a typical day of their daily life and according to the occupational areas established by the COPM, namely, self-care, productivity and leisure. Once the person has indicated such occupations, the therapist asks how important they are to the person and asks them to choose up to five problems faced for occupational performance. Based on the occupational problems listed, the person is asked to assign, to each one, a grade for their own performance and a grade for satisfaction with how they perform, based on a scale of 1 to 10 points. Thus, the COPM is used both as an initial assessment to identify problems for occupational performance that will support the implementation of an intervention, and as a reassessment measure after the completion of the referred intervention. In addition, the COPM can be used as a measure of occupational performance in research with the aim of increasing knowledge and understanding of occupation from the conception that occupation is a concept and a variable and, in addition, to demonstrate the link between occupation and other variables, when we seek to identify occupational performance problems that may appear in the form of personal and environmental characteristics (Magalhães et al., 2009).

The analysis of the COPM results occurs with the computation of the answers of each participant regarding the indication of importance of the occupations that they want, need or are expected to perform (within the areas of self-care, productivity and leisure), ranging from 1 (not at all important) to 10 (extremely important); the mention of the five main occupational performance problems and their classification according to the performance scale, which varies from 1 (unable to do it) to 10 (I do it extremely well), and the degree of satisfaction with the performance according to the scale of 1 (not at all satisfied) to 10 (extremely satisfied). After scores are taken, the total performance score is calculated by summing the performance scores divided by the number of issues. The same can be done to obtain the total satisfaction score, adding the scores and then dividing them by the number of problems (Magalhães et al., 2009, p. 42).

Due to the fact that the present study focuses on the evaluation that mothers make about their occupational performance, in terms of degree of performance and satisfaction, the application of the COPM turned to the understanding of occupational changes after the birth of a child with ASD, considering this birth one of the possible determinants for the problems faced in the performance of these occupations. As a way of deepening the investigation into the occupational performance of mothers and finding out if functional problems were related to the birth of the child, mothers were also asked to think about their occupational life before birth, list up to five problems faced for performance occupational and value the degree of performance and satisfaction with such performance.

Data analysis

The sociodemographic characterization of the participants included data regarding the age of the mothers, level of education and type of occupation, and the age of their children described numerically.

EPAD conceives the comparative analysis of the total values within the dimensions of the Development and Past/Non-Adaptation subscales (Franco, 2016b). In this way, the individual values of each mother within each dimension are summed, and in the end the average of all mothers is calculated. When carrying out the comparative analysis, it is identified in which dimensions there is the highest score, thus indicating whether or not the mother adapts.

The analysis of the COPM results consists of computing the responses of each participant regarding the degree of importance attributed to occupations (within the areas of self-care, productivity and leisure), ranging from 1 (not at all important) to 10 (extremely important); mentioning the five main occupational performance problems, classifying them according to the performance scale, which varies from 1 (unable to do it) to 10 (I do it extremely well), and the degree of satisfaction with the performance according to scale 1 (nothing satisfied) to 10 (extremely satisfied). With that, together with each mother, it was identified which occupations they performed before the birth of the child, which were affected after birth and which they started to perform after the birth of the child (Law et al., 1990). As a criterion adopted in the research, the score from 0 to 6 in performance and satisfaction indicates where there is impaired occupational performance.

Results

Eleven mothers of children diagnosed with ASD aged between 2 and 9 years at the time of collection participated in this study.

The mothers were between 26 and 42 years old, had an education level between incomplete elementary school and post-graduation and were all married. Regarding work, four mothers did not work and/or stopped working to take care of the child, three worked at home (craftswoman, baker and businesswoman) and four worked outside the home (2 teachers, 1 nurse and 1 agronomist).

Considering that for the EPAD the score obtained in the Development subscale must be higher than that in the Non-Adaptation subscale, the results indicated that the mothers were in favorable development to adapt to the birth of the child in ASD and to be the mother of a child with ASD, as the mean scores on the Developmental and Non-adaptive subscales were 120 and 72 points, respectively. Such values indicate, therefore, that there are no negative aspects interfering in the process of adaptation to the child.

Figure 1 shows the scores for each dimension of the Development subscales (aesthetics, capacity, future, social support and resilience) and Non-Adaptation (depression, diagnosis, functionality, guilt and past/idealization).

The results presented in Figure 1 indicate that mothers are managing to invest emotionally in their children in terms of aesthetics, capacity and future components, having resilience and social support to deal with changes and demands arising from ASD, favoring their own development and adaptation. In the same direction, the scores indicate that depression, guilt and diagnosis are not compromising the perception of functionality and past/idealization, which favors the development and adaptation process, according to the instrument's own evaluation instructions.

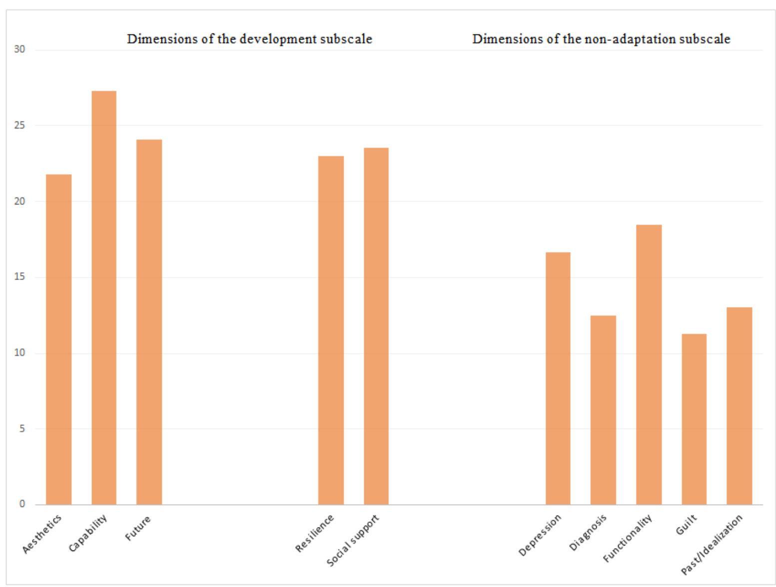

Figure 1. EPAD results for mothers of children with ASD. Source: Author's data.

The results obtained with the COPM reflect the occupational performance of mothers after the birth of their children, that is, the occupations that they indicated as being most important to them and that present functional problems for performance, quantifying the levels of performance and satisfaction of those listed occupations to a greater degree of importance. There is evidence of functional problems in the productivity category, and work was indicated by eight mothers: six attributing scores ≤5 and two attributing scores ≤6, for performance and satisfaction. Problems with housekeeping were reported by two mothers and problems with shopping by two others, with these mothers giving scores ≤6 for performance and satisfaction. Problems going to the bank was indicated by a mother, who assigned a score of 1 for performance and satisfaction. In the self-care category, problems with going to the beauty salon were indicated by two mothers, with scores ≤5. Problems with bathing were indicated by a mother, who assigned a score of 5 for performance and satisfaction. Finally, in the leisure category, two mothers indicated problems with reading and two with physical activity, with attribution of grades ≤5. Traveling was indicated as a problem by two mothers, who assigned a score ≤2, and visiting friends was indicated by one mother, with a score ≤3, for performance and satisfaction.

As a way of understanding whether the mothers' occupational performance and functional problems would be related to the birth of the child with ASD, mothers were asked to think about their occupational life before birth, list up to five problems faced for occupational performance and value the degree of performance and satisfaction. Mothers indicated up to five occupations that they wanted, needed or were expected to perform, but did not mention that they faced functional problems; on the contrary, the score given by most mothers (n=7) was ≥7 for performance and/or satisfaction.

Table 1 presents up to five problems faced for the occupational performance of mothers after the birth of children with ASD and the values attributed to their performance and satisfaction. In addition, it presents the occupations listed as important and the grades for their performance and/or satisfaction before the birth of these children.

Table 1. Occupational performance and satisfaction of mothers before and after the birth of children with ASD.

	BEFORE BIRTH			AFTER BIRTH		
Mother	**Occupations indicated as important**	**Performance**	**Satisfaction**	**Functional problems**	**Performance**	**Satisfaction**
M1	Going to the beauty salon	10	10	**Working**	**1**	**1**
	Watching TV	5	10	Reading	7	10
	Going to parties	10	10	**Going to the beauty salon**	**1**	**1**
	Travelling	10	10	Travelling	8	10
	Reading	10	10			
M2	Going out to dance	10	10	Craftsmanship	10	10
	Travelling	9	10	Going out to dance	10	10
	Taking care of the house	9	8	**Taking care of the house**	**5**	**6**
	Craftsmanship	10	10	**Travelling**	**2**	**2**
M3	Taking a shower	10	10	**Working**	**3**	**3**
	Feeding	10	8	**Taking care of the house**	**5**	**5**
	Working	10	10	Feeding	7	5
	Taking care of the house	8	8	Preparing a meal	8	8
				Taking a shower	7	5
M4	Travelling	9	10	**Reading**	**1**	**1**
	Going to the beauty salon	10	10	**Travelling**	**1**	**1**
	Physical activity	9	10	**Visiting friends**	**3**	**1**
	Going shopping	10	10	**Going shopping**	**3**	**1**
				Going to the bank	**1**	**1**
M5	Working	10	7	Physical activity	10	10
	Going to parties	10	10	**Working**	**1**	**1**
	Watching TV	10	10	Video calls	9	9
	Visiting parents	10	10	Driving	7	7
	Going to the cinema	8	10	**Going shopping**	**5**	**4**
M6	Working	8	6	**Working**	**6**	**4**
	Visiting family members	8	9	Visiting family members	10	10
	Doing pilates	10	10	**Taking a shower**	**5**	**5**
	Reading	10	10	**Reading**	**3**	**6**
M7	Going to the movies	10	10	**Trabalhar**	**6**	**5**
	Taking care of the house	10	10	Going to the movies	5	8
	Working	10	10	Preparing meals	8	8
	Going to the beauty salon	10	10	Visiting family members	8	9
	Visiting family members	10	10			
M8	Working	10	10	Travelling	8	10
	Travelling	10	10	**Working**	**5**	**5**
	Going to the beauty salon	8	8	Visiting family members	8	10
	Going to parties	7	4	Dancing	2	10
	Dancing	8	8			

Table1. Continued...

	BEFORE BIRTH			AFTER BIRTH		
Mother	**Occupations indicated as important**	**Performance**	**Satisfaction**	**Functional problems**	**Performance**	**Satisfaction**
M9	Visiting friends	8	8	Physical activity	3	9
	Travelling	7	9	Gardening	2	9
	Physical activity	6	10	Visiting friends	7	7
				Working	**2**	**4**
				Viajar	3	9
M10	Personal care at home	10	10	Taking care of the house	4	10
	Reading	8	8	Working	7	10
	Taking care of the house	7	10	**Physical activity**	**1**	**5**
				Watching a movie	7	7
M11	Working	10	10	**Going to the beauty salon**	**4**	**5**
	Travelling	8	10	**Physical activity**	**4**	**5**
	Studying	7	8	**Working**	**3**	**1**
	Going to the beauty salon	10	10			
	Physical activity	10	10			

Source: Author's data.

Discussion

The results of the present study indicate that mothers of children with ASD were developing and adapted to their children with ASD. However, they also indicate that mothers evaluated the presence of functional problems for occupational performance after the birth of these children.

The results indicating that mothers are adapted to their children can be discussed in the light of the literature on the process of working through grief and re-idealizing the child imagined as perfect (Franco, 2009). As already mentioned, when a baby with a disability is born, there may be a rupture in the development of mothers, who previously imagined the baby as perfect, competent and promising (Franco, 2016a). As a result, these mothers may not relate emotionally to their children and exercise functional parenting dominated by the action of caring.

Several factors are associated with the process of adaptation and development of healthy parenting in relation to these children, including the characteristics of the children, symptomatological manifestations, the way in which the diagnosis were transmitted, the level of education and socioeconomic conditions of the fathers and/or mothers, sources information and parental resilience (Feitosa, 2020). In addition, the mother's beliefs and expectations, derived from her own life experiences, regarding the child's birth, are threatened when the child is diagnosed with a disability and/or neurodevelopmental disorder, which can undermine the relationship with them, and, subsequently, the process of acceptance (Dantas et al., 2019).

The data presented here demonstrate that the mothers overcame the initial crisis marked by feelings of depression, guilt, anger and denial. Through personal resources, such as

resilience, which is based on family cohesion and the child itself, mothers were able to use their own resources to continue their development. In addition, the support network made up of family, friends and specialized services was indispensable for the development of these mothers in the face of ASD demands (Franco, 2009; Franco & Apolónio, 2002).

The literature reports that the hope of a cure is present in mothers and fathers of children with a disability and/or neurodevelopmental disorder, with the belief that, soon after the announcement of the diagnosis, the news will come that it has a cure, that it will be fast and accessible (Franco, 2016a). Until a diagnosis is confirmed, many mothers go through several health professionals and institutions (Lopes et al., 2019). The way in which the diagnosis is presented is of great importance, as it conveys information about what it is, what the prognosis is and demands for care and treatment, which favors that mothers feel enlightened, guided and welcomed (Londero et al., 2021). The greater the knowledge about the condition of the child, the more qualified the mothers are to deal with their development and with their own emotions, being able to review beliefs and values about the child (Glat & Pletsch, 2012). Therefore, understanding the development of their own child favors mothers to adapt to the new reality and, by adapting, they are able to reorganize themselves and live with the demands (Boivin et al., 2015; Baleiro et al., 2012).

Accordingly, to the extent that mothers share their anxieties and responsibilities, they feel protected, as the information received about the diagnosis and the support directly interfere with their ability to develop means of coping with the conditions that are being exposed, and thus they are able to resume their own development and adapt to the situation (Milbrath et al., 2011).

In a literature review, Londero et al. (2021) found that for the process of parental adaptation to occur, there must be an early identification of the negative and positive factors that influence the child's re-idealization process, the existence of a family-centered approach focused on solving family problems and, ultimately, building support networks aimed specifically at families with children with disabilities and/or neurodevelopmental disorders.

Based on the theoretical model by Franco & Apolónio (2002), it is understood that the results obtained must be considered within a continuum of adaptation/development, that is, some mothers may be more adapted and developed than others and vice-versa.

In this research, although mothers were adapted to their children, the results indicated the presence of functional problems in occupational performance after the birth of their children in ASD. Taking into account the importance and centrality of occupations for human existence, when these mothers fail to perform some occupations that make sense in their lives, there is an impact on the expression of their own individuality and on the constitution of personal and social identity (Polatajko et al., 2013).

Functional problems in the productivity category, specifically in work performance due to the demands of caring for the child, were reported by most mothers. Some mothers had to stop working, others managed to develop some type of work with income at home and few are still able to work outside, but indicated levels of performance and satisfaction ≤6 and 5 (according to the valuation of the instrument used).

In a scoping review, Sim et al. (2021) found that mothers sought jobs that were flexible, allowing them to continue taking care of children with a disability and/or neurodevelopmental disorder. Research carried out by Polezi (2021) reports that work was one of the most impacted occupations, with mothers having to stop working and/or

reduce their workload. Zaidman-Zait & Curle (2016) also identified that mothers of children with ASD, to meet the needs of the children, gave up their jobs and social life, which caused ruptures in their personal and family routine.

Crisostomo et al. (2019) point out that not carrying out the work occupation brings a negative feeling of loss of identity, in addition to causing financial difficulties, as there will be only one person working in the family, which can result in instability and financial insecurity in the face of expenses brought by the disability and/or neurodevelopmental disorder.

Society praises the maternal role in caring for children, and mothers of children with ASD are required to prioritize meeting the demands of these children. As a result, these mothers often face difficulties in carrying out activities related to the daily maintenance of the house (Pinto et al., 2016). According to Aguiar (2018), the care required by children with ASD implies a decrease in the time that mothers have to take care of the house or carry out some activity on the street, and mothers try to carry out some of these activities when their children are at school.

Hoefman et al. (2014) also pointed out that such mothers find it difficult to carry out domestic activities and other activities involving the family context. In the study carried out by Estanieski & Guarany (2015), mothers reported that the biggest problems in occupational performance were in self-care and leisure activities, followed by organization and cleaning of the house, and the occupation of shopping appears with the lowest score.

In the self-care category, mothers reported problems going to the beauty salon and taking a shower. Dantas et al. (2019) indicate that comprehensive care for children with ASD generates a lack of time to perform self-care, which can lead to loss of identity, affecting self-esteem and mental health. Caring for the child with ASD leads the mother to oblivion, leaving aside her personal interests, not being able to take care of her life as a woman and failing to perform occupations such as going to the gym and the beauty salon (Pontes & Araújo, 2022). Thus, the childcare routine with ASD is an overload for mothers, which leads them to neglect their own care (Piovesan et al., 2015).

For mothers of children with ASD, performing some kind of self-care is often overlapping their own needs with those of their children (Fadda & Cury, 2019). Mothers demonstrate understanding that self-care can be performed when there is some time left, denoting that taking care of oneself is unnecessary and that there is no reason to do so (Constantinis et al., 2018).

Finally, in the leisure category, mothers indicated problems with reading, physical activity, traveling and/or visiting friends.

Leisure is considered as a primordial occupation, since it favors the person to have time for themselves while doing what they like and is pleasurable. The characteristics of ASD have repercussions on the mother's isolation, as she reduces social interaction due to stereotyped and repetitive behaviors and the child's interaction and communication difficulties (Machado et al., 2018). According to Silva et al. (2020), these mothers felt alone in caring for their children, with difficulties in carrying out leisure activities, which led to a low quality of life. Behnia et al. (2017) observed an occupational imbalance in mothers of children with ASD due to the little time spent performing occupations that are meaningful to them, such as leisure and self-care. Sen & Yurtsever (2007) found that mothers of children with ASD have their social lives altered due to caring for their children, often not managing to have time reserved for socializing with other family members.

According to Barrozo et al. (2015), the type of disability and/or disorder and the degree of dependence of the child directly influence the occupational life of mothers. With their occupational performance affected, these mothers are vulnerable and suffer physical, psychological and social impacts that can lead to loss of perspective on life, change of routine and financial difficulties (Montenegro et al. 2020). In addition, considering that occupational performance is the result of the interaction between the person and the occupation in a given environment (Polatajko et al., 2013), the occupational performance of mothers also depends on the favorable conditions or not for each environment they transit (physical, cultural, social and institutional). The mothers in this study demonstrated that functional problems in carrying out occupations after the birth of their children were accompanied not only by ASD, but also by the availability or not of a support network at the time and environment, when and where they lived.

Mothers of children with a disability and/or neurodevelopmental disorder, by linking their way of life to these children, superimpose their demands on their own demands, and their occupations as women are left in the background or even forgotten (Guerra et al., 2015). Mothers who do not have family support to share care with their children, have limited time for themselves and are unable to carry out their occupations (Conceição et al., 2020).

Mothers who rely on the help of family and friends, whether to take these children to school, to go out for a walk or even to stay with them, are able to perform some occupations. On the other hand, according to Xavier (2008), depending on the degree of dependence of their children, some mothers prefer not to receive any help from family or friends, even if they feel the need. This happens because these mothers do not feel safe in handing over their children to people they believe are not prepared to deal with this type of situation.

According to Pontes & Araújo (2022), for mothers of children with ASD, it is incongruous to engage in meaningful occupations that are not linked to child care. Faced with this sole purpose of life, existence as a woman is annulled.

When we consider that every human being is an occupational being and that the performance of each occupation is a unique experience for each person (Polatajko et al., 2013), the meaning that each occupation has for each mother is distinctive and, therefore, being able to perform the occupations they would like even after the birth of their children with ASD would provide the rescue of meanings for living and the sense of identity.

Accepting and adapting to disability is not a simple process for any mother, for this reason, interventions should not only include babies and children with a disability and/or neurodevelopmental disorder, but be centered on family development, including the demands of family as a whole (Perrin et al., 2007). For this to happen, the availability of therapeutic support with practice based on the client and occupation is necessary, so that occupational needs are met and the mother has an active role in defining therapeutic goals (Pontes & Polatajko, 2016). In the case of mothers of children with ASD who are experiencing changes and difficulties with their own occupational performance, the intervention will focus on occupations that are significant to them and the characteristics of the environment where they live.

Final Considerations

The results presented in this article indicate that mothers of children with ASD were in a favorable development to adapt to the birth of these children and to be their mother.

The indices presented by the mothers indicated that they are managing to invest emotionally in their children in terms of aesthetics, capacity and future components, having resilience and social support to deal with changes and demands arising from ASD, favoring their own development and adaptation. In the same direction, the scores indicate that depression, guilt and diagnosis were not compromising the perception of functionality and past/idealization, which would also be favoring the process of development and adaptation.

However, mothers evaluated the presence of functional problems for occupational performance after the birth of their children. Functional problems in the productivity category, specifically for work performance due to the demands of caring for the children, were mentioned by most mothers. In the self-care category, some mothers reported problems going to the beauty salon and taking a shower. In the leisure category, some mothers indicated problems with reading, physical activity, traveling and/or visiting friends.

It is concluded that the adaptation of the mothers depends on the process of re-idealizing the child imagined as perfect, involving factors such as transmission of the diagnosis, information, characteristics of the children, socioeconomic conditions, resilience, beliefs and expectations of the mothers. In addition, these mothers, even adapted to children with ASD, may have functional problems in occupational performance.

This research has some limitations, such as sample size and quantitatively homogeneous sample composition, that is, there were 11 mothers of children with ASD with a variety of ages, socioeconomic and educational conditions. Therefore, there are not equal numbers of mothers and children with the same characteristics, which does not allow statistically significant comparisons in relation to adaptation and occupational performance. In addition, the survey also did not measure the level of support required by the children, which constitutes another limitation, and the findings are limited to these characteristics of the sample.

New studies are needed to understand the adaptation process of mothers of children with ASD and to identify the difficulties faced in the occupational performance of these mothers, in order to subsidize intervention programs centered on the real needs of these mothers and with a focus on meaningful occupations for them, based on the characteristics of the environment where they live.

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