



Changes Experienced by Brazilian Parents of Children with Autism Spectrum Disorder in Their Work Routine and Social Life

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Abstract

This study aimed to explore the situations and changes Brazilian parents of children with autism spectrum disorder (ASD) experience in their work routine and social life and to understand the impact of them on their well-being. The cross-sectional study sample comprised 461 parents of children with ASD who completed an online questionnaire containing multiple-choice and open-ended questions. A descriptive analysis summarized the quantitative data, while a content analysis organized and elicited meaning from qualitative data. Most parents expressed a marked or moderate impact on social life. Around 34% had to leave their jobs to care for their child with ASD. For those who kept their jobs, 53.3% had a marked impact on their work routine, while 39.6% had a moderate impact. Our findings suggested that the severity of the child's ASD symptoms, the high costs of ASD-related therapy, and all changes Brazilian parents need to make in their work routine and social life to adapt to the new reality influenced their overall well-being. Many parents cited mental health issues such as depression and anxiety. Thus, as the challenges of raising a child with ASD are enormous, parents must have people who can support them, whether family and friends or specialized professionals. Additionally, encouraging them to join existing support groups would be very helpful in assisting them in dealing with any challenges and balancing all dimensions of well-being.

Subject Areas

Pediatrics, Psychology

Keywords

Autism, ASD, Autistic Disorder, Neurodevelopmental Disorder, Well-Being

1. Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by communication and social interaction difficulties, restricted interests, and stereotyped behavior patterns. The levels of ASD range from mild to severe symptoms. People with mild symptoms require minimal support to help them function in their daily activities, and those with severe symptoms require very substantial support to learn the skills needed for everyday living [1].

Epidemiological studies have indicated an increase in the prevalence of ASD, with a prevalence of four to five times more in boys than in girls [2]. It is unclear whether this represents increased ASD or more effective identification methods [3]. A study, which included Australia and countries from Asia, North America, Europe, and Africa, showed a prevalence of ASD ranging from 0.02% to 3.66%, with an estimated global prevalence of 0.6% (95% CI: 0.4% to 1%) [2]. Brazil has no official data on the prevalence of ASD. A single epidemiological study in a southeastern city estimated a prevalence of 27.2/10,000 [4] [5].

Compared to parents of typically developing children, parents of children with ASD often experience additional demands, requiring them to make arrangements in their own daily lives [6]. At this point, it might be seen as a problem that both parents continue to work full-time [7]. Thus, one of the parents is expected to end or disrupt his/her career to care for the child, commonly the mother. Those heads of families who need to keep working are concerned about the workload that interferes with the time to practice activities that influence the child's development [8].

As children with ASD usually have difficulties interacting with other people, some parents prefer not to attend social events that can influence their child's behavior [9]. Due to the lack of information from others about ASD, some parents also face prejudice on their social networks and often report changes in their relationships with family and friends, making social interaction increasingly restricted [10].

The changes parents need to make to their daily routine to meet the demands of their child with ASD can significantly affect their overall well-being, which directly relates to the quality of life. It is commonly viewed as having eight interdependent dimensions: physical, emotional, intellectual, spiritual, environmental, social, financial, and occupational [11]. The first four refer to the body's internal state, feelings, mind, and spirit (having meaning and purpose in life and a sense of balance and peace). The others refer to how a person interacts with the external world and how it influences him/her. Each dimension plays an important role in the overall quality of life. If one dimension is out of balance, the others are usually affected [12].

Thus, considering that the literature describes the effects of the stress of parenting a child with ASD, as well as the negative experiences parents face daily, this study aimed to explore the situations and changes experienced by Brazilian parents of children with ASD in their work routine and social life and to under-

stand the well-being dimensions (listed in **Table 1**) most affected by them.

2. Data and Methodology

2.1. Study Design and Recruitment Procedure

Quantitative and qualitative data were collected through a cross-sectional study design in which participants were recruited through social networking sites, including Facebook, Twitter, Instagram, and WhatsApp. Support groups, communities, and associations for parents of autistic people helped to disseminate the research. Participants eligible for participation were parents of children or adolescents with ASD of both sexes residing in Brazil aged 18 years or older. Participation was voluntary, and all participants who met the inclusion criteria and agreed to participate provided electronic informed consent. This study focused on a sample of 461 parents (423 mothers and 38 fathers). Parents who did not meet the inclusion criteria ($n = 27$) were excluded from the analysis, as shown in **Figure 1**. The Research Ethics Committee of the Federal University of Parana approved the study (Protocol No. 3743074).

2.2. Measures

The Portuguese questionnaire was edited in a Google Form[®], and its web link remained available from February 1st to May 30th, 2020. The electronic form included questions about the characteristics of parents (e.g., age, gender, marital status, and work status) and characteristics of children (e.g., age, gender, ASD level, and age at diagnosis (see **Table 2**). It also included multiple-choice questions related to changes or situations possibly experienced by parents in their social life (e.g., difficulties with the child's behavior when attending social events, **Table 3**) and work routine (e.g., difficulties with work schedule, **Table 4**). Response options for questions with more than two ordered categories followed the Likert scale. Two open-ended questions allowed parents to freely comment on their reactions to receiving their child's ASD diagnosis and on the changes/arrangements they had to make in their work routine and social life due to the needs of their child with ASD.

2.3. Statistical Analysis

Descriptive statistics were used to summarize the participants' characteristics and describe the quantitative data. Continuous variables were expressed as mean \pm standard deviation (SD) and interquartile range (IQR = third – first quartile). Categorical variables were expressed as frequencies and percentages. Content analysis [13] was used to organize and extract meaning from the qualitative data. First, the parents' reports were read fully to get a general idea of the data. Themes (*i.e.*, the wellness dimensions) were then structured according to a list of codes (**Table 1**). The procedure used to code the data sought to relate fragments of parents' comments to each wellness dimension that emerged during the systematic reading. Analyzes were performed using the R software [14].

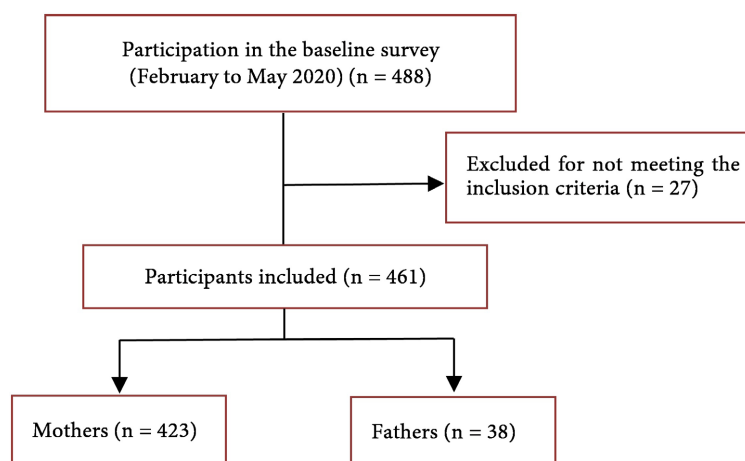


Figure 1. Flowchart of the conducted cross-sectional study.

Table 1. Themes and codes established during the systematic reading.

Themes (Wellness dimensions)	Codes (Words and phrases representing each theme)
Emotional	Stress, worry, anxiety, distress, mental or emotional exhaustion, loneliness, resilience, low self-esteem, depression, suffering, frustration, irritability, mental health problems.
Financial	Expenses, income, financial difficulties, financial dependence.
Occupational	Reduction of workload, freelancer, own business, home office, self-employed, job change, flexible workload, leave the job, public sector, private sector, job performance, lack of concentration, lack of motivation, absences from work, leave of absence, empathy and understanding from managers and co-workers, advancing in the career, professional perspective, promotion opportunities, work-life, work routine.
Physical	Physical exhaustion, tiredness, poor sleep quality, lack of disposition, stressful daily routine, food quality, health care.
Social	Social life, restricted social life, limited social life, non-existent social life, child's behavior, crowded and noisy places, family support, social events invitations, travel for pleasure, preference to stay at home, house parties, child-directed comments, relationships with friends and family, leisure activities, peoples' lack of understanding of the disorder, peoples' lack of empathy.
Intellectual	Improvement courses, time to study, update knowledge.
Environmental	Housing conditions.
Spiritual	Stop going to church, have no personal life, have no time for relaxation, have no time to themselves, live only for the child.

3. Results

3.1. Participants' Characteristics

The sample comprised 461 parents (423 mothers and 38 fathers) aged 18 to 63 years (mean = 37.6, SD = 6.9). Overall, 75.5% were married, 93.9% were primary caregivers, and 53.4% received no support from their family or close people to help them with the child's care demands (Table 2).

The age of children or adolescents (385 boys and 76 girls) ranged from 1 to 18 years, while the age at diagnosis ranged from 1 to 16 years. At the survey time, 13.2% of ASD diagnoses had been confirmed recently (less than a year). Additionally, 25.8%, 17%, 12.4%, and 8% had been confirmed 1, 2, 3, and 4 years before the survey.

Of the 461 parents, 255 (55.3%) had jobs (31 fathers aged 30 to 58 years and 224 mothers aged 21 to 61). In addition, 158 (34.3%) had to leave their job to care for their child with ASD: 154 mothers aged 18 to 63 (113 married, 19 divorced, and 22 single) and 4 fathers aged 48 to 59 (two married and two divorced).

3.2. Descriptive Analysis

A summary of the parents' responses to social life and work routine situations is presented next, according to the options provided for each question.

3.2.1. Experiences of Brazilian Parents in Social Life

Of the 461 parents who responded to the survey questions, 50.6% stated that the child's ASD condition significantly affects their social life. For 38.8%, it affects a little, while for 10.6%, it does not affect at all (Table 3). Furthermore, 73.1% (315 mothers and 22 fathers) stated they prefer staying at home, avoiding places that interfere with their child's behavior. Often, 36.7% decide not to go somewhere because of their child's behavior, while 40.1% sometimes make this decision. In contrast, 23.2% never or rarely decide not to go somewhere for this reason.

Feeling uncomfortable with comments or gestures directed at their child is also why 26.2% (117 mothers and 4 fathers) often decide not to go somewhere. Of the 424 parents (92%) who attended parties and social events, 291 reported little fun, while 59 and 74 reported lots of fun and no fun, respectively. Furthermore, 20.4% (91 mothers and 3 fathers) reported they often are not invited to parties or social events due to their child's behavior.

3.2.2. Experiences of Brazilian Parents in their Work Routine

Of the 255 parents with a job (Table 4), 53.3% (121 mothers and 15 fathers) perceived a marked impact on their work routine, while 39.6% perceived some impact. Most parents (75.3%) reported that the child's care demands make them tired, often interfering with the development of their work activities. For 36.1%, not having a person to help them care for their child often makes their daily work routine difficult. Reconciling the child's care with the work schedule was reported as challenging for 54.9% of parents (7 fathers and 133 mothers).

Table 2. Characteristics of parents participating in the study and their children with ASD.

Characteristics	Information	Total (N = 461)
Parents' age (years)	Mean ± SD	37.6 ± 6.9
	IQR	42 – 33 = 9
Primary caregivers	Yes	433 (93.9%)
Parents' gender	Female	423 (91.7%)
	Married	348 (75.5%)
Parents' marital status	Single	50 (10.8%)
	Others	63 (13.7%)
	Mild	258 (56.0%)
Child's level of autism	Moderate	185 (40.1%)
	Severe	18 (3.9%)
Age of the child with ASD (years)	Mean ± SD	6.7 ± 3.7
	IQR	9 – 4 = 5
Gender of the child with ASD	Male	385 (83.5%)
Child's age at diagnosis of ASD (years)	Mean ± SD	3.7 ± 2.6
	IQR	4 – 2 = 2
Nanny or caregiver	No	409 (88.7%)
Support from family or close people	No	246 (53.4%)
	Yes	158 (34.3%)
Need to leave the job to take care of the child	No	255 (55.3%)
	Did not have a job	48 (10.4%)
Time since diagnosis of ASD (years)	Mean ± SD	3.1 ± 2.9
	IQR	4 – 1 = 3

Note: IQR interquartile range, SD standard deviation, and ASD autism spectrum disorder.

Table 3. Parents' answers to questions related to their social life (N = 461).

Questions related to parents' social life	Answer options		
	Number (%)		
1) When you go to parties or social events with your child with ASD, how much do you interact and have fun with people? Note: parents who said they never attend parties or social events: 37 (8.0%)	Too much	A little	Nothing
	59 (12.8)	291 (63.1)	74 (16.1)
2) Do you prefer to stay at home, avoiding going to places that interfere with your child's behavior?	Yes	No	--
	337 (73.1)	124 (26.9)	
3) Have you ever decided not to go somewhere because of your child's behavior with ASD?	Never/Rarely	Sometimes	Often
	107 (23.2)	185 (40.1)	169 (36.7)

Continued

4) Have you ever decided not to go somewhere because you feel uncomfortable with comments or gestures from others directed at your child with ASD?	Never/Rarely 182 (39.5)	Sometimes 158 (34.3)	Often 121 (26.2)
5) Has anyone declined to invite you to a party or a social event due to your child's ASD behavior?	Never/Rarely 235 (51.0)	Sometimes 132 (28.6)	Often 94 (20.4)
6) In your opinion, how much does your child's ASD condition affect your social life?	Nothing 49 (10.6)	A little 179 (38.8)	Too much 233 (50.6)

Note: Questions translated into English from Portuguese form. ASD: autism spectrum disorder.

Table 4. Parents' answers to questions related to their work routine (N = 255).

Questions on parents' work routine	Answer options			
	Number (%)			
1) Do you have difficulty with your daily work routine because you do not have someone to help care for your child?	Never 18 (7.0)	Rarely 28 (11.0)	Sometimes 117 (45.9)	Often 92 (36.1)
2) Does the care required by your child with ASD make you tired, interfering with the development of your work activities?	Never 1 (0.4)	Rarely 7 (2.7)	Sometimes 55 (21.6)	Often 192 (75.3)
3) How much can you dedicate to your career since your child's ASD diagnosis?	Too much 70 (27.5)	A little 178 (69.8)	Nothing 7 (2.7)	--
4) Has your workload changed since your child's ASD diagnosis?	There was no change 123 (48.2)		Decreased 106 (41.6)	Increased 26 (10.2)
5) How often is your daily work routine affected by the care demands required by your child with ASD? (e.g., missing work, arriving late, or leaving work early).	Never 5 (2.0)	Rarely 28 (11.0)	Sometimes 109 (42.7)	Often 113 (44.3)
6) Is it easy to reconcile your daily work routine with the care demands of your child with ASD?	Easy 84 (32.9)	Neither easy nor difficult 31 (12.2)		Difficult 140 (54.9)
7) In your opinion, how much does your child's ASD condition affect your daily work routine?	Nothing 18 (7.1)	A little 101 (39.6)	Too much 136 (53.3)	--

Note: Questions translated into English from the original Portuguese form. ASD: autism spectrum disorder.

In addition, 44.3% often had their daily work routine affected (e.g., missing work, arriving late, or leaving work early). Around 52% (120 mothers and 12 fa-

thers) had to change their workload. A total of 106 parents decreased their workload to reconcile their work routine with the child's care demands.

After the child's diagnosis of ASD, 69.8% of parents could dedicate little time to their careers. For 27.5%, such dedication was not affected.

3.3. Content Analysis

3.3.1. Parents' Reactions when the Child's ASD Diagnosis Was Received

Reactions expressed by some parents when they received their child's diagnosis of ASD included: feelings of shock, doubt, insecurity, despair, and worry. One said: *"When I received the diagnosis, the world came crashing down for me."* Another two expressed, *"I received the diagnosis recently, I am very impacted and worried."* and *"It was not easy to receive the diagnosis. I had many doubts."* Others expressed relief: *"It was a relief to receive the diagnosis and thus be able to seek appropriate treatment for him."*

A new phase began after the child's diagnosis, which included access to treatment services and therapies. At this point, parents realized the difficulty of finding qualified professionals, the impact on finances, and the changes they would have to make to balance work life and family functioning.

3.3.2. The Impact on Well-Being Caused by Changes in the Work Routine

Of the 255 parents with a job, 92.9% (29 fathers and 208 mothers) perceived their work routine as markedly or moderately affected by the care demands of their child with ASD (Table 4). A systematic reading of their comments, summarized in Figure 2, indicated they correlate mainly with the following wellness dimensions: occupational, financial, emotional, physical, and intellectual.

Although no marked differences are suggested between the impacts expressed by fathers and mothers with jobs, mothers mentioned difficulties related to the realization of improvement courses, continuity of studies and career progression, and the lack of empathy and understanding of bosses and colleagues about flexible working hours (Figure 2). Most parents reported depression, stress, and physical and emotional exhaustion. Some of them, for example, said, *"I feel exhausted, without motivation for my work life."* or *"It is stressful to balance my work schedule with the child's therapy."* and *"Exhaustion and worry affect my performance at work and increase stress, depression affects my work life constantly."*

Concerning parents who reported no impact on their work routine (2 fathers and 16 mothers), they typically commented: *"I have a support network, so it had no impact on my work routine."* or *"I have no difficulties. My boss is very understanding."* or *"I am self-employed, so I can balance my work with my son's therapy."*

Most parents who had to leave their jobs to care for their child with ASD were mothers (154 mothers vs. 4 fathers). The impacts caused by this change (Figure 3) are mainly related to financial, emotional, and physical wellness, with mothers also expressing an impact on intellectual wellness. Several mothers expressed resilience.

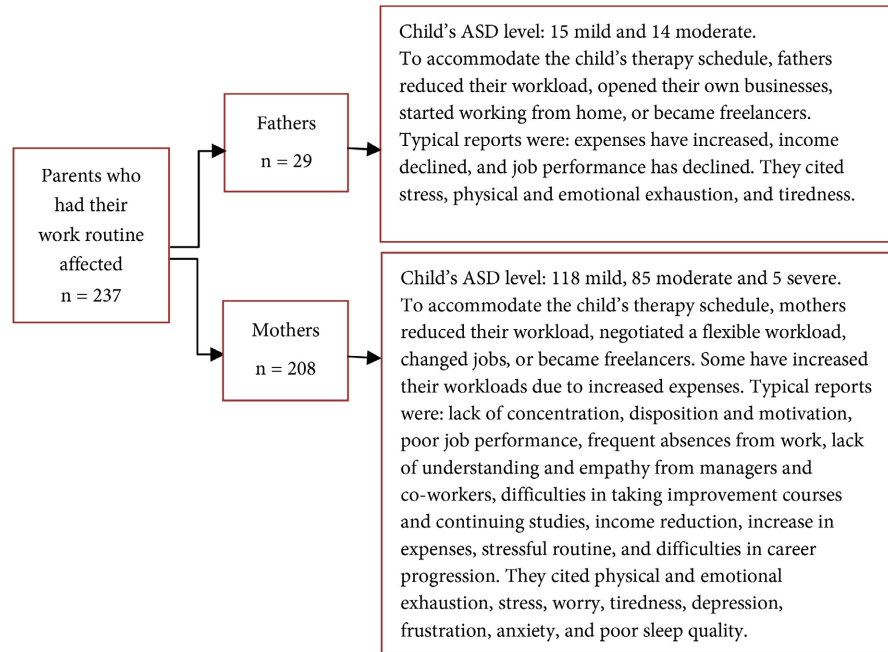


Figure 2. Changes in work routine and impacts on well-being according to parents' comments.

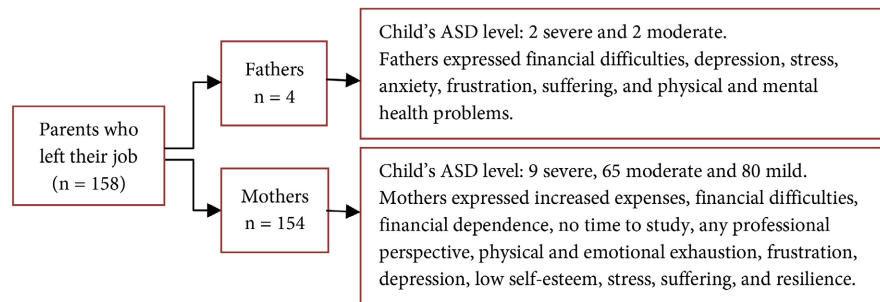


Figure 3. Summary of the impacts extracted from the comments of parents who left their jobs.

A father who had to leave his job said, *“I suffer and feel frustrated because I had to abandon my career and go through financial difficulties; I have depression, nervous crises, and anxiety.”* Two mothers expressed, *“It took me a while to accept it; my work was everything to me, but all was for the good of my son.”* and *“It was hard to leave the job and college I loved; the financial situation became difficult, but we had no other option.”*

3.3.3. The Impact on Well-Being Caused by Changes in the Social Life

Of the 461 parents in the study, 89.4% (29 fathers and 383 mothers) perceived social life as affected by the child's ASD condition (Table 3). Reasons included: restriction of places they can attend with their child and no support from family and friends (Figure 4). In addition to social wellness, the impacts caused by changes in social life correlate with emotional wellness. Mothers typically expressed

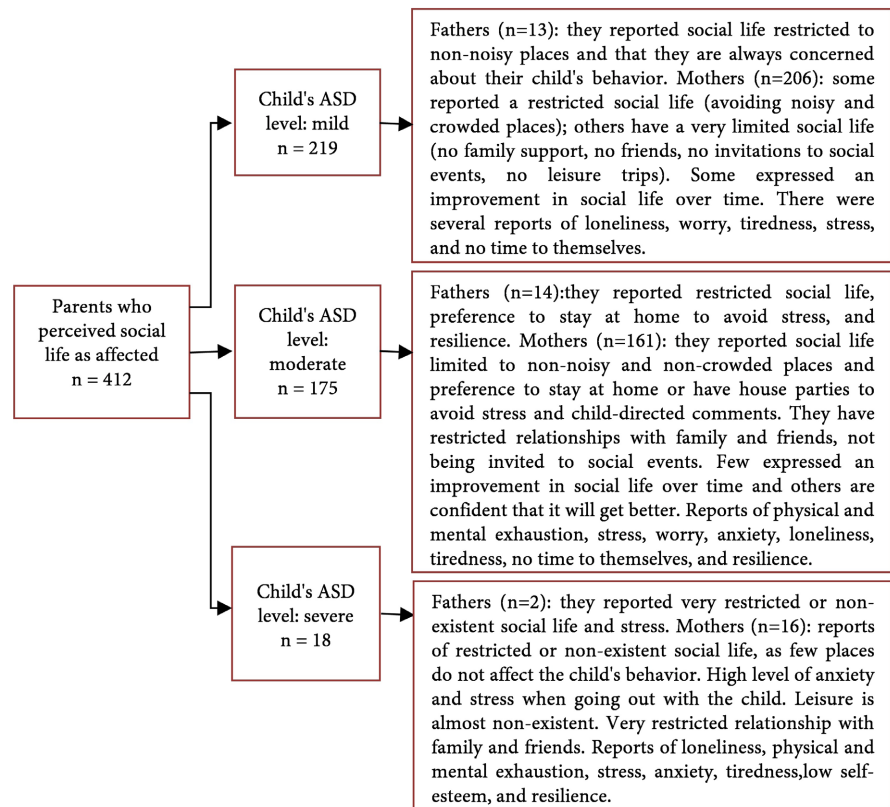


Figure 4. Summary based on fragments extracted from parents' comments on their social life.

loneliness, stress, and anxiety, as well as not having time for themselves (to meditate and do things that bring peace and relaxation), thus also affecting their spiritual wellness.

Justifications given by mothers who had their social life improved over time were the effectiveness of the child's treatment, the increase in the child's age, and the adaptation of their social life to the child's restrictions. Two of the mothers said: *"With the therapies, her behavior has greatly improved over time, now she is much calmer and socializes very well."* and *"Now that he is ten years old, many things have improved, and we can already attend restaurants, parties, and other places he feels comfortable."*

Parents who did not have their social life affected (40 mothers and 9 fathers) declared to maintain a social life since their child's diagnosis. A father said, *"Since the diagnosis, we have been advised to maintain our social life. At first, it was complicated, but over time our son adapted."* Other parents commented similarly, expressing empathy and support from friends and family. A mother said, *"My family and friends love my son; he is my best gift."* Another stated, *"Nothing has changed since my son was diagnosed; he remains very dear to my friends and family."*

Finally, for the 8% of parents who declared that they never attend parties and social events (Table 3), the reasons included: people's lack of understanding

about the disorder, often manifested by discriminatory attitudes, friends and family do not invite to events and refuse invitations, and the child's difficulty adapting to noisy and crowded places. Two of the statements given by these parents were, "*Friends stopped inviting us to parties and events, and when we invited them, they give us excuses.*" and "*Comments directed at my son by people who do not know about ASD bother me, so I stopped attending parties and events.*"

4. Discussion

Parents of children with ASD have unique stories and challenges that provide intense and varied emotions. The first challenge is that diagnosing autism can be tricky, mainly because no test can detect it. Thus, the journey of parents in the search for a diagnosis can be difficult and time-consuming [15] [16], particularly in children with milder symptoms [17]. Typically, autism is diagnosed in children aged 18 to 24 months or older, sometimes younger. Accurate early diagnosis is essential to treat the child and relieve the parents' stress [10] [18]. In this study, 75% were diagnosed up to 4 years of age, most between 2 and 3 years. There were diagnoses at older ages (e.g., at 15 and 16 years).

Although receiving a child's ASD diagnosis can be difficult and negatively affect parents, it helps them understand the disorder, search for treatment, and manage the child's behavior. At this moment, support from those who have faced the same challenges is desirable and essential, as is support from family, friends, and qualified professionals [19] [20]. In this study, support from family and friends and empathy and understanding from bosses and co-workers were emphasized as lacking by several parents, corroborating previous studies [21] [22].

Common challenges of parenting a child with ASD include finances, stress due to childcare duties, lack of time for self-care, and stigmatization. This study indicated that these challenges affect the parents' overall well-being. Swarbrick [12] states that overall well-being is significantly affected when not all wellness dimensions are balanced. Thus, depending on the intensity a wellness dimension is affected, others are usually triggered, significantly affecting the individual's overall well-being.

Of the 255 parents with jobs, 92.9% had their work routine affected by the care demands required by their child with ASD (53.3% markedly and 39.6% moderately). These parents often miss work, reduce work hours, turn down promotion opportunities, and earn less income [23]. Furthermore, the disruption of emotional wellness generally relates to difficulties maintaining a balance between work life and family functioning and the need to put the career in the background [24] [25]. Among the emotional problems reported in this study, stress and depression were the most cited, corroborating other studies that identified high levels of stress [26] and depression [27] [28] among parents of children with ASD. In addition, physical exhaustion and tiredness affected the par-

ents' physical wellness, while lack of time and motivation to update and acquire new knowledge (remaining competitive in the job market) affected their intellectual wellness.

Comments from parents with a job also highlighted the main difference between Brazil's public and private sectors concerning parents of children with ASD. For those working in the public sector, Brazilian law allows up to a 50% reduction in working hours without the need for compensation for working hours and salary discounts [29]. Parents in this situation mentioned this law as fundamental and beneficial. In the private sector, no law guarantees this benefit. In this case, an agreement between the worker and the company can be sought, with a salary reduction proportional to the working day [30]. In this study, several employers from the private sector agreed to reduce parents' workloads with a salary reduction. Other parents, however, had to change jobs as an agreement could not be reached. Thus, the need for a private sector policy to help parents of autistic children became evident.

Concerning parents who had to leave their jobs to care for their child with ASD, their occupational and financial wellness were markedly affected. Consequently, the emotional wellness of many of them was affected due to several reasons, including concern about the high costs of ASD-related therapy, lack of career prospects, financial dependence, and difficulties in continuing their studies (intellectual wellness).

Some mothers cited an increase in the husband's working hours to meet financial needs, as they had to leave work. Others, heads of the family, also mentioned the need to increase the working hours for the same reason. Emotional problems cited were stress, depression, and anxiety, with several parents mentioning frustration related to a lack of career prospects. A few parents also mentioned that financial difficulties affected food quality, health care, and housing conditions (physical and environmental wellness). Thus, it can be noted that when one wellness dimension is disrupted, it triggers others, affecting the individual's overall well-being [11]. The interdependence of the eight-wellness dimensions could be noticed from the parents' comments.

Of the 461 parents, 89.4% considered that their child's ASD condition affects their social life (50.6% markedly and 38.8% moderately). Isolation from social life usually occurs due to the people's lack of understanding of the disorder, manifested through discriminatory attitudes [31]. In this study, parents of children diagnosed with severe ASD symptoms ($n = 18$) expressed the most significant impact on social life and, consequently, a high level of stress and anxiety. A fact that explains the parents' stress concerning social life is that their child's behavior makes them uncomfortable going to specific places, and prejudice usually generates discomfort [7]. A positive association between the severity of ASD symptoms and parents' stress levels is suggested by some studies [32] [33] [34].

Some parents of children with mild or moderate ASD symptoms have reported an improvement in social life over time, which they related to the treatment effectiveness, the child's increasing age, and the adaptation of the rear-

rangement of the family system to the new context. According to Bluth *et al.* [35], maintaining a social life and relying on the support of friends and family can positively affect the parents' well-being. In this study, parents who demonstrated social wellness expressed empathy and support from friends and family. Thus, from this perspective, sensitization and awareness about autism are fundamental [22], as it is crucial to help such parents to identify people who can support them, either in their family or through a support group or specialized professionals [36].

Despite the small proportion of fathers participating in this study, our findings from the qualitative data do not suggest a clearly distinct impact on the well-being of fathers and mothers. On the other hand, they suggest that the severity of the child's ASD symptoms influences the parents' well-being with different intensities due to their children's different difficulties.

5. Study Limitations

A limitation of this study is that our findings may not be generalizable to the general population because the study included only parents who volunteered to respond to the survey and had internet access. In addition, the sample was predominantly mothers. Besides, online surveys involve potential bias since respondents may not understand the questions correctly. Despite the limitations, the present study provides insights into how the changes experienced by parents of children diagnosed with ASD, both in their work routine and social life, can affect their well-being.

6. Conclusion

This study showed that the changes parents of children with ASD need to make to reorganize their lives and adapt to the new reality are enormous. Maintaining a balance between work life and family functioning is a challenge that often leads to difficult work-related decisions. The rearrangement of social life is also necessary because the child has difficulties interacting with other people. Consequently, the overall parents' well-being is often affected, mainly if they do not have people who can support them.

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Conflicts of Interest

The authors declare no conflicts of interest.

References

- [1] American Psychiatric Association (2013) Diagnostic and Statistical Manual of

- Mental Disorders. 5th Edition, American Psychiatric Association Publishing, Washington DC. <https://doi.org/10.1176/appi.books.9780890425596>
- [2] Salari, N., Rasoulpoor, S., Rasoulpoor, S., Shohaimi, S., Jafarpour, S., Abdoli, N., Khaledi-Paveh, B and Mohammadi, M. (2022) The Global Prevalence of Autism Spectrum Disorder: A Comprehensive Systematic Review and Meta-Analysis. *Italian Journal of Pediatrics*, **48**, Article No. 112. <https://doi.org/10.1186/s13052-022-01310-w>
- [3] Lundström, S., Reichenberg, A., Anckarsäter, H., Lichtenstein, P. and Gillberg, C. (2015) Autism Phenotype versus Registered Diagnosis in Swedish Children: Prevalence Trends Over 10 Years in General Population Samples. *BMJ*, **350**, Article No. h1961. <https://doi.org/10.1136/bmj.h1961>
- [4] Paula, C.S., Ribeiro, S.H., Fombonne, E. and Mercadante, M.T. (2011) Brief Report: Prevalence of Pervasive Developmental Disorder in Brazil: A Pilot Study. *Journal of Autism and Developmental Disorders*, **41**, 1738-1742. <https://doi.org/10.1007/s10803-011-1200-6>
- [5] Brentani, H., Polanczyk, G.V. and Miguel, E.C. (2021) *Brazil and Autism*. In: Volkmar, F.R., Ed., *Encyclopedia of Autism Spectrum Disorders*, Springer, Cham, 734-744. https://doi.org/10.1007/978-3-319-91280-6_102021
- [6] Miranda, A., Mira, A.B.C., Rosello, B. and Baixauli, I. (2019) Parenting Stress in Mothers of Children with Autism without Intellectual Disability: Mediation of Behavioral Problems and Coping Strategies. *Frontiers in Psychology*, **10**, Article 464. <https://doi.org/10.3389/fpsyg.2019.00464>
- [7] Rosenzweig, J.M., Brennan, E.M., Huffstutter, K. and Bradley, J.R. (2008) Child Care and Employed Parents of Children with Emotional or Behavioral Disorders. *Journal of Emotional and Behavioral Disorders*, **16**, 78-89. <https://doi.org/10.1177/1063426607312538>
- [8] Minatel, M.M. and Matsukura, T.S. (2014) Famílias de Crianças e Adolescentes com Autismo: Cotidiano e Realidade de Cuidados em Diferentes Etapas do Desenvolvimento. *Revista de Terapia Ocupacional Universidade de São Paulo*, **25**, 126-134. <https://doi.org/10.11606/issn.2238-6149.v25i2p126-134>
- [9] McStay, R.L., Trembath, D. and Dissanayake, C. (2014) Stress and Family Quality of Life in Parents of Children with Autism Spectrum Disorder: Parent Gender and the Double ABCX Model. *Journal of Autism and Developmental Disorders*, **44**, 3101-3118. <https://doi.org/10.1007/s10803-014-2178-7>
- [10] Gomes, P.T.M., Lima, L.H.L., Bueno, M.K.G., Araújo, L.A. and Souza, N.M. (2015) Autism in Brazil: A Systematic Review of Family Challenges and Coping Strategies. *Jornal de Pediatria*, **91**, 111-121. <https://doi.org/10.1016/j.jped.2014.08.009>
- [11] Swarbrick, P. and Yudof, J. (2015) Wellness in Eight Dimensions. Collaborative Support Programs of New Jersey, Freehold.
- [12] Swarbrick, M. (2006) A Wellness Approach. *Psychiatric Rehabilitation Journal*, **29**, 311-314. <https://doi.org/10.2975/29.2006.311.314>
- [13] Gibbs, G.R. (2007) Analyzing Qualitative Data. SAGE, London. <https://doi.org/10.4135/9781849208574>
- [14] R Core Team (2020) R: A Language and Environment for Statistical Computing. R Foundation for Statistical Computing, Vienna. <http://www.R-project.org/>
- [15] Xavier, J.S., Marchiori, T. and Schwartzman, J.S. (2019) Parents Seeking a Diagnosis of Autism Spectrum Disorder for their Child. *Psicologia: Teoria e Prática*, **21**, 170-185. <https://doi.org/10.5935/1980-6906/psicologia.v21n1p170-185>

- [16] Smith-Young, J., Chafe, R. and Audas, R. (2020) "Managing the Wait": Parents' Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed with Autism Spectrum Disorder. *Health Services Insights*, **13**. <https://doi.org/10.1177/1178632920902141>
- [17] Larsen, K. (2015) The Early Diagnosis of Preschool Children with Autism Spectrum Disorder in Norway: A Study of Diagnostic Age and Its Associated Factors. *Scandinavian Journal of Child and Adolescent Psychiatry and Psychology*, **3**, 136-145. <https://doi.org/10.21307/sjcapp-2015-014>
- [18] Hus, Y. and Segal, O. (2021) Challenges Surrounding the Diagnosis of Autism in Children. *Neuropsychiatric Disease and Treatment*, **17**, 3509-3529. <https://doi.org/10.2147/NDT.S282569>
- [19] Hartley, S.L. and Schultz, H.M. (2015) Support Needs of Fathers and Mothers of Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, **45**, 1636-1648. <https://doi.org/10.1007/s10803-014-2318-0>
- [20] Aguiar, M.C.M. and Pondé, M.P. (2020) Autism: Impact of the Diagnosis in the Parents. *Jornal Brasileiro de Psiquiatria*, **69**, 149-155. <https://doi.org/10.1590/0047-2085000000276>
- [21] Ludlow, A., Skelly, C. and Rohleder P. (2012) Challenges Faced by Parents of Children Diagnosed with Autism Spectrum Disorder. *Journal of Health Psychology*, **17**, 702-711. <https://doi.org/10.1177/1359105311422955>
- [22] Bonfim, T.A., Giacon-Arruda, B.C.C., Hermes-Uliana, C., Galera, S.A.F. and Marcheti, M.A. (2020) Family Experiences in Discovering Autism Spectrum Disorder: Implications for Family Nursing. *Revista Brasileira de Enfermagem*, **73**, e20190489. <https://doi.org/10.1590/0034-7167-2019-0489>
- [23] Baker, D.L. and Drapela, L.A. (2010) Mostly the Mother: Concentration of Adverse Employment Effects on Mothers of Children with Autism. *The Social Science Journal*, **47**, 578-592. <https://doi.org/10.1016/j.soscij.2010.01.013>
- [24] Veld, D.M.J., Howlin, P., Hoddenbach, E., Mulder F., Wolf, I., Koot H.M., Lindauer R. and Begeer, S. (2017) Moderating Effects of Parental Characteristics on the Effectiveness of a Theory of Mind Training for Children with Autism: A Randomized Controlled Trial. *Journal of Autism and Developmental Disorders*, **47**, 1987-1997. <https://doi.org/10.1007/s10803-017-3117-1>
- [25] Ozdemir, N.K. and Koç, M. (2022) Career Adaptability of Parents of Children with Autism Spectrum Disorder. *Current Psychology*. <https://doi.org/10.1007/s12144-021-02649-9>
- [26] Lyons, A.M., Leon, S.C., Phelps, C.E.R. and Dunleavy, A.M. (2010) The Impact of Child Symptom Severity on Stress among Parents of Children with ASD: The Moderating Role of Coping Styles. *Journal of Child and Family Studies*, **19**, 516-524. <https://doi.org/10.1007/s10826-009-9323-5>
- [27] Singer, G.H.S. (2006) Meta-Analysis of Comparative Studies of Depression in Mothers of Children with and without Developmental Disabilities. *American Journal on Mental Retardation*, **111**, 155-169. [https://doi.org/10.1352/0895-8017\(2006\)111\[155:MOCSOD\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2006)111[155:MOCSOD]2.0.CO;2)
- [28] Olsson, M.B. and Hwang, C.P. (2007) Depression in Mothers and Fathers of Children with Intellectual Disability. *Journal of Intellectual Disability Research*, **45**, 535-543. <https://doi.org/10.1046/j.1365-2788.2001.00372.x>
- [29] Lei nº 13.370 de 12 de dezembro de 2016. Estende o direito a horário especial ao servidor público federal que tenha cônjuge, filho ou dependente com deficiência de

- qualquer natureza e revoga a exigência de compensação de horário. Diário Oficial da União; 13 dez. 2016.
http://www.planalto.gov.br/ccivil_03/_ato2015-2018/2016/lei/l13370.htm
- [30] Moura, A. (2021) Redução na carga horária de trabalho para pais de autistas, é possível? Direito das pessoas com autismo. <https://www.adriellymoura.com/>
- [31] Broady, T.R., Stoyles, G.J. and Morse, C.M. (2017) Understanding Carers' Lived Experience of Stigma: The Voice of Families with a Child on the Autism Spectrum. *Health and Social Care in the Community*, **25**, 224-233.
<https://doi.org/10.1111/hsc.12297>
- [32] Bitsika, V. and Sharpley, C.F. (2017) The Association between Autism Spectrum Disorder Symptoms in High-Functioning Male Adolescents and their Mothers' Anxiety and Depression. *Journal of Developmental and Physical Disabilities*, **29**, 461-473. <https://doi.org/10.1007/s10882-017-9537-1>
- [33] Tomeny, T.S. (2017) Parenting Stress as an Indirect Pathway to Mental Health Concerns among Mothers of Children with Autism Spectrum Disorder. *Autism*, **21**, 907-911. <https://doi.org/10.1177/1362361316655322>
- [34] Al-Oran, H.M. and AL-Sagarat, A.Y. (2016) Parenting Stress of Children with Autistic Disorder. *Open Access Library Journal*, **3**, e2791.
<https://doi.org/10.4236/oalib.1102791>
- [35] Bluth, K., Roberson, N.E.P., Billen, M.R. and Sams, M.J. (2013) A Stress Model for Couples Parenting Children with Autism Spectrum Disorders and the Introduction of a Mindfulness Intervention. *Journal of Family Theory & Review*, **5**, 194-213.
<https://doi.org/10.1111/jftr.12015>
- [36] Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H. and Baghdadli, A. (2019) Coping Strategies of Parents of Children with Autism Spectrum Disorder: a Systematic Review. *European Child & Adolescent Psychiatry*, **28**, 747-758. <https://doi.org/10.1007/s00787-018-1183-3>