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Burden of mothers of children diagnosed with autism spectrum disorder: mixed method study

Sobrecarga de mães com filhos diagnosticados com transtorno do espectro autista: estudo de método misto

Sobrecarga de madres con hijos diagnosticados con trastorno del espectro autista: estudio del método mixto

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ABSTRACT

Objective: To analyze the maternal burden related to the care of children diagnosed with autism spectrum disorder.
Method: Study with a mixed-method sequential explanatory design held at the Association of Friends and Families of Special Children and in a WhatsApp® Messenger group, with 51 (quantitative phase) and six (qualitative phase) mothers, between January and October 2019. For data collection, in the quantitative phase, a sociodemographic, economic and child care characterization form and a Zarit Burden Interview instrument were used. Semi-structured interview was used in the qualitative phase. Descriptive bivariate and multivariate analysis (quantitative) and Bardin analysis (qualitative) were performed.
Results: A total of 64.7% mothers felt burdened, with mild to moderate burden (52.9%). Four analytical categories on elements that trigger maternal burden emerged.
Conclusions: There is an urgent need to identify maternal burden related to the care of children with autism spectrum disorder, during assistance in Primary Health Care.
Keywords: Autistic disorder. Mother-child relations. Caregivers.

RESUMO

Objetivo: Analisar a sobrecarga materna relacionada aos cuidados com filhos diagnosticados com transtorno do espectro autista.
Método: Estudo de método misto, sequencial explanatório, realizado na Associação de Pais e Amigos dos Excepcionais e em grupo de *WhatsApp® Messenger*, com 51 mães (fase quantitativa) e seis (fase qualitativa), entre janeiro e outubro de 2019. Para coleta de dados, utilizaram-se, na fase quantitativa, de formulário de caracterização sociodemográfica, econômica e do cuidados prestados aos filhos; e do instrumento *Zarit Burden Interview*. Na fase qualitativa, empregou-se uma entrevista semiestruturada. Realizaram-se análise descritiva, bivariada e multivariada (dados quantitativos) e análise de conteúdo de Bardin (dados qualitativos).
Resultados:64,7% das mães se sentiam sobrecarregadas, com sobrecarga leve a moderada (52,9%). Emergiram quatro categorias analíticas sobre elementos desencadeadores da sobrecarga materna.
Conclusões: Urge identificação da sobrecarga materna relacionada aos cuidados de crianças com transtorno do espectro autista, durante a assistência na Atenção Primária à Saúde.
Palavras-chave: Transtorno autístico. Relações mãe-filho. Cuidadores.

RESUMEN

Objetivo: Analizar la carga materna relacionada a la atención de niños con trastorno del espectro autista.
Método: Estudio de método mixto, secuencial explicativo, en la Asociación de Padres y Amigos de los Excepcionales y en grupo de *WhatsApp® Messenger*, con 51 (fase cuantitativa) y seis (fase cualitativa) madres, entre enero y octubre/2019. Para recolección de datos, se utilizó de formulario de caracterización sociodemográfica, económica y la atención brindada al niño; y del instrumento *Zarit Burden Interview* (fase cuantitativa); guion para entrevistas semiestructuradas (fase cualitativa). Se realizó análisis descriptivo bivariado y multivariado (cuantitativos) y análisis de contenido (cualitativos).
Resultados: Total de 64,7% de las madres se sintieron abrumadas, con sobrecarga leve a moderada (52,9%). Surgieron cuatro categorías analíticas sobre elementos que desencadenan la sobrecarga materna.
Conclusiones: Es importante identificar la carga materna relacionada a la atención de niños con trastorno del espectro autista, en la Atención Primaria de Salud.
Palabras clave: Trastorno autístico. Relaciones madre-hijo. Cuidadores.

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INTRODUCTION

Autism Spectrum Disorder (ASD) is a heterogeneous group of neurodevelopmental phenotypes (1), whose diagnosis is largely clinically subjective, although the availability of different scales has contributed to refine the assessment process and help clarify the diagnosis (2). Essential deficits are identified in two domains: communication/social interaction and repetitive and restrictive behavior patterns (3).

From an epidemiological point of view, according to data from the World Health Organization (WHO), around the world, one in every 160 children has ASD. The prevalence of ASD in many low- and middle-income countries is still unknown (4). As for gender, the first systematically calculated estimate of the relative proportion of boys and girls with ASD, through a meta-analysis of prevalence studies conducted since the introduction of the Diagnostic and Statistical Manual of Mental Disorders in 1994 (DSM-IV), and of the International Classification of Diseases, Tenth Revision, established a male-to-female ratio of 3:1(5).

Behavioral complications associated with the diagnosis of ASD require support in the behavioral, educational, family, health, leisure and other areas (3). Although these complications interfere in the lives of all family members, the mothers of children with ASD usually seek assistance, devote themselves to caring for their children and make daily adjustments. Hence, the social, affective and professional lives of these women are impacted and they are more likely to suffer physical and emotional strain (6). Thus, it can be said that the condition of being a mother of a child diagnosed with ASD triggers physical and mental demands that deserve attention from health professionals (7).

In view of the above considerations, which justify the development of studies aimed to analyze the experiences of mothers whose children were diagnosed with ASD, with an emphasis on factors that play a relevant role in the burden of care (8), and because the literature on the difficulties faced by mothers of children with autism is limited and imprecise (9), the following guiding questions were established in the present study: Are mothers of children diagnosed with ASD burdened? What aspects of the maternal experience contribute to this burden? Therefore, the present study aimed to analyze the maternal burden related to caring for children diagnosed with autism spectrum disorder.

METHOD

Study with a mixed-method sequential explanatory design (QUAN-qual) that consists in two different phases: quantitative phase, followed by a qualitative phase. Qualitative results were mobilized for a more in-depth analysis of the quantitative results (10). Cross-sectional, descriptive and analytical design was used in the quantitative phase. It included only participants with some level of burden in the first phase.

The study was conducted in the Association of Friends and Families of Special Children (APAE) in an inland municipality of the State of Piauí, Brazil, and in a WhatsApp® Messenger group titled Friends and Parents of Autists (APA). This environment is a support group, created in 2017, due to the need for parents, family members and professionals who care for children diagnosed with ASD to discuss and exchange views about their experiences, from the diagnosis process to the monitoring of the children. The group has currently 124 participants. These are fathers and mothers, nurses, psychologists, educational psychologists, teachers and leaders in the area. After being personally invited to participate in the study via WhatsApp® Messenger, the participants selected the sites for data collection.

Data were collected between January and September 2019. A population of 80 mothers of children diagnosed with ASD was obtained, as follows: Thirty mothers from the APAE and 50 from the APA. The following inclusion criteria were established for the composition of the sample: mothers (aged 18 years and over) of children under 12 years old (according to the definition of childhood of the Child and Adolescent Statute) diagnosed with ASD by pediatric neurologists. Mothers of children with other diagnoses associated with ASD that could increase maternal burden were excluded. It was a population survey: the mothers who agreed to participate in the study and met the above criteria were included. Thus, 51 mothers of children diagnosed with ASD participated in the quantitative phase of the study and 6 mothers participated in the qualitative phase.

In the first phase, semi-structured interviews were carried out with 51 mothers, using a form that included socioeconomic, demographic and questions related to the characterization of the care provided to their children. This instrument was subjected to a pre-test, applied and used in a sample identical to the sample provided for this study.

At the same meeting, the researcher applied the Brazilian version, validated from the Caregiver Burden Inventory (Zarit Burden Interview – ZBI). Developed by Zarit et al. in 1985, the tool aims to measure aspects related to caregivers: health quality, psychological well-being, emotional and financial stability, social and individual life, to assess the burden imposed by the care for individuals with mental and physical disabilities (11). The Brazilian version includes 22 questions, scored 0-4, according to the presence and intensity of responses for each item. Caregiver burden is obtained by the sum of the scores of the total questions (12).

The interviews carried out individually, in a reserved room and at a previously agreed date and time lasted in average 20 to 40 minutes and were audio-recorded. This phase was carried out in an APAE room, while the mothers awaited their children's therapy sessions, or in the participants' homes. The mothers were allowed to set the dates, times and places best suited to them.

In the second phase, participants who had some level of burden, measured in the previous phase, were included. A total of 39 names were listed, with the inclusion of six participants. The sampling criterion was not used in this phase, as data saturation occurred very early in the field phase.

Semi-structured interviews were carried out based on the following guiding question: how is your day-to-day care of your child with ASD? From this inquiry, other empathic questions were raised, based on statements that needed better elucidation, always paying attention not to induce the participant's speech.

Data analysis in mixed-method research occurs both in the quantitative approach (descriptive, bivariate and multivariate analysis) and in the qualitative (description and thematic text analysis). For data analysis, the Statistical Package for Social Sciences for Windows (SPSS) (2009), version 19.0 was used to generate the results. Descriptive statistics, means and standard deviation of the variables were performed. The means of categorical variables were statistically analyzed by Student's t test, and one-way ANOVA was used to compare more than two groups. Variables with p-value <0.20 in the bivariate analysis were included in the multivariate model, with the application of Linear Regression. For all statistical analyses, a confidence level of 95% (p<0.05) was considered.

Analysis of qualitative data was done in three phases: pre-analysis, through floating reading of the material; exploration of the material in order to define the categories; and condensing the information for reflective and critical interpretation. Pre- analysis occurred in five phases: floating reading; organization of the material, in order to meet the criteria of completeness, representativeness, homogeneity and relevance; formulation of hypotheses and objectives or flexible initial assumptions that allowed the emergence of hypotheses based on exploratory procedures; reference of indices and elaboration of indicators adopted in the analysis; and material preparation [13].

The material exploration phase, also called analysis, involved the systematic application of the decisions taken. It consisted of coding, decomposition or enumeration operations, based on previously formulated rules. Finally, data were divided into categories through the treatment of the results obtained and interpretations, and raw data were transformed into new and significant knowledge [13].

The study complied with the Resolution of the National Health Council no 466/12 and 510/2016, of the Research Ethics Committee of Universidade Federal do Piauí, and was approved according to Protocol no 3,055,460. Also, in order to preserve participants' anonymity, their names were replaced by a code, i.e. letter M followed by the interview order number (M1, M2,M3…M51). All participants signed the Informed Consent Form.

RESULTS

Quantitative phase

Analysis of the level of maternal burden related to the care of children diagnosed with ASD, through the application of the Zarit Scale, showed that of the 51 mothers, 39 (76.5%) had some level of burden, with a prevalence of mild to moderate (52.9%) (Table 1).

The participants were adult women, with a mean age of 36 years ± 7 years, more prevalent in the age group between 36 and 56 years (56.9%), who considered themselves brown (58.8%), lived in the city where the study was conducted (68.6%), were Catholic (62.2%), married (68.8%), had completed higher education (52.9%) and reported having only one child (51.0%). Most of them worked at home (52.9%), with an average burden higher than that of the mothers who had an employment relationship (average = 33.2 points). Most mothers came from families with purchasing power of one minimum wage (54.9%) (Table 2).

Analysis of the burden of the sample of mothers in relation to socioeconomic and demographic characteristics, as shown

Table 1 – Classification of levels of burden of mothers of children diagnosed with Autism Spectrum Disorder, according to the Zarit Scale. Piauí, PI, Brazil, 2021

Scores	Burden level	N	%
0 – 20	Absence or little burden	12	23.5
21 – 40	Light to moderate burden	27	52.9
41 – 60	Moderate to severe burden	9	17.7
61 – 88	Severe burden	3	5.9
Total		51	100

Source: Research data, 2019

in Table 2, showed that burden was associated with number of children (p-value = 0.044), and burden was higher among mothers of only one child (mean = 35.9 points) compared to those with two children (mean = 26.0 points) and three or more children (mean = 26.1 points).

Regarding the characterization of children with ASD and the maternal care provided, it was found that the children were aged between two and 11 years, most of them 6- 11 years (54.9%), with a prevalence of males (86, 3%). As for the age at which they were diagnosed with ASD, there was a prevalence of children aged 1-3 years (72.5%), and most required support level 1 (66.7%). As for the main symptoms, speech and communication problems were found in 62.7% of the children (Table 3).

According to Table 3, 94.1% were monitored by a psychologist, 82.4% by a speech therapist and 54.9% by a psychopedagogist, at least once or twice a week (80.4%). Also regarding health care, 51.0% of children had access to health schemes. Many mothers said t most of their time was devoted to their children diagnosed with ASD, with a prevalence of eight or more hours a day (68.6%). Also, 70.6% took care of the children alone. As for leisure activities, 92.2% of the mothers reported the children performed outdoor activities.

Analysis of the burden faced by the mothers of the sample related to the characteristics of the children and the care provided, as shown in Table 3, revealed that the burden was associated with the child's age when at the time of diagnosis (p-value = 0.023),. The burden was greater among mothers whose children were diagnosed with ASD early, between 1 and 3 years (mean = 33.8 points), compared to the age group of 4-10 years (mean = 23.7 points).

Also according to Table 3, there was an association between the burden of participants related to the symptoms of the children (p-value = 0.014), with greater burden among mothers of children who had all symptoms of the ASD symptom triad (social interaction, repetitive and stereotyped communication and behaviors) burden and maternal self-perception of feeling burdened (p-value 0.000), with a higher mean among mothers who reported being burdened (mean = 36.1 points).

The results of the Multivariate Linear Regression Analysis to assess factors independently associated with maternal burden are shown in Table 4. The variables related to burden were origin (p=0.028), number of children (p=0.013), age at diagnosis (p=0.046), level of autism based on the support required (p=0.031), child with all the symptoms of ASD triad (p=0.007) and mother who feels overburdened (p=0.000).

Table 2 – Distribution of socioeconomic and demographic characteristics of mothers, according to means of burden. Piauí, PI, Brazil, 2021

Variables	N (%)	Zarit-mean (SD)	p-value
Mother's age (years)			0.951*
23 – 35	22 (43.1)	30.9 (11.1)	
36 – 56	29 (56.9)	31.2 (16.5)	
Ethnicity			0.296**
White	7 (13.7)	38.1 (20.6)	
Brown	30 (58.8)	28.7 (11.3)	
Black	13 (26.5)	33.6 (16.3)	
Indigenous	1 (2.0)	18.0 (-)	
Origin			0.056*
Municipality of the study	35 (68.6)	28.5 (13.4)	
Surrounding municipalities	16 (31.4)	36.7 (15.0)	

Table 2 – Cont.

Variables	N (%)	Zarit-mean (SD)	p-value
Religion			0.393**
Catholic	32 (62.2)	29.3 (13.6)	
Spiritualist	5 (9.8)	27.2 (10.5)	
Evangelical	11 (21.6)	35.8 (17.6)	
Other	3 (5.9)	39.3 (11.5)	
Marital status			0.231**
Single	11 (21.6)	36.9 (12.8)	
Married	35 (68.8)	29.9 (14.9)	
Separated/Divorced	2 (3.9)	36.5 (0.7)	
Widowed	3 (5.9)	19.3 (7.3)	
Education			0.495**
Elementary School	7 (13.7)	37.1 (19.9)	
High School	17 (33.3)	30.1 (13.3)	
Higher Education	27 (52.9)	30.1 (13.5)	
Number of children			**0.044****
One	26 (51.0)	35.9 (16.2)	
Two	19 (37.3)	26.0 (9.7)	
Three or more	6 (11.8)	26.1 (12.2)	
Work outside the home			0.249*
No	27 (52.9)	33.2 (15.4)	
Yes	24 (47.1)	28.6 (12.7)	
Family income (minimum wage)			0.170**
1	28 (54.9)	34.3 (15.0)	
2	6 (11.8)	24.1 (9.3)	
> 3	17 (33.3)	28,1 (13.7)	

Source: Research data, 2019
* = Student T test; ** = One-way Anova

Table 3 – Distribution of the characteristics of the children and the care provided, according to the means of burden. Piauí, PI, Brazil, 2021

Variables	N (%)	Zarit-Mean (SD)	p-value
Age (years)			0.888*
2 – 5	23 (45.1)	30.7 (12.7)	
6 – 11	28 (54.9)	31.3 (15.7)	
Age when diagnosed (years)			**0.023***
1 – 3	37 (72.5)	33.8 (15.6)	
4 – 10	14 (27,5)	23.7 (5.6)	
Gender			0.562*
Female	07 (13.7)	28.1 (11.9)	
Male	44 (86.3)	31.5 (14.7)	
Autism level based on required support			0.176**
Level 1 – requires support	34 (66.7)	28.5 (12.0)	
Level 2 – requires substantial support	14 (27.5)	35.1 (17.2)	
Level 3 – Maximum support	03 (5.9)	40.6 (20.8)	
Main symptoms[1]			
Speech and communication problems	32 (62.7)	29.5 (13.5)	0.326*
Stereotyped body movements	18 (35.3)	32.1 (14.5)	0.698*
Poor social interaction	12 (23.5)	30.4 (14.2)	0.853*
all the symptoms of the ASD triad	23 (45.1)	36.4 (14.4)	**0.014***
Treatment performed[1]			
Occupational Therapist	24 (45.1)	29.7 (15.3)	0.545*
Speech Therapy	42 (82.4)	31.5 (14.4)	0.651*
Psychology	48 (94.1)	31.7 (14.5)	0.227*
Psychopedagogy	28 (54.9)	33.8 (15.6)	0.126*
Follow-up frequency (weekly)			0.368*
1 – 2	41 (80.4)	30.1 (13.5)	
≥ 3	10 (19.6)	34.8 (17.3)	

Table 3 – Cont.

Variables	N (%)	Zarit-Mean (SD)	p-value
Health scheme			0.505*
No	25 (49.0)	32.4 (13.3)	
Yes	26 (51.0)	29.7 (15.3)	
Hourly load dedicated to care (hours per day)			0.273*
< 8	16 (31.4)	27.8 (10.9)	
≥ 8	35 (68.6)	32.6 (15.5)	
Is the only caregiver			0.247*
No	15 (29.4)	27.4 (13.1)	
Yes	36 (70.6)	32.6 (14.6)	
Leisure time away from home			0.152*
No	04 (7.8)	41.0 (18.4)	
Yes	47 (92.2)	30.2 (13.8)	
Feels burdened			**0.000***
No	18 (35.3)	21.8 (7.9)	
Yes	33 (64.7)	36.1 (14.6)	

Source: Research data, 2019

[1]This variable could be tested more than once.

* = Student t-test; ** = One-way ANOVA

Mothers who lived in surrounding municipalities had, on average, scores 5.6 points higher than those of mothers who lived in the municipality where the study was conducted, and mothers of two or more children had an average reduction of 4.32 points in the total burden score compared to mothers who had only one child. Moreover, participants whose children were diagnosed later (when they were aged 4-10 years) had a mean reduction of 0.77 points in the burden score compared to mothers whose children were diagnosed with ASD before the age of three. There was also an average increase of 4.16 points in the burden score among mothers of children with support level 3 (in extreme support at all times), compared to level 2 and level 1; and an average increase of 4.57 points among participants whose children had all the symptoms of the ASD triad compared to those who had two or only one of the symptoms. Finally, mothers with self-perceived burden had, on average, a score of 11.45 points higher than mothers who did not have such self-perception.

The model shown in Table 4 explains 35.4% of the variability of the total maternal burden score. The variables that most explained such variability were, respectively, mother who feels burdened, origin, level of autism based on the support demanded, and child with all symptoms of the ASD triad.

Qualitative phase

After the quantitative phase, aspects related to the highest levels of burden among the participants were investigated, and the following analytical categories were generated: Burden related to the fact of being the only caregiver; Burden

Table 4 – Multivariate Linear Regression Analysis to assess factors independently related to maternal burden. Piauí, PI, Brazil, 2021

Variables	b (CI 95%)	Beta	p-value
Origin	5.61 (-2.33 to 13.5)	0.184	**0.028***
Number of children	-4.32 (-9.72 to 1.06)	-0.210	**0.013***
Family income	-1.43 (-5.44 to 2.57)	-0.092	0.067
Age at diagnosis	-0.77(-3.11 to 1.57)	-0.082	**0.046***
Level of autism based on the support demanded	4.16 (-1.58 to 9.90)	0.175	**0.031***
Has all symptoms of the ASD triad	4.57 (-2.95 to 12.10)	0.160	**0.007***
Out-of-home leisure activities	-4.41 (-16.9 to 8.14)	-0.084	0.076
Feels overburdened	11.45 (4.10 to 18.80)	0.386	**<0.001***

Source: Research data, 2019; *Significant from multivariate linear regression.

related to the paternal role; Burden related to financial support; and Burden related to the child's behavior.

In the category Burden related to the fact of being the only caregiver, the participants reported their daily experiences in caring for children diagnosed with ASD and emphasized that they were the only persons involved in caregiving. These reports supported the quantitative evidence that determined a high percentage of mothers who claimed to be the only providers of care for their children.

The mothers exposed stressful routines that caused fatigue, and sometimes exhaustion. The days perceived as the most exhausting led to significant pain, represented in the speeches by crying, stress, mental and sleep disorders, which culminated in the use of medications. According to the reports, mothers were the main caregivers of their children.

> *I wake up every day and do pretty much the same thing with him, but it's not easy (laughs)* [...].*Not always, but some days I feel really tired. There are days when I cry* [...], *a child with autism demands a lot* [...] *And, then, the burden is quite heavy, I cry today, but feel better in no time at all and then I feel bad again tomorrow* [...] (M 08).
>
> *I feel overburdened because I'm the only person who takes care of him, sometimes my oldest son helps me, but I don't have the support of a mother, a sister* [...] *it's my responsibility* (M14).
>
> [...] *I'm responsible for everything in the house, so sometimes I can feel very stressed, there are times that I think I'll go crazy if I don't take this antidepressant,* [...] *I feel very overburdened… So, I saw a psychiatrist, a psychologist, after my son was diagnosed with ASD* [...] (M 31).

In the category Burden related to the paternal role, the participants highlighted the importance of father involvement in the care of children diagnosed with ASD. Some mothers reported that the fathers of the children did not accept the diagnosis, which sometimes culminated in abandonment and emotional stress caused by the fact that the fathers are not present in their children's daily lives, or do not participate in care activities, contributing to trigger maternal burden.

> [...] *I separated from my daughter's father when she was only one month old.* [...] *it is a very complicated relationship, in which he has no participation in her life, after finding out about the diagnosis, we tried to talk to him and his family, unsuccessfully, he does not accept the diagnosis* (M7).
>
> *I chose to separate from his father in the situation we were in, when I learned that my son had autism, and he, as a father, did not accept it and still does not accept it* [...] *his father never showed interest in the situation, also because he lives very far away and thinks this is something temporary* (M8).

In the category Burden related to financial support, the economic aspect is one of the most significant problems related to the care of children with ASD, mainly because of the need for specialized medical assistance. Thus, the benefit provided by the government – a right established by law, is significant. All the same, it was reported that the assistance is not sufficient to ensure satisfactory conditions of transportation, especially when assistance is available in other municipalities. In these cases, mothers and children face a stressful journey. Some mothers performed informal work to supplement the family income, which culminated in an increase in the burden, as these women had to deal with a triple work shift.

> *It's difficult, because all appointments are private, and have to be paid for* (M5).
>
> *It's not the exact number of appointments he should have, but I don't give them up, because I save money and, I do odd jobs, any work I can do at home, I do. As for the therapies* [...] *I can't afford it, because I pay for transportation to come here twice a week* (M8).
>
> *I really need government aid, because there are many sessions, and I don't work* [...] *I often miss sessions due to lack of money, from Nazaré I can come here in the City Hall car, but from the countryside to Nazaré I have to pay because I have to come by motorbike, it's very difficult. Traveling along a dusty road, under a hot sun, very stressful* (M18).

In the category Burden related to the behavior of the children, maternal reports showed that the changes in the behavior of children diagnosed with ASD affected the dynamics and family life. It was also found that mothers had difficulty in taking their children to environments outside the home setting, usually because of the inadequate expected normotypic behavior, as the children could display agitation and anger. While reporting that this leisure routine is necessary for the progress of their children, the women were often not able to ensure it, as this would increase their burden. They also stressed that they were uncomfortable with attitudes of non-acceptance, judgment or punishment.

> *His autism is of moderate degree with hyperactivity, so it's even more complicated* [...]. *Sometimes I lose patience, I lose control* [...] *some people say: 'Woman, but how do you manage to get out? I don't need them to feel sorry for me... some people say: 'Oh my God, and what will your life be like?'* (M8).
>
> *When I found out he had autism, my social life changed a lot. I take fewer walks, because he has crises and people don't understand and frown, it's horrible. Sometimes I want to go out with him, but I don't feel well* [...] *I can't stand they way people look at us.* (M14).
>
> [...] *sometimes, I even plan to go out, because I know it is very important for his development, and I end up giving up because when I get to the places I want to go, I have no peace, I get stressed* (M18).

DISCUSSION

The results obtained for prevalence of maternal burden related to the care of children with ASD are consistent with those from other studies [9,14]. The identification of maternal burden, ranging from mild to severe (76.6%) was similar to that of maternal self-perception of burden (64.7%), with a significant association between these two variables. Qualitative data emerging from maternal reports also contributed to confirm the quantitative results, as mothers repeatedly reported in the interviews a feeling of burden related to the care provided to their children. Therefore, the findings were consistent with those of a study carried out in Salvador, Bahia, aimed to analyze the subjective aspects associated with parents' perceptions about the changes that occurred in their lives after the birth of their children with ASD, in which the participants reported emotional and physical burden arising from caring for autistic children[7].

Consistent perceptions of maternal burden stem from the fact that mothers of children with ASD must manage different roles in order to face the challenges posed by the disability [8]. Most mothers are the only caregivers of their children, and this entails implications and deprivations in their personal lives, such as poor emotional well-being, and a feeling of burden; despair with the incurable nature of the disorder, and frustration with the lack of cooperation from the fathers of children, not expected by mothers [15]. This leads to several health problems, which can trigger serious disorders, such as depression and other psychosocial problems [8].

Quantitative analysis showed that, despite their physical presence, the fathers of children diagnosed with ASD do not participate in the process of caring for them. Hence, mothers, as the sole caregivers, face burden. Although most mothers who participated in the study were married, the reports showed that many fathers do not accept their children's diagnosis, which causes family tensions that affect marital life. In this context, the qualitative results confirmed the quantitative results, as the testimonies of the participants reflected the feeling of abandonment and loneliness, due to the restricted paternal involvement in the division of child care responsibilities.

Based on this information, it is suggested that greater parental involvement in the care of children with ASD would have a positive effect on reducing maternal burden and improving the quality of life of mothers (16).

It was found that having a child with ASD triggers a significant burden for mothers, related to child care. This phenomenon is related to traditional culture, in which they play the role of the main caregivers of their children instead of sharing it with their fathers. On the one hand, due to social demands, women have stayed at home to take care of children, especially when disabled. On the other hand, women generally identify with these roles, which also makes them more willing to give up personal interests for the sake of the family. Thus, the burden of child care usually falls on mothers, not fathers (14).

As for the quantitative variable on the therapies, it was found that mothers perceived health care as important for the development of their children. At the same time, qualitative analysis revealed that activities related to these therapies, especially when they involved moving to neighboring cities, had implications for maternal burden, generating intense physical and mental fatigue. In the meantime, there were higher levels of burden associated with the fact that the participants lived in cities surrounding the site where the study was carried out and where the therapeutic centers are located.

It is inferred that the availability and ease of accessing ASD monitoring facilities, as also observed in a study that aimed to determine the burden of care perceived by the main caregivers of autistic children or adolescents who visit health facilities in the city of Lucknow, Uttar Pradesh, in India, should be the most likely reason for the lower perception of burden identified by mothers who lived in the same city where the study was carried out (17).

As shown in the quantitative results, most participants came from low-income families, and due to the need to take care of their children, they could not work outside the home. Qualitative analysis allowed for a more comprehensive understanding of this situation, demonstrating, through the mothers' reports, feelings of concern and frustration because of their low income, which made it difficult for them to assist and monitor their children. Interestingly, although these mothers did not have employment contracts, their average burden was greater than that of mothers who worked outside the home and, consequently, had a lower income. This fact deserves attention, since poor or limited income is associated with higher levels of maternal burden, and a possible explanation for this finding is the fact that most of these mothers might not be able to provide any kind of assistance to their autistic children (17).

As for the variable children's behavior, although 92.2% of the participants reported engaging in leisure activities with the children, the reports revealed that most of them avoided areas of social interaction. It was found that that the children's behavior often generates discomfort and embarrassment for the mothers, because this behavior is judged by strangers. Thus, despite considering leisure to be fundamental for the abbreviation of burden symptoms, the mothers said they were not able to fully enjoy it. Therefore, this was a qualitative fact that contrasted with data shown in the quantitative analysis.

In this regard, a study that aimed to gain insight on the experiences of mothers of children with ASD in Egypt confirmed that the wide range of symptoms that distinguish children with ASD and accompany them throughout life affects mothers, who feel socially isolated and constrained with the behavior of their children in public and, for this reason, they prefer to keep them at home, which has a negative impact on the social life of the children and the families (15). However, it is important to reflect that this situation results from the fact that society, in general, has difficulties in including neurodivergent people in their different environments.

The referred study also showed an association between the burden of mothers in relation to the number of children, with a higher prevalence among mothers who have only one child. This data converged with a cross-sectional study that aimed to examine caregiver burden and stress coping styles of 131 parents of children with ASD enrolled in a private teaching practice center in Istanbul, which identified a significantly higher caregiver burden for parents of one child compared to parents of more children (9). Qualitative analysis showed that having more than one child, especially if the other child is older than the autistic sibling, can help reduce the task of caring for the child with ASD alone, and thus reduce maternal burden. This fact was also identified in a study that aimed to assess the level of stress in mothers of children with ASD (18). Furthermore, neurotypical siblings of children with ASD tend to maintain a protective and empathetic sense, helping these children, which contributes positively to their development, as children with ASD do not have adequate social support (19); and collaborates to reduce maternal burden.

Another variable associated with maternal burden was the child's age at diagnosis. A higher level of burden was detected among mothers whose children were diagnosed with ASD early (between 1-3 years). It is inferred that this association is due to the fact that for most signs of ASD, the higher level of support is predictive of an earlier age at diagnosis (20). A cross-sectional study with 90 caregivers (aged <60 years) of children and adolescents diagnosed with ASD, assisted in public and private health facilities that offered treatment for autism in Lucknow, Uttar Pradesh, India, also found that caregivers whose children were diagnosed under the age of 24 months perceived greater burden, with decrease in the perceived burden as the age of diagnosis increased, which was statistically significant for the patient's behavior (17).

There was also an association between the burden of the participants in relation to the symptoms of the children, with greater burden among mothers of children who had all the symptoms of the ASD symptom triad: social interaction, repetitive and stereotyped communication and behaviors. This finding corroborates a study that aimed to assess the quality of life of Chinese parents of preschool children with ASD and the association with child social impairment and child care burden, which found that the greater the worsening of ASD symptoms, the higher the level of parental stress and burden, especially for mothers (14). In this regard, there was also a positive correlation between the level of support needed to care for the children and the total burden of care perceived by the mothers. This data is consistent with relevant literature studies (16–17).

CONCLUSION

The prevalence of symptoms of burden in the study sample was high, confirming data from national and international surveys. The identification of maternal burden, ranging from mild to severe, corroborates the maternal self-perception of burden, demonstrating that the participants provided an accurate account of their own health condition. In this context, the qualitative data emerging from the maternal experience also contributed to confirm the quantitative results.

One limitation of this study is the presentation of information obtained at a given time. Therefore, it may be subject to temporal and sociocultural influences.

Thus, the importance of implementing the identification of signs and symptoms of burden in the routine of assistance and care for mothers of children diagnosed with autism spectrum disorder, in Primary Health Care, is highlighted. Therefore, it is necessary to offer proper training to health professionals, especially nurses, so that they can develop care based on comprehensive knowledge of the process of reducing maternal burden related to the care of children with the aforementioned diagnosis**.**

Data from the present study can be used in the creation of valuable resources for the assistance to women, especially mothers who care for children with autism spectrum disorder, as well as to strengthen the performance of further research in this area of human knowledge. Finally, it should be stressed that knowledge of the factors that impact maternal burden can contribute to the planning and development of strategies for guidance/reorientation and assistance to mothers and neurodivergent children, whose rights must be respected. Also, social inclusion of these people in all spaces of social coexistence must be guaranteed.

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