

## Perceptions of mothers of children with autism about a support network and self-care strategies

*Percepções de mães de crianças com autismo sobre rede apoiadora e estratégias de cuidado consigo*  
*Percepciones de madres de niños con autismo sobre la red de apoyo y estrategias de autocuidado*

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### Abstract

**Objective:** To analyze the perceptions of mothers of children with autism regarding the existing support network and self-care strategies that might be offered by therapeutic services in waiting rooms. **Methods:** A qualitative, exploratory and descriptive study carried out in October 2021, duly approved by the ethics committee under opinion No. 4,767,339. Semi-structured interviews were conducted with 29 mothers of children diagnosed with Autistic Spectrum Disorder, through thematic content analysis. **Results:** Given the therapeutic needs of their children, it is up to the mothers to take care of all the monitoring logistics of the family, in a patriarchal representation that has not yet broken away from the romanticism of motherhood. The mothers point out the need for moments that may provide physical activity, stretching, meditation and aesthetic care since, due to the overload to which they are subjected and the absence of support network offered to them, therapeutic places might also come to be self-care environments. **Conclusion:** It is emphasized that the services need to recognize the distinctive signs of patriarchy and, at the same time, offer welcoming, listening and assistance to other needs that permeate the aspects of being the mother of a child with autism.

**Descriptors:** Women's health; Mothers; Autism Spectrum Disorder; Self-care; Waiting rooms.

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### Whats is already known on this?

Mothers take on the care demands of children with ASD on their own. Therefore, it is necessary that by therapeutic services devise welcoming and self-care strategies for them.

### What this study adds?

The study reveals the main support matrix of mothers of children with ASD, along with the discovery of fundamental strategies to provide more comprehensive care to these women.



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### Resumo

**Objetivo:** Analisar as percepções das mães de crianças com autismo quanto à rede de apoio existente e as estratégias de cuidado para si que poderiam ser oferecidas pelos serviços terapêuticos em sala de espera. **Métodos:** Estudo qualitativo, exploratório e descritivo, realizado em outubro de 2021, aprovado pelo comitê de ética, parecer 4.767.339. Empregou-se a entrevista semiestruturada com 29 mães de crianças diagnosticadas com Transtorno do Espectro Autista, através da análise temática de conteúdo. **Resultados:** Perante a necessidade terapêutica dos filhos, cabe às mães toda a logística de acompanhamento da família, em uma representação patriarcal que ainda não rompeu com o romantismo da maternidade. As mães apontam a necessidade de momentos que pudessem proporcionar a realização de atividade física, alongamento, meditação e de cuidados estéticos, pois devido à sobrecarga a qual são submetidas e à carência da rede de apoio a elas ofertadas, os locais terapêuticos poderiam também vir a ser ambientes de autocuidado. **Conclusão:** Ressalta-se que os serviços precisam reconhecer as marcas do patriarcalismo e, ao mesmo tempo, ofertar acolhimento, escuta e atendimento a outras necessidades que permeiam a maternagem de uma criança com autismo.

**Descritores:** Saúde da mulher; Mães; Transtorno do Espectro Autista; Autocuidado; Salas de espera.

### Resumen

**Objetivo:** Analizar las percepciones de madres de niños con autismo en relación a la red de apoyo existente y a las estrategias de autocuidado que podrían ofrecer los servicios terapéuticos en las salas de espera. **Métodos:** Estudio cualitativo, exploratorio y descriptivo realizado en octubre de 2021 y aprobado por el Comité de Ética conforme dictamen número 4.767.339. Se realizaron entrevistas semiestructuradas a 29 madres de niños diagnosticados con Trastorno del Espectro Autista, a través de análisis temático de contenido. **Resultados:** Ante la necesidad terapéutica de sus hijos, toda la logística de seguimiento de la familia es responsabilidad de las madres, en una representación patriarcal que todavía no logra alejarse del romanticismo de la maternidad. Las madres señalan la necesidad de contar con momentos que pudieran proporcionar oportunidades para realizar actividad física, elongación, meditación y cuidados estéticos puesto que, debido a la sobrecarga a la cual están sometidas y a la ausencia de una red de apoyo, las instituciones terapéuticas también podrían convertirse en ambientes de autocuidado. **Conclusión:** Se destaca que los servicios de salud deben reconocer las indiscutibles marcas del patriarcado y, al mismo tiempo, acoger, escuchar y atender otras necesidades inherentes a ser madre de un niño con autismo.

**Descriptorios:** Salud de la mujer; Madres; Trastorno del Espectro Autista; Autocuidado; Salas de espera.

## INTRODUCTION

In a context marked by gender inequalities attributed to historical, cultural and social factors inherent to patriarchy, it is up to mothers to care for family members, and undoubtedly, when it comes to the Autistic Spectrum Disorder (ASD) diagnosis, it is also them that strive for this discovery, treatment and compulsory changes in lifestyle to adapt to the new demands of their children's therapeutic process.<sup>(1)</sup>

According to Law No. 12,764/2012, an individual with ASD is considered a person with a disability and, therefore, subjected to rights for all legal purposes. Furthermore, according to the Diagnostic and Statistical Manual of Mental Disorders V (DSM-V), autism can be defined as a developmental disorder whose behaviors have the following predominance: social and communication deficiencies, establishing interaction difficulties; and restricted, fixed and intense interests whose behavior proves to be stereotyped and repetitive.<sup>(2)</sup>

In addition to the experience of motherhood that is still culturally romanticized by society, mother of children with ASD carry with them an atypical motherhood, which comprises the set of responsibilities aimed at everyday life surrounded by multiprofessional child care. With that, it is inevitable that there will be changes in the daily routine linked to a tangle of feelings that range from fear to anguish due to the diagnosis and, above all, to the social prejudice that these children may experience.<sup>(3)</sup>

Therefore, it is of utmost importance to promote actions aimed at these women who are also mothers and caregivers, who oftentimes give up their professional careers, their marital and social life or moments of leisure and care for their own health to experience intense motherhood full of uncertainties.<sup>(4)</sup>

Therefore, it is evident that, in the vast majority of homes, these mothers undergo progressive stress, depression, job abandonment and the entire panorama of personal development and self-care perspectives. In addition, it is worth noting that these women are the closest referents for their children; therefore, as these mothers are not in sound physical and mental health, this will reflect on their relationship with their children, as well as on their development.<sup>(5)</sup>

However, although this scenario marked by overload of demands and responsibilities is not a rule, it is part of a pattern; and it is possible to infer that mothers of children with disabilities are the family members who wear out the most to fit within the therapeutic demands and those of their children's daily routine, which should confer child therapists greater awareness and empathy regarding their well-being condition.<sup>(6)</sup> In addition, it is important to note that the multiprofessional follow-up occurs simultaneously and without any prior discharge projection, considering that this therapeutic discharge will depend on

each child's evolution, which suggests an indefinite period of assistance and permanence in therapeutic services.<sup>(7)</sup>

Corroborating with the above, it is possible to infer how the routine of these mothers is modified due to the need to comply with the therapeutic cycles, and how often these women's health, in addition to other demands of their own such as work and leisure, can be neglected depending on the commitment degree of the existing support network that sustains this additional routine. Thus, the study object was the following: support network and care strategies to be developed by therapeutic services for mothers of children with ASD, in waiting rooms. And the research question was as follow: Which are the perceptions of mothers of children with ASD about the support network and care strategies for themselves offered by therapeutic services in waiting rooms?

The relevance and contributions of the study are based on highlighting the demands of women who are almost always in a position of neglecting self-care, given the high demand for responsibilities and commitment of weekly and daily time in therapies, where efficacy of the therapeutic treatments takes place over long periods of multiprofessional assistance and without prior discharge projection, weakening the viability of the care provided to these women. Thus, it becomes important to reveal care strategies that can be offered in waiting rooms by the services that assist these children, while the therapeutic sessions takes place, rendering this period profitable and focused on comprehensive care for these women.

Thus, the objective of this study was to analyze the perceptions of mothers of children with autism regarding the existing support network and self-care strategies that might be offered by therapeutic services in waiting rooms.

## METHODS

A qualitative, exploratory and descriptive research study.<sup>(8)</sup> It was carried out in a private network institution and in another from the public network for comparative purposes of the maternal perceptions about the study object. Thus, the Center for Therapeutic Specialties (CRESCER) was listed, belonging to the private health network, which assists children with ASD and other demands, offering services in the areas of Psychology, Speech Therapy, Occupational Therapy, Physiotherapy, Psychomotricity, Music Therapy and Psychopedagogy. The locus referring to the public health network was the Municipal Polyclinic, which offers services in the areas of Speech Therapy and Occupational Therapy. Both institutions are located in the municipality of Petrolina, Pernambuco.

The study participants were mothers of children diagnosed with ASD without any other associated components, who were accompanying their children in the waiting rooms during the collection period. The women excluded were the mothers of children whose diagnoses were still under investigation or who had any other type of caregiver, regardless of the degree of kinship.

This research had the collaboration of those responsible for managing the clinics, in addition to the service welcoming team. Thus, there was a first contact by the researcher with these members, in order to agree upon on the days and times for the collection procedures, as well as the mothers' availability for that moment.

Semi-structured interviews were carried out in a calm and private environment while the mothers were waiting for their children. The interviews were recorded using a cell phone for later transcription and analysis of the results. The research used a non-probability sample of the intentional type, with sampling closure by theoretical saturation, which did not allow the inclusion of new participants when the data obtained began to present, according to the researcher's evaluative understanding, a redundancy and/or repetition segment, with data collection continuity no longer necessary, totaling 16 interviews in the private network and 13 in the public one.<sup>(8)</sup>

The script included identification questions such as: age, marital status, schooling, number of children, religion, age when the child was diagnosed with ASD, current number of therapies for the child, how many hours a week are allocated to therapies, and who is the person that most accompanies the child in the therapies. Therefore, the guiding questions were as follows: 1. Do you have a support network in terms of housework and/or care for your child? 1.1 Who would be those people that help you? 1.2 How is this routine now? 2. Have you had the necessary support to carry out your personal activities (going to the doctor, doing physical activity, having a moment of leisure...)? 3. For you, how might therapy spaces also be care spaces for the mothers? 3.1 If some type of physical activity was offered to you, would you be willing to participate regularly? 3.2 Which activity(ies) or services do you suggest?

Furthermore, in view of the situation of facing the pandemic caused by the new Coronavirus, valid biosafety measures were adopted for the interviewer and interviewee during the interviews, such as mask use and safe distance; in addition, gel alcohol was offered before starting the recordings.

The empirical material was analyzed based on thematic content analysis, going through three treatment phases: pre-analysis, where the initial access to the documents was carried out; the reading phase; organization, structuring of the schemes; and transcription of the material, which served as the analysis *corpus*. As a second phase, or exploration of the material, the coding units, selection of counting rules and enumeration due to collective characteristics were defined. In the last phase, through conclusion and explanation, the empirical material obtained had meanings and validation, considering the entire appraisal of the material collected.<sup>(9)</sup>

In order to ensure and maintain reliability of the confidentiality process, the participants were identified in the interview script only by the initial "AM 1" (Atypical Mother 1) and, thus, successively, listed according to the order in which the instrument was applied, considering whether the therapy is in the private or public network (AM 1 Public or Private).

The research was approved by the Committee of Ethics in Research involving Human Beings of the Sertão Integration College (*Faculdade de Integração do Sertão*, FIS) on June 10<sup>th</sup>, 2021, through opinion No. 4,767,339; however, the data were only collected in the first half of October 2021, after articulation with the services where the collection procedure was carried out, ending on February 17<sup>th</sup>, 2022.

## RESULTS

In the private network, among the 16 participating mothers, the age group varied between 25 and 45 years old: regarding marital status, there were 02 in a stable relationships, 04 single and 10 married. Among them, 12 assume the therapeutic routine and care for their children; in 01 case, the routine is assumed by the father and, in 03, by both parents. As for the schooling level, there was 01 with complete Elementary School, 03 attending undergraduate courses, 06 with complete undergraduate studies and 06 with a graduate degree (03 specialists, 02 MScs and 01 PhD). In relation to the number of children, the mothers stated having between 01 and 03. The predominant religion was Catholic, with 09. The mothers stated that their children were diagnosed with ASD when they were between 1 and 5 years old. Furthermore, referring to the number of therapies underwent by the children, a minimum of 03 and a maximum of 10 therapies per week were obtained.

In the public network, among the 13 participating mothers, the age group varied between 28 and 42 years old; regarding marital status, 03 were married, 04 were single and 06 were divorced. Among them, 11 assume the therapeutic routine and care for their children, in no case is the routine assumed by the father and, in 02, by both parents. In relation to the schooling level, it was verified that 02 had incomplete Elementary School, 03 had complete Elementary School, 06 had complete High School and 02 were graduates. In relation to the number of children, the mothers stated having between 01 and 03. The predominant religion was Catholic, with 07. The mothers stated that their children were diagnosed with ASD when they were between 1 year and 8 months and 5 years and 7 months of age. However, in relation to the number of therapies underwent by the children, the mothers indicated a minimum of 01 and a maximum of 03.

It should be noted that, regardless of marital status, there is convergence with the literature, in which both in the public and private networks, it is the mothers that mostly assume the therapeutic routine and care for their children, evidencing too much burden for them.<sup>(1)</sup> Furthermore, when the participants' schooling level is verified, higher levels are observed in the private network, which leads to greater access to information and knowledge on the topic due to better financial conditions.<sup>(10)</sup>

With regard to the age when the children were diagnosed with autism, there is little difference, as the diagnosis is currently becoming increasingly precocious. However, early diagnosis is not accompanied by therapeutic accessibility at ideal levels for taking advantage of brain neuroplasticity in childhood, culminating in future damage to children's quality of life.<sup>(11)</sup>

03 categories emerged from the analysis requested, namely: "Support network and the distinctive signs of patriarchy"; "Challenges in self-care"; and "Can child therapy spaces become maternal care spaces?".

### Support network and the distinctive signs of patriarchy

When the mothers talk about their support network possibilities, it is a unanimous perception how they become the only ones responsible for unfolding to fulfill their demands related to work, house chores, family care and monitoring their children.

[...] everything is very complicated, because I have to divide myself between the therapy routine and work. My husband helps me, but not always [...]. (AM 16 Private)

[...] I work, but as it is close to home and belongs to my family, I take my son. I spend the day outside, I enter at 8am and leave at 5pm. On the therapy days I bring him and I try to help as much as I can, I can't bring him more often so he can be better monitored, because I earn per day worked, so it's difficult [...]. (AM 6 Public)

[...] I used to work, but I left my job to take care of him [...]. Then I got pregnant with my second child and found out that the other one is also autistic, so my routine is to take care of the house in the morning, the eldest goes to school this year, the youngest stays with me, and in the afternoon, I bring them both to therapy [...]. (AM 9 Public)

In these testimonies, it is observed that, given the need for therapeutic monitoring of their children, it is up to the mothers to abandon their jobs or adapt their work schedules and that, even with a weak division of this responsibility with the fathers, as presented in AM 2's narrative, all the logistics of interaction and participation with the therapists still remains with the mothers since, in a patriarchal representation that has not yet broken away from the stigma of "good mother", it is up to them to take care of their family.

[...] I'm in the home office modality and in a short time I'll be back in-person, I still don't know how it will be. At this moment, my husband and I are taking turns on the therapy days, but the whole participation routine and keeping abreast of what's happening in the sessions and talking to the therapists, everything, it's me [...]. (AM 2 Private)

### Challenges in self-care

When asked about having time to develop self-care, such as going to the doctor, performing physical activity or contemplating leisure time, these women showed that there are limitations, as they almost always need the availability of someone who will assume care and responsibilities with their children in their absence, even if temporary.

[...] I don't have time for physical activity. Leisure is shared with the children, my husband, my family and a few friends. And so, we create this time, but to say that I have a lot, I don't [...]. (AM 11 Private)

[...] if necessary, I have my children to help me, but I have to make arrangements in advance for them to organize themselves at work, but I do physical activity only if it's at night, but I'm already very tired [...]. (AM 15 Private)

[...] I don't always have. When my sister-in-law can, she helps me. I've already missed appointments because I didn't have anyone to take care of my son [...]. (AM 8 Public)

[...] if I need to, sometimes I can get someone, but most of the times I can't get anyone to help me [...]. (AM 10 Public)

These testimonies suggest a society still rooted in patriarchy where self-care practices and fulfillment of these women's health demands are impaired due to the weakness of the support network and a scarce division of therapeutic responsibilities with the fathers.

### Can child therapy spaces become maternal care spaces?

In the mothers' perception, child care places might become maternal care spaces while waiting for the children in the waiting rooms. Among the precautions that emerged are a place that allows listening

based on the families' routine, promoting acquisition of information, clarification of doubts and exchange of experiences.

[...] It would be very good if there was a professional to talk to the mothers during this period that we're in the waiting room, especially for the beginning of therapies, [...]  
(AM 2 Private)

[...] There could be a moment to talk with the mothers to clarify our doubts [...].  
(AM 3 Public)

In addition to the conversation circles, another aspect revealed was that the therapeutic space should have an arrangement that allowed them to continue their work tasks remotely, given that duration of the therapies demands a good part of a daily work shift.

[...] there might be a room to feel more comfortable, as we spend a lot of time in the waiting room and it would be possible to work in a home office system while waiting for the therapy to end. In addition to that, there could be an educational activity, a talk with the mothers and fathers who are here in the waiting room, even to provide psychological support, even if it was once a month [...]. (AM 13 Private)

Due to the intensified process of professional assistance required for children with ASD, it is possible to readjust the mothers' routine if the therapeutic spaces also become allies in this process of looking at mothers as subjects to be cared for. Therefore, the mothers point out in their statements the need for moments that could provide opportunities for physical activity, stretching, meditation and aesthetic care.

[...] I believe that a conversation circle with the mothers and a professional during the waiting time would be very good. Physical activity would also be important [...].  
(AM 2 Public)

[...] Meditation would be my choice, because the week is such a rush, it would be great [...].  
(AM 4 Public)

[...] all therapeutic care places could be transformed into a more productive environment because, in my case, I spend a very significant amount of time in the waiting room, I arrive at 1pm and only leave at 5pm, three days a week. So, there might be a self-knowledge course for the mothers, a conversation circle, because there are many mothers who need it and don't have this information. In addition to that, a moment devoted to beauty could be offered, something to work on the self-esteem and confidence of these mothers, who are also women and do not have that time [...]. (AM 3 Private)

These women's testimonies show that welcoming mothers of children with ASD becomes indispensable and, in their testimonies, they reveal possibilities for promoting support, comfort and well-being to the detriment of the mismatch they often experience in their self-care routine.

## DISCUSSION

House chores and routine care for the children have always been dictated as intrinsic elements of the female universe and, for that reason, when men perform this same actions, they start from a patriarchal social imaginary that is not part of their duties. In this regard, when possible, men would become mere supporters of these activities, corroborating the idea that their collaboration is but "secondary help", with no obligation to be performed.

In this way, and as shown in the study, this scenario contributes to a significant burden on mothers and, on the other hand, generates greater relief and comfort in the face of fathers' duties. In this convergence, having a child with autism triggers high stress and fatigue levels for the mothers due to the fact that they fully assume the care and therapeutic routine of their children, when such care should be equally shared.<sup>(12)</sup>

According to the reports included in this study, when these women take the full responsibility of caring for their children diagnosed with ASD, they experience renunciation of their work activities, self-care and isolation, assuming a lonely and overburdened motherhood, both physically and mentally.<sup>(13)</sup>

Thus, although there are large variations in commitment in ASD, it is fundamental to consider the changes and impacts in the family context that can generate the most diverse conflicts, such as marital issues, impact on the relationship with other children, basic financial implications, and even burden on one of the family members. In this sense, reflection and dialogue between the parents becomes necessary so that such a scenario is avoided, as this entire responsibility is imposed on the mother.<sup>(14)</sup>

However, it is known that, in view of the historicity of patriarchy, an ideal of a mother who “does everything, she can handle everything” was disseminated, attributing feminine and maternal stereotypes such as “super mother/woman”, “strong mother/woman who bears everything” and “mother/warrior woman”. Thus, at the core of these speeches, it is noticed that every demand required by a child should be attributed to the mothers, who make a large part of their time available for routine child care and, thus, have their self-care relationships impaired due to the absence of a support network and inequality in paternal participation.

Such paradigm emerged in the mid-XVIII century and was consolidated by similar generations, reproducing an ideal of a mother who, as the social standard imposes, should annul herself to live only for the sake of the child.<sup>(15)</sup> In the meantime, it is known that daily care and interventions render the therapeutic routine of mothers of children of ASD completely scheduled and exhausting, a fact that, added to domestic and work tasks, can trigger psychological diseases such as anxiety, depression and panic syndrome.<sup>(16)</sup>

In this sense, it is understood that not all mothers of children with disabilities have family support or financial conditions to pay a home caregiver for their children. In the family context, these problems can be related mainly due to the broken link, physical distance, time availability or even the family's interest in collaborating with the process of caring for these children.<sup>(17)</sup> In another scenario, it is understood that not all family environments earn enough incomes to pay a professional or service that can help with the daily demands of these children. However, when in some situations any of these support axes can be maintained, these mothers' routine becomes less fatigued and allows them to perform other activities and reduce the burden.<sup>(18)</sup>

Contrary to the cultural context imposed on mothers, a number of studies indicate that the “care process” generates positive results in human beings' life and, in the case of these women, it would contribute benefits to themselves and better quality of the care they provide to their children. In this sense, even if slowly and gradually, it becomes necessary to incorporate the figure of the father for an equal division of care at home and even the multiprofessional intervention processes.<sup>(19)</sup>

In this context, the study suggests that child therapy spaces should also become places where these mothers are welcomed, as a female care strategy in the face of the predominant cultural influence of patriarchy, where self-care is neglected to the detriment of child care. Therefore, both private and public network therapeutic clinics might, within their possibilities and knowing the frequency and duration of the sessions, offer care to these women.<sup>(20)</sup>

It is believed that taking advantage of the moment these mothers are in the waiting rooms for each therapeutic session of their children would contribute countless benefits, such as improvements in mental and physical health or breaking the emotional tension naturally established by the environment, in addition to representing a unique opportunity to indulge in a self-care moment.<sup>(21)</sup> Faced with this, it is opportune for services to begin to understand that most of these women face atypical motherhood in a unique way, with strong patriarchal influences of gender inequalities, oftentimes relying on insufficient or faulty support networks and that these mothers' burden with regard to the assistance offered to their children is particularly prevalent.<sup>(22)</sup>

It is expected that society does not naturalize and starts to question the father's absence in child care, mainly when it comes to children with disabilities. However, it is known that this social understanding requires time and needs to be initiated by the entire society and, mainly, by women themselves, recognizing themselves as a responsible part of the care and education of their children, although not merely as the only ones to abdicate themselves and their own life to manage all their extrinsic demands.<sup>(23)</sup>

Moreover, it is expected that sharing care of the children goes through a social and cultural re-signification process. This process of re-signifying being a father still needs to break down walls that are solidified by ideologies that men are responsible for providing for the home and that are marked by minimal interference or lack of care for the children. Furthermore, it should be noted that, as the image of men in the family context is still linked to gender inequalities, lonely and overburdened motherhood

becomes natural in a romanticized view of maternal fatigue, even among the professionals who monitor children with ASD.

It is known that when the father assumes his responsibilities for caring for the children, he not only reduces the burden on the mother, but also contributes greatly to development of the children. However, such context can become even more difficult when there is no longer a marriage relationship between the parents since, in these cases, the vast majority of men are exempt from this role of caregiver and direct companion of the children and, in the case of children with ASD, this scenario is even more troubled due to the broad and continuous need for a health care network.<sup>(24)</sup>

Another aspect worth noting is the elaboration of public policies that promote self-care for atypical mothers, in order to guide and sensitize therapeutic services aimed at children with ASD to institute physical activity or relaxation practices such as yoga, music, psychological assistance, coexistence groups and exchange of experiences, as mentioned by the interviewees.<sup>(25)</sup>

Bearing in mind that the follow-up routine for these women requires a large part of their day and that there is a significant gap in the support network, as shown in the study, it is considered almost unfeasible to carry out some type of female self-care that is not linked to waiting for their children. Therefore, the veiled cry of tiredness and maternal burden needs to give way to a therapeutic children's health network that recognizes not only children as care objects, but also the mothers.

The study limitation was related to the time to collect the interviews, which were conducted while the mothers were waiting for their children in therapeutic sessions, acting as a limiting factor for the end and conclusion in deepening of the testimonies, which in some situations were marked by the fear that the session would end. As contributions, the study allowed conferring visibility to the maternal care demands and to raise possibilities of these care measures for the services that provide therapeutic assistance.

## CONCLUSION

In view of the objective proposed in the study, it is revealed that the atypical motherhood process and its peculiarities, such as the therapeutic routine and the broad demand for child care, are added to other specificities of a work and domestic nature that cause daily burdens due to the existing gap regarding paternal participation and/or collaboration of a present support matrix. Therefore, this misalignment opens a fissure that makes it evident how the responsibility of caring for the children becomes a solitary action and an exclusive duty of the mother.

As for these women's self-care, there is negligence mainly due to organization of the routine regarding maintenance of the therapeutic agenda, which is necessary for the progress of children with ASD. This entire situation directly implies a compromise in the care of these mothers when it comes to the practice of physical activities, health care, and moments of social interaction and leisure with friends and family. Thus, this context not only affects the physical health but also the mental health of these women who also need care and prevention of the disease process.

In view of this, it was observed that these mothers spend part of a shift in the waiting rooms of their children's therapeutic follow-up clinics and that, when asked about their availability to participate in physical activities while waiting for each session, they showed themselves willing to if services were available. Thus, they suggest physical exercise practices such as meditation, yoga or labor gymnastics, and even highlight the need for a moment of interaction with other mothers mediated by a therapist, as well as they pointed out the need for a private room so that they can carry out their work activities during this period.

However, it is urgent for therapeutic services to recognize the distinctive signs of patriarchy, considering that deconstruction of this legacy becomes important from the perspective of expanding care for mothers as well. That said, it is also worth considering the waiting time they can better use, greatly contributing to health promotion in its broadest concept; in addition to offering welcoming, listening and assistance to other needs that permeate motherhood of children with autism, providing shelter to the weaknesses and tiredness imposed by the daily routine.

## CONTRIBUTIONS

Study conception or design: Luna AWN, Melo MCP. Data collection: Luna AWN, Santos, MVP. Data analysis and interpretation: Luna AWN, Melo MCP. Writing of the article or critical review: Luna AWN, Melo MCP, Santos ADB, Calado JIF. Final approval of the version to be published: Melo MCP, Santos ADB, Calado JIF.



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