

Maternal narratives: family changes following an Autism Spectrum Disorder diagnosis

Narrativas maternas: as mudanças familiares diante do diagnóstico de Transtorno do Espectro Autista

Narrativas maternas: los cambios familiares ante el diagnóstico de Trastorno del Espectro Autista

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Abstract:

Objective: to understand the perceptions of a family member regarding changes in families resulting from a diagnosis of Autism Spectrum Disorder (Level 3 support needs) in their children. **Methods:** a qualitative, cross-sectional study conducted in 2024 with women from a municipality in the far south of the state of Rio Grande do Sul, Brazil. Inductive reflexive thematic analysis was employed. Results: nine women with children at different developmental stages participated. Three themes emerged: a) *the children's diagnosis and its implications*, b) *changes in relationships*, and c) *responsibility centered on the mother*. The diagnosis marked a turning point in the families' lives, particularly for the women/mothers, who assumed the central caregiving role. Maternal experiences revealed a lack of professional preparedness regarding the initial demands of the diagnosis and its impact on marital and social relationships; these relationships were often characterized by the severing of previous ties and the formation of new support networks among families of atypical children. **Conclusion:** the study demonstrates how these changes affect the entire family dynamic, ranging from the continuous pursuit of the children's development to the demands imposed by intensive care, which require significant adjustments to daily routines.

Keywords: Family relations; Autism spectrum disorder; Mothering.

Resumo:

Objetivo: compreender as percepções de um membro do núcleo familiar sobre as mudanças nas famílias decorrentes do diagnóstico de Transtorno do Espectro Autista, nível de suporte 3, em seus filhos. **Método:** estudo qualitativo e transversal realizado em 2024 com mulheres de um município do extremo sul do Rio Grande do Sul. Utilizou-se a análise temática reflexiva indutiva. **Resultados:** nove mulheres participaram com filhos em diferentes ciclos. Emergiram três temas: a) *o diagnóstico do filho e suas implicações*, b) *mudanças nas relações*, e c) *responsabilidade centrada na figura materna*. O diagnóstico constituiu um marco de transformação na vida das famílias, especialmente das mulheres/mães, que assumiram o papel central no cuidado. As experiências maternas mostraram fragilidade no preparo dos profissionais diante das demandas iniciais do diagnóstico e do impacto nas relações conjugais e sociais, frequentemente marcadas pelo afastamento de vínculos prévios e pela formação de novas redes de apoio entre as famílias atípicas. **Conclusão:** o estudo demonstra como as mudanças afetam toda a dinâmica familiar, desde a busca contínua pelo desenvolvimento dos filhos até as exigências impostas pelos cuidados intensivos, que demandam ampla adaptação da rotina.

Palavras-Chave: Relações familiares; Transtorno do espectro autista; Maternagem.

Resumen:

Objetivo: comprender las percepciones de un miembro del núcleo familiar sobre los cambios en las familias derivados del diagnóstico de Trastorno del Espectro Autista, nivel de apoyo 3, en sus hijos. **Método:** estudio cualitativo y transversal realizado en 2024 con mujeres de un municipio del extremo sur de Rio Grande do Sul. Se utilizó el análisis temático reflexivo inductivo. **Resultados:** participaron nueve mujeres con hijos en diferentes etapas del desarrollo. Emergieron tres temas: a) *el diagnóstico del hijo y sus implicaciones*, b) *cambios en las relaciones*, y c) *responsabilidad centrada en la figura materna*. El diagnóstico constituyó un hito de transformación en la vida de las familias, especialmente de las mujeres/madres, quienes asumieron el papel central en el cuidado. Las experiencias maternas mostraron deficiencias en la preparación de los profesionales ante las demandas iniciales asociadas al diagnóstico y su impacto en las relaciones conyugales y sociales, frecuentemente marcadas por el distanciamiento de vínculos previos y la formación de nuevas redes de apoyo entre las familias atípicas. **Conclusión:** el estudio demuestra cómo los cambios afectan toda la dinámica familiar, desde la búsqueda continua del desarrollo de los hijos hasta las exigencias impuestas por los cuidados intensivos, que requieren una amplia adaptación de la rutina.

Palabras clave: Relaciones familiares; Trastorno del espectro autista; Maternaje.

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INTRODUCTION

From a systemic perspective, the family is understood as a dynamic system in constant transformation, experiencing events such as the birth and growth of its members. Based on this individual and familial development – known as the life cycle – one can understand how families organize themselves and face challenges and transitions across different life stages¹. Thus, changes emerging along this path can trigger reactions throughout the family system and in individual members, producing lasting impacts²⁻³.

Such transformations stem from events that mutually affect family members and can be understood through two axes: the vertical axis, comprising transgenerational patterns (such as expectations, beliefs, and family labels transmitted across generations); and the horizontal axis, encompassing stressors experienced over time¹. These horizontal stressors may be predictable, such as children leaving home, or unpredictable, such as the diagnosis of a neurodevelopmental disorder. When an unpredictable horizontal stressor arises, it demands new forms of organization and adaptation from all family members, challenging the family's identity, functioning, and structure⁴.

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by persistent deficits in communication and social interaction, as well as restricted, repetitive patterns of behavior, interests, or activities. Its core characteristics are usually present from early development, although they may not fully manifest or be noticed until social demands exceed the individual's capabilities⁵. In this context, the diagnosis can constitute a critical event in the family life cycle, especially in cases requiring greater support, calling for intensive and continuous care from the earliest years of life⁶.

The onset of this new reality often triggers an emotional whirlwind for parents and caregivers – characterized by frustration, fear, guilt, and uncertainty – which is exacerbated by structural barriers such as a lack of professional preparedness during initial encounters, high costs, and a scarcity of specialized services in outlying areas⁷⁻⁸. This prolonged journey, often undertaken without adequate support, not only delays diagnosis and early intervention but also has cumulative effects on the family's mental health and undermines their coping resources⁹.

Consequently, parents and caregivers often need to reassess their roles within the family dynamic, creating tension between managing finances and the burden of caregiving¹⁰. A notable aspect of this scenario is the concentration of caregiving duties on a single family member – almost always the mother – who simultaneously becomes the primary source of affection and the person responsible for organizing family life and therapeutic care¹¹.

Receiving a diagnosis marks not only the beginning of a therapeutic process but also ushers in a series of profound, lasting changes in daily routines, interpersonal relationships, and the organization of the home environment¹². Few studies have examined in depth how marital, parental, and support-network dynamics are reconfigured, particularly when caregiving responsibilities fall almost exclusively on one caregiver. Thus, this study aims to understand the perceptions held by a family member regarding the changes families undergo following a diagnosis of Autism Spectrum Disorder (Support Level 3) in their children.

METHODS

This is a cross-sectional qualitative study. The qualitative approach allows for the investigation of subjective and perceptual aspects of phenomena within a specific time and space¹³.

Women from a municipality in the extreme south of the state of Rio Grande do Sul, Brazil, were interviewed, having been invited via social media (Instagram and Facebook). Initial contact involved a brief presentation and an explanation of the study's characteristics and objectives. The inclusion criterion was being a parent or caregiver who resided or had previously resided with the family member with ASD. Conversely, the exclusion criteria were: the children lacking a formal diagnosis and/or family members who were not the primary caregivers.

Following the invitation, participants received the Free and Informed Consent Form (FICF), containing information on voluntary participation, which was signed after all questions had been answered. Subsequently, interviews were scheduled according to the families' availability and conducted in a safe, private setting. When necessary, the children received support from research assistants to ensure the interview proceeded with minimal interference.

Data collection took place in person between August and October 2024, using semi-structured interviews (lasting 45 to 142 minutes). The instrument used was developed and reviewed by the research team and underwent a pilot interview for methodological adjustment and refinement.

Interviews began with the collection of sociodemographic and health data, aiming to reduce anxiety and establish the necessary rapport. Subsequently, topics such as diagnosis, family relationships, hopes/expectations, and support networks were explored through open-ended questions. Interview audio was recorded, and the interviews were transcribed verbatim. The recordings were used solely for research purposes and were subsequently deleted from the computers and servers where they had originally been stored.

This study was approved by the Research Ethics Committee (Opinion No. 6,887,926), in compliance with the guidelines of Resolution 510/2016 of the National Health Council¹⁴. To ensure confidentiality, pseudonyms were used in this study, referencing the first names of authors who have established a significant body of work and serve as key references in Systemic Family Therapy.

To understand the participants' perceptions, an inductive Reflexive Thematic Analysis (RTA) was conducted, following the stages proposed by Braun and Clarke¹⁵: (1) data familiarization; (2) initial coding; (3) searching for themes; (4) reviewing and refining themes; (5) defining and naming final themes; and (6) report production.

Given that this study is based on inductive analysis, data coding and theme categorization were derived from the participants' statements. RTA fostered collaboration among researchers and reflective engagement with the data, enabling an in-depth discussion of the phenomenon under study¹⁵.

RESULTS

Three families with young children, three with adolescent children, and three with adult children were selected; all the children diagnosed with ASD and the families were represented by women. The nine women ranged in age from 35 to 71 years. The children ranged in age from 3 to 46 years. Seven of them were diagnosed before the age of 3, while one was diagnosed at 3 years and 3 months, and another only at age 9 (Table 1).

Table 1. Sociodemographic characteristics of mothers and their children with ASD. Rio Grande do Sul, Brazil, 2024.

Participant	Age	Race/Color	Educational level	Family structure	Age of children with ASD	Age of diagnosis
Maria	38	White	Complete Secondary Education	Single, 1 daughter	3	1 year and 7 months
Mathilde	36	Mixed/Brown	Complete Higher Education	Single, 1 daughter	5	2 year
Mônica	35	White	Complete Higher Education	Civil union, 1 son	8	1 year and 11 months
Betty	48	White	Complete Higher Education	Married, 1 son	14	2 years and 6 months
Paula	38	White	Complete Higher Education	Lives with partner, 2 children	17	2 years and 4 months
Vera	50	White	Complete Higher Education	Married, 1 son	19	3 years and 3 months
Solange	58	Black	Complete Higher Education	Married, 3 children	32	2 years
Patrícia	55	White	Incomplete Primary Education	Dating, 2 children	34	9 years
Virgínia	71	White	Complete Primary Education	Married, 4 children	46	1 year and 6 months

Based on the participants' statements, three themes were developed. The first theme was *"The children's diagnosis and its implications,"* comprising two subthemes: *"Family members' perceptions of early neurodivergent traits"* and *"Receiving the diagnosis and the lack of professional preparedness."* The second theme was *"Changes in relationships,"* which encompassed three subthemes: *"Adjustments to family dynamics and routines,"* *"Couple dynamics"* and *"Support from extended family, friends, and the atypical community."* Finally, the third theme was titled *"Responsibility centered on the mother,"* including two subthemes: *"Lack of paternal involvement and maternal overburden"* and *"The meaning of autism and the experience of atypical motherhood."*

The children's diagnosis and its implications

The journeys of the nine participants reveal perspectives ranging from the emergence of early signs to the confirmation of ASD. Their accounts highlight the uncertainties and comparisons involved, the impact of the diagnosis – which oscillates between relief and anguish – and the recurring lack of preparedness among healthcare professionals to support and guide families through this process. These subthemes intertwine to demonstrate that the diagnostic process is more than a simple clinical act; it is a turning point that redefines personal and family priorities.

- Family members' perceptions of early neurodivergent traits

The identification of the initial neurodivergent traits was marked by comparisons with the development of other children, warnings from others, and maternal perception. For some participants, this realization arose from noticing differences in expected early childhood behavior. Virgínia reported observing her son in relation to older children, even though her concerns were dismissed by those close to her:

I was so distressed [...] I found it so, so strange; how come he doesn't cry? If a child wakes up, they wake up and cry, right? [...] There's nothing wrong; it's all in your head.

Likewise, Solange showed concern upon noticing something different from what she knew and understood about motherhood:

It was obvious that the baby was different; he cried constantly, wouldn't sleep, and only calmed down while nursing. It was an insane routine, a baby who wouldn't let go of you for a single moment, twenty-four hours a day.

Other mothers reported not noticing any differences that deviated from their caregiving routines, only becoming aware of them through warnings from family members or institutions, such as the child's school. In this instance, Mônica reported not noticing anything out of the ordinary, with the issue being brought to her attention by her husband:

It was actually Moises's father, Gregory, who brought up the diagnosis. But Gregory, since he spent a lot of time with children, started pointing things out to me: "Look, when I get home, Moises doesn't... he doesn't look at me."

On the other hand, 48-year-old Betty noticed certain characteristics in her son regarding organization, but the warning came from the school, relaying what the teacher and the educational psychologist had said:

Murray doesn't play with the other children; Murray isolates himself.

- Receiving the diagnosis and the lack of professional preparedness

The search for clinical answers often confronted families with the minimization of their complaints and the lack of preparedness among healthcare professionals. Paula recounted a consultation where she had to intervene due to the doctor's lack of knowledge:

"Doctor, is it autism?" Then he sat there thinking, picked up the phone [...] called someone, and said, "Tell me one thing: if I order an MRI, will it tell me if the child has autism?" I took the phone out of his hand, put it back on the hook [...] and said, "Doctor, there is no test in the world that can tell whether my son is autistic or not," that much I knew.

Similarly, Patrícia also saw her concerns dismissed on the grounds that the developmental delay was due to her son's prematurity. The investigation into ASD only began after another professional intervened during an on-call consultation:

The doctors say no, that it's normal because he is premature.

These families' feelings oscillated between a sense of bewilderment regarding their children's interactions and self-doubt, as if their own perceptions were mistaken or based on unfounded worry, particularly given the frequent dismissal of clinical findings by healthcare professionals and the lack of support. Vera described the feelings she experienced when her son's diagnosis was confirmed:

The grief turns to fight in no time. You go out and seek therapy, treatment, and figure out what's best for your child [...] everyone says, "Grief passes." Grief doesn't pass.

Similarly, Maria described the initial impact of not knowing about the condition:

It was a shock, because I didn't know anything about it, you know? [...] What's going to happen to my daughter? [...] We're always fighting, always striving.

Changes in relationships

A diagnosis of ASD requiring substantial support necessitated adjustments to the participants' domestic routines, professional lives, marital relationships, and social and community support networks. Consequently, the mothers shared the changes that occurred in their relationships.

- Adjustments to family dynamics and routines

Adjustments to their daily routine began to require physical changes to the home and alterations to the mothers' working lives. Mônica shared the structural modifications needed in her home due to her son's specific needs:

He can't stay, remain at school. And we had to make adaptations to the house, to his room [...]. So, we ended up having to build [...] a new house.

Devoting herself entirely to caring for her son also led to her stepping away from the job market. Patrícia had to put her career on hold due to the increasing behavioral demands associated with her son:

Michael became very aggressive [...] the outbursts, the hitting [...] so I was forced to stop working outside the home.

Similarly, Mathilde also portrayed the limitations imposed on her professional life:

I used to just work, and now I can't work as much because I have her.

Furthermore, the simultaneous aging of mothers and children has given a new dimension to the accumulated fatigue, as Vera highlighted:

There's a whole system in place with David [...] We get more tired, you know? Especially since we're getting older [...]. It's not just the autism we're dealing with; age is catching up with us, too.

- Couple dynamics

Parental roles are essentially shaped by the arrival of a new family member, which brings about changes in the marital subsystem. The demands of intensive caregiving had a direct impact on the marital relationship, resulting in emotional distance, overload, and conflict. Virgínia highlighted the shift in priorities within her marriage:

My husband never understood that. I'll take a back seat, and he'll take a back seat. [Our son is] the priority for everything: health, education.

The burden associated with financial dependence and relationship conflicts was reported by Solange:

I still had to deal with that [marital infidelity], which was deeply painful. And I had no way out... What was I supposed to do on my own, unable to work? It was psychological torture.

For Patrícia, daily demands make it difficult to maintain the current emotional bond:

My relationship is hanging by a thread... Because of my son, because of my struggles. Because I can't manage to... We can't go out; we can't have time to ourselves.

In some cases, the strain culminated in marital separation, as shared by Paula:

We were already arguing a bit; our relationship had become worn out because I had turned into nothing but Carl's mom in the relationship.

In contrast, Mônica reported that the need to reorganize care brought the former couple closer together again following a period of regression in their son:

Moises started regressing significantly and having many crises, so I said [to my spouse], "Look, I need you," and that created both the need and the desire to rekindle our relationship.

- Support from extended family, friends, and the atypical community.

Amidst so many transformations, support networks and the extension of care become fundamental for mothers of children with atypical development who require higher levels of support. However, the responses varied widely, ranging from a refusal to accept the diagnosis to offering only occasional assistance. Betty recounted her mother's rejection:

My mother doesn't accept it [...]. I've heard her say things like, 'Wow, that boy is going to kill you one of these days, isn't he?'

In contrast, Maria identified the maternal figure as her primary source of support, albeit within a complex relationship:

My mom and I have a bit of a complicated relationship, you know? But she's the only one who helps me. It's about what she wants, what she can do, what she thinks... but she does help me, right?

The distancing from family and friends also manifested as exclusion from events and a gradual drifting apart. Paula highlighted the lack of invitations for her son:

My mother has five grandchildren; Carl is the only boy [...]. Carl has never been invited to a sleepover [...]. He is never included.

Virgínia, meanwhile, mentioned the prolonged estrangement from her son's godparents:

Jay is forty-six years old [...]. I think, well, it's been about forty years since they stopped seeking us. Of course, they forgot, right?

Solange reflected on the changes in her social circle prior to the diagnosis:

It's all a struggle, isn't it? For schools, for quality care, for everything [...]. The friendships you had before, the life you had before, it feels like [...]. It doesn't even feel like yours anymore.

Faced with this isolation, connecting with the "atypical community" emerged as a source of support, practical guidance, and mutual financial assistance. Maria highlighted the exchange of information among mothers:

"Oh, my son wins this." [mothers share with each other]. That's how we get the information.

Patricia emphasized collaborative financial support:

"I don't have the money," "I don't have the medicine" [...] "I don't have the money for the consultation." One gives 20 [reais], another gives 10.

Mathilde, in turn, emphasized the importance of these spaces for interpersonal connection:

Mothers of children with special needs are all overburdened, so there are usually groups where they can vent or call for help. They support one another.

Responsibility centered on the mother

The accounts highlight the centralization of care and routine organization in the maternal figure, frequently accompanied by paternal withdrawal or reduced paternal involvement:

- Lack of paternal involvement and maternal overburden

The role of care is permeated by social and gender determinants, which often assign women, especially mothers, the central responsibility for maintaining and organizing activities involving their children. The physical and emotional overburden resulting from isolated care was expressed by Mônica in her daily routine:

I get like that [...]. I turn into a real general [authoritarian] [...]. That's a bit hard for me, too; I end up realizing that I wind up a bit alone.

Paula described the fluctuation of feelings experienced in her daily life as a mother:

Atypical motherhood is exhausting. It's one day at a time [...] there are days when we just go through the motions [...] when we take it in stride. But there are days when it [atypical motherhood] really takes a toll on you.

The feeling of self-negation and the constant sense of failure were pointed out by Patrícia and Mathilde, respectively:

I put my own life on hold for the sake of my son, you know? (Patrícia)

Something always falls apart, whether it's your diet, your mindset, your body, your home, or the child. (Mathilde)

Regarding the father figure, the testimonies revealed physical absence, a disengagement from responsibilities, and the placing of blame on the mother for the diagnosis. Maria reported the father's estrangement from their daughter:

Her father goes there every now and then [...]. Just to be a nuisance [...]. I don't consider him part of the picture.

Mathilde, meanwhile, shared her paternal family's reaction to the diagnosis:

Her father didn't stick around, right? When I mentioned the diagnosis [...]. He, his mother, and his grandmother, they said I wanted her to be autistic.

Betty highlighted the differences in how the mother and father processed the diagnosis:

To this day, he still doesn't accept it [his son's diagnosis] [...]. I think that, as a man [...]. You have a different perspective. As a mother, we accept everything.

Virgínia mentioned her lack of confidence in her husband's ability to handle their son's crises:

He doesn't have patience; he wouldn't understand [...]. In a way, I was protecting him; he wouldn't have known how to handle it [...]. I trusted my daughters far more than I trusted him.

On the other hand, Mônica reported having actively demanded the sharing of tasks with her partner:

You need to share this with me. I can't take it anymore; I'm buckling under the strain. And today, I finally have someone to share the responsibility with.

- The meaning of autism and the experience of atypical motherhood

The experience of atypical motherhood encompasses a strong emotional bond with one's children, accompanied by the strain caused by social barriers and a lack of institutional support. Maria expressed her distress regarding her daughter's limitations:

I'm sorry, I can't stand autism, because it hurts; it's hard. I don't see my daughter happy, smiling, talking, or shouting. So, autism reminds me [...] of the pain of not seeing my daughter happy.

Paula spoke of her affection for her son alongside the strain caused by the lack of autonomy:

I love my son, and my son would be exactly who he is [...] with or without autism. He is affectionate, he is respectful [...]. Perhaps he would have greater autonomy without the diagnosis [...]. Yes, autism is part of who he is, but I still [...] hate autism [...]. This lack of autonomy takes a toll on me.

The perception of the diagnosis as synonymous with the struggle for rights and services was highlighted by Paula and Mathilde:

I even forget that my son is autistic; I only remember when I'm here [...] at some therapy session [...] fighting for public policies. (Paula)

Autism isn't difficult; the society we live in is. Because there's no support [...]. If there were support, autism wouldn't be a problem. (Mathilde)

Participants Betty and Mônica emphasized the need for recognition of the individual and the guarantee of social rights:

If you're talking about autism, you're talking about a person with a disability [...] you're talking about a human being [...]. I think there is a lot of room for improvement, specifically regarding public policies. (Betty)

I view autism [...] plurally: the right to belong, to exist [...] to be respected [...] to occupy spaces [...] to have the freedom to be who one is [...] to have our rights guaranteed as well. So that I can always [...] be his voice, too, whenever the need arises. (Mônica)

DISCUSSION

The findings of this study showed that the diagnosis marked a turning point of profound transformation in the lives of families, especially for women, who assumed a central role in caregiving. Maternal experiences revealed a recurring lack of preparedness among health professionals to recognize and address initial concerns, contributing to diagnostic delays and feelings of invalidation.

Changes in family, marital, and social relationships demonstrated a reconfiguration of support networks, often characterized by the distancing of previous ties and the forging of new connections with other families raising children with atypical development. The centrality of motherhood in daily caregiving revealed a physical, emotional, and subjective burden, marked by personal sacrifices, loneliness, and ambivalent feelings.

From a systemic perspective, the arrival of a diagnosis can be understood as an unpredictable horizontal stressor capable of destabilizing the system's equilibrium and requiring continuous reorganization among its members throughout the life cycle^{1-4,15}. In this study, the stressor stemmed from the shattering of idealized developmental expectations, manifested through the observation of atypical behaviors and comparisons with peers. However, the data also showed that maternal perceptions and initial warning signs often faced validation barriers within both the family circle and health and educational institutions.

Existing literature points to a lack of specific knowledge regarding the spectrum, which can lead to inadequate assessments, diagnostic errors, and long-term neurodevelopmental consequences⁹. The data obtained corroborate this view and go further by highlighting the emotional toll of this journey: the lack of preparedness and the attitudes of professionals during initial consultations fostered feelings of invalidation, uncertainty, and loneliness among the participants. Thus, as previous studies indicate, a lack of adequate technical and institutional support exacerbates the psychological distress experienced by caregivers^{8,16-17}, turning what should be an opportunity for guidance and support into an additional source of stress and burden.

Receiving the diagnosis, therefore, entails profound changes that extend beyond the clinical setting, requiring families to reorganize their domestic, financial, and work routines. In this study, all accounts revealed that this reorganization fell disproportionately upon the mother. As they reassessed their roles, the participants reported giving up their professional careers, studies, and leisure time to meet the demands of providing continuous, intensive care for their children. Studies have identified career interruption as a recurring feature in the lives of mothers of children with ASD, in contrast to the continuity of work routines observed among parents of typically developing children^{11,12,18}.

The centering of caregiving on the mother figure does not stem from individual choice but from deeply rooted social and gender determinants; mothers are expected to act as the primary coordinators and managers of therapeutic, emotional, and domestic needs¹⁹. This phenomenon is not limited to families with atypical children but traces back to the historical sexual division of labor, which cast women as caregivers while assigning men the role of providers²⁰.

Maternal burden was also significantly exacerbated by the absence or limited involvement of the father figure. This imbalance in the division of parenting tasks led to emotional distance, tension, relationship breakdowns, and, in some instances, the dissolution of marital bonds. The transition to parenthood can trigger marital conflict when it is not a shared experience¹, particularly in families with atypical children, where a diagnosis often alters the marital dynamic, necessitating new caregiving arrangements and frequently overburdening one partner²¹. In this context, daily caregiving falls primarily to women, intensifying feelings of loneliness and exhaustion¹².

The diagnosis also had repercussions for the family's extended support networks and pre-existing social relationships. Participants reported gradually drifting apart from family members and friends due to a lack of acceptance regarding the diagnosis and the exclusion of

their children from group events. Often, support networks were present only sporadically, failing to provide effective emotional support. From a systemic perspective, when external networks fail to offer emotional and practical support in such situations, the family system tends to turn inward, adopting a self-reliant and protective dynamic; this can intensify feelings of isolation, a pattern observed even in some atypical families²².

In contrast to the erosion of traditional social networks, this study revealed the emergence of the "atypical community" as a fundamental protective factor. Engagement in groups and associations formed by other mothers in similar circumstances, a phenomenon also highlighted in another Brazilian study²³, created spaces for listening, information exchange, and emotional strengthening. These bonds not only provided practical support but also contributed to the reconstruction of maternal identity and a sense of belonging.

Analysis of the accounts underscored the urgent need for their voices to be heard, a point emphasized by all study participants, who shared how rarely they had the opportunity to express their pain and their desire to actively collaborate in the fight for rights and the strengthening of support networks. In sharing what autism meant in their lives, the participants emphasized their desire to be seen, heard, and respected in their unique circumstances, asserting their right to participate in social spaces with dignity and recognition.

This struggle extends beyond caring for their children; it also encompasses the visibility of these mothers – and other women – and their stories, fostering a more sensitive perspective on the family system as a whole. Despite the many challenges, these women were able to develop coping strategies and networks of solidarity that allowed them to redefine the nature of caregiving and the experience of atypical motherhood.

CONCLUSION

Following the ASD diagnosis, the family system underwent a series of profound and lasting changes, affecting everything from daily routines to marital and social relationships. The centrality of mothers in the narratives highlights the responsibility women bear in addressing the practical, emotional, and subjective demands associated with ongoing caregiving.

Maternal experiences revealed a recurring lack of preparedness among health professionals to recognize and address initial needs, contributing to diagnostic delays and feelings of invalidation. Changes in family, marital, and social relationships were marked by the distancing from previous ties and the forging of new social connections, particularly with other atypical families.

The study's gender-specific focus is highlighted as a potential limitation; although the research was widely publicized, all participants were women. This focus should be taken into account when analyzing family changes following an ASD diagnosis, given that the findings underscored the central role mothers play in atypical families. The absence of men significantly reflects the secondary role many fathers still occupy regarding caregiving responsibilities within parenting contexts, as noted by the participants themselves.

While the detailed analysis in this study allowed for an in-depth exploration of family changes following the diagnosis, there is a need for future research to also investigate the experiences and subjective implications for fathers. Such a broader perspective would allow for an exploration of shared parental responsibility and gender dynamics in the care of children, adolescents, and adults with ASD.

This research provides valuable insights for developing support strategies that are more responsive to the realities of atypical families. By highlighting the burdens, relational rearrangements, and the reconstruction of support networks associated with atypical motherhood, the findings point to the urgent need for intersectoral public policies that foster shared responsibility for care, quality access to services, and the strengthening of support networks.

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