



THE PSYCHOLOGICAL SUFFERING IN THE MOTHERHOOD OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

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Abstract:

This research aims to understand the dimensions that constitute the psychological suffering of mothers of children diagnosed with Autism Spectrum Disorder (ASD), based on their subjective experiences and the adaptations required by atypical motherhood. Motherhood, often shaped by social and personal idealizations, undergoes a significant rupture when the child is diagnosed with a developmental disorder. The diagnosis of ASD demands emotional, practical, and identity reorganization, requiring the construction of new meanings for the mother-child bond and for the maternal experience itself. Moreover, since the responsibility of care often falls primarily on the mother, there is an increased physical and emotional burden, which may trigger feelings such as guilt, exhaustion, and frustration. The main objective of this study is to analyze the factors that affect the psychological suffering of these women, based on three analytical axes: (1) the journey of motherhood and the discovery of ASD; (2) the impacts of the diagnosis and the adaptation processes; and (3) coping strategies and mental health care. Structured interviews were conducted with two mothers and qualitatively analyzed in light of specialized literature on motherhood, identity, overload, and care. The data reveal different ways of experiencing the diagnosis and daily demands, but converge on the perception of an intense process of subjective resignification and life reorganization. This study aims to contribute theoretical and practical reflections that promote welcoming, listening, and care for mothers of children with atypical development, emphasizing the importance of support networks and psychological strategies tailored to their specific experiences.

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1. Introduction

Motherhood involves a series of challenges that affect a woman's body, emotions, and social life. From the beginning of pregnancy, women undergo significant transformations that impact their identity and the way they relate to the world around them (Piccinini et al., 2008). Even in situations considered normative, this process can be accompanied by feelings of insecurity, doubt, and anguish. When, in addition to this, the diagnosis of Autism Spectrum Disorder (ASD) is given to a child, these difficulties deepen, requiring the mother to undertake a process of resignification in response to this rupture of expectations and the accumulation of caregiving responsibilities.

According to the Diagnostic and Statistical Manual of Mental Disorders – DSM-5 (APA, 2014), autism is classified as a neurodevelopmental disorder and characterized by difficulties in social interaction and communication, as well as restricted and repetitive patterns of behavior, interests, and activities.

Moura and Araújo (2004) argue that, in Western culture, motherhood has historically been conceived as a natural destiny for women, reinforcing idealizations of the maternal role. Chodorow (1990) points out that this essentialist view, constructed over centuries, associates femininity with caregiving, self-sacrifice, and unconditional love, which forms a social imaginary that many women internalize from an early age. This process of subjectivation, as Ciampa (1987) describes, results in what he calls “myth-identity”: a socially imposed identity sustained by collective norms and expectations that do not always align with lived reality.

For a long time, maternal care was seen as a natural part of motherhood, and, therefore, an essentially feminine function. However, authors like Chodorow (1990) argue that this association stems more from social and cultural constructions than from biological nature. Historical research (Ariès, 1981; Badinter, 1985; Donzelot, 1986) shows that the idea of maternal love as instinctive and natural is, in fact, a recent invention, promoted by philosophical, medical, and political discourses since the 18th century.

Although the notion of motherhood as an exclusively female responsibility remains dominant, Patricia Hill Collins (2000) highlights that in many African diaspora communities – such as among African Americans – child rearing has historically been shared among women in the community. This form of collective motherhood, built on solidarity and resistance networks, helped to reduce the individual burden on mothers, even though it did not eliminate structural and social pressures.

Within this context, the diagnosis of Autism Spectrum Disorder (ASD) acts as a breaking point. It destabilizes the internalized idea of the “perfect mother” and the “ideal child,” compelling many women to reconstruct not only their parental projects but also deeper aspects of their own identity. This reconstruction, marked by emotional, social, and symbolic challenges, is particularly intense in Western culture, where the ideal of the

devoted, strong, and tireless mother still prevails — a model that often silences the real suffering and vulnerability inherent in the maternal experience.

Núñez (2007) emphasizes that the diagnosis of a disability in a child represents a crisis that disrupts family dynamics, requiring both emotional and practical reorganization. As Souza and Silva (2025) point out, self-care and emotional support are essential for preserving the mental health of these women, who often give up personal aspects of their lives in order to care for their children.

This article presents the results of a qualitative study conducted through structured interviews with two mothers of children diagnosed with ASD. The goal was to investigate their experiences related to psychological suffering in atypical motherhood, exploring three analytical axes: (1) the motherhood journey and the discovery of ASD; (2) the impacts of the diagnosis and the adaptations experienced; and (3) the care and coping strategies adopted. Through attentive listening and theoretical articulation, this study seeks to understand how suffering manifests in their narratives and how these women mobilize resources to cope with the demands of atypical motherhood.

2. Literature Review

Motherhood deeply marks a woman's life path, being permeated by idealizations and desires often formed during childhood. Throughout pregnancy, the woman undergoes biological, psychological, and social transformations that directly influence her self-perception and the way she constructs her experience as a mother (Piccinini et al., 2008). However, beyond individual changes, motherhood is also embedded in social and historical constructions that, from an early age, associate being a woman with the maternal function, naturalizing this role as an essential and identity-defining destiny (Moura & Araújo, 2004). This socially constructed ideal, which portrays motherhood as a space of complete fulfillment and unconditional love, often conflicts with the concrete lived experience of motherhood — especially when unexpected situations arise, such as having a child with atypical development. In such cases, feelings of frustration, ambivalence, and overload may emerge, requiring a continuous process of resignification.

The idealization of motherhood begins to unravel — sometimes gradually, sometimes abruptly — when the first signs appear that the child's development does not follow the expected course. At this moment, the image the mother built during pregnancy — full of expectations and projections — gives way to the encounter with the real child, with their singularities, challenges, and limitations (Smeha & Cezar, 2011). This is a delicate process in which the imagined maternal identity (Ciampa, 1987) begins to dissolve amidst uncertainty, the search for answers, and often the lack of a clear diagnosis. As the mothers' narratives revealed, this initial stage is marked by intense feelings of anguish and loneliness, often exacerbated by the difficulty in naming or understanding their suffering, along with the pressure to maintain an idealized performance in a reality that demands deep and constant adaptations.

3. Materials and Methods

This is a cross-sectional qualitative study, whose fieldwork was carried out through the development and application of a structured interview questionnaire aimed at mothers of children diagnosed with Autism Spectrum Disorder (ASD). The objective was to investigate the dimensions that constitute the psychological suffering in the motherhood of children with ASD, articulating this issue with the lived realities and burdens these women experience, as well as the coping strategies adopted to maintain their mental health in atypical motherhood and to face the challenges encountered.

The investigation was conducted through the participation of two mothers of children diagnosed with ASD. Both participants reside in the city of Limeira and attend a psychotherapy clinic also located in the same municipality in the state of São Paulo, Brazil.

To preserve their identities, the mothers were identified as Mother A and Mother B. Regarding age, Mother A is 41 years old and married; Mother B is 37 years old and divorced. Both completed high school, and Mother B is currently pursuing a degree in pedagogy.

The interview questionnaire addressed nine thematic areas: demographic data (age, marital status, educational level); the discovery of motherhood; pregnancy experiences; perception of atypical developmental traits; knowledge about ASD before and after the diagnosis; perceived stress levels; support networks (family, friends, institutions); frequency and types of therapies used; and coping strategies adopted.

The project was approved by the Research Ethics Committee on Human Subjects of the Centro Universitário Einstein – UniEinstein, under protocol number 7.192.972. After signing the Informed Consent Form, the participants took part in individual interviews, which posed no risk to their well-being.

For the purpose of data analysis, three thematic categories were created:

- **Topic 1** – From Idealization to Resignification: Transformations of Maternal Identity in Atypical Motherhood;
- **Topic 2** – Impacts of Diagnosis and Adaptation (knowledge before and after the diagnosis; perceived stress);
- **Topic 3** – Therapeutic Practices and Coping Strategies in Atypical Motherhood: A Perspective on Multidimensional Care.

4. Results and Discussion

4.1 From Idealization to Resignification: Transformations of Maternal Identity in Atypical Motherhood

Through the conducted interviews, both participants – Mother A and Mother B – reported that their pregnancies were planned and celebrated. However, throughout this journey, their maternal experiences were permeated by idealized expectations, intense emotions, and adaptation processes that deeply marked their identities as mothers.

In the case of Mother B, the idealization was expressed explicitly: since childhood, she dreamed of having a boy, imagined the decoration of the baby's room, and desired a natural birth. These expectations reflect what Ciampa (1987) describes as a "myth-identity" — a social and culturally constructed identity —. With the discovery of her child's ASD diagnosis, these idealized images dissolved. The child did not correspond to what had been expected, generating a rupture that required a subjective repositioning. B reported consulting several pediatricians until receiving the diagnosis, and upon receiving it, she felt a sense of relief — finally able to name what she had already sensed and to begin providing appropriate therapies to her son, while also reorganizing her own path as a mother.

Mother A experienced her pregnancy amid marital difficulties. Although her idealizations were not verbalized as clearly as Mother B's, there was still an underlying expectation of motherhood that was deconstructed as atypical behaviors emerged in her child. She mentioned significant changes in her daily routine and social withdrawal, revealing a process of identity metamorphosis — a shift from an expected identity to a new one, reconstructed from the concrete and transformative experiences of atypical motherhood (Ciampa, 1987).

In both cases, the experience of motherhood was marked by a significant rupture of expectations. These women found themselves having to let go of part of their idealizations and construct new meanings around what it means to be a mother.

4.2 Impacts of Diagnosis and Adaptation

Mother A reported that her child seemed to "stagnate" at a certain stage of development, beginning to present more intense sensory crises, especially in unfamiliar or overstimulating environments. Faced with this situation, she stopped attending social gatherings, distanced herself from friends, and began investigating her child's behaviors. It is common for mothers in similar situations to withdraw from social settings as a form of protection against potential judgment directed at themselves or their children. They recognize their child's vulnerability to prejudice and feel responsible for shielding them from discrimination (Smeha & Cezar, 2011). Mother A also expressed uncertainty about how to handle her son's crying crises, particularly due to a lack of information about ASD. This highlights the importance of access to services that provide guidance and support, helping mothers understand their child's specific needs and develop the necessary skills to foster their development (Russa et al., 2015), thus reducing feelings of helplessness.

For Mother B, the perception occurred differently. Because she works in an educational setting, her awareness of developmental milestones was more refined. She was able to identify non-functional play behaviors and speech delays, recognizing that something needed to be investigated. Her greatest source of anguish, however, was the diagnostic process itself, as she consulted multiple physicians who dismissed her concerns. Walking this path without a diagnosis led to a profound sense of helplessness.

It is important to note that each person experiences the diagnosis in a unique way. In the interviews, two different responses to this experience were observed. Mother A shared intense feelings of guilt, questioning whether she had done something wrong. This emotional response reflects the historical burden placed on mothers by outdated theories that associated autism with maternal emotional coldness. One of the most well-known theories was proposed by Leo Kanner in his 1943 study “Autistic Disturbances of Affective Contact,” which introduced the damaging concept of the “refrigerator mother” (Corrêa, 2017). Although this theory has since been disproven, its legacy continues to influence discourses that place blame on mothers and intensify their suffering.

In contrast, Mother B reported feeling relieved when she finally received the diagnosis, as it allowed her to name what she had sensed and to begin researching and seeking appropriate care for her child. As Smeha and Cezar (2011) affirm, each mother’s experience may include sadness, shock, guilt, or even a sense of relief in finally being able to offer adequate support.

In both cases, the diagnosis led to significant changes in the mothers’ lives. Each woman assumed a routine filled with responsibilities — taking their children to therapies, school, medical appointments, and more. The role of caregiver became a central part of their lives, and in most cases, this responsibility falls predominantly on the mother (Smeha & Cezar, 2011). Historically, women have taken on caregiving roles, and having a child with atypical development often intensifies this responsibility, resulting in task overload (Kostycz & Ienk, 2024).

Mother A described her daily life as intense and filled with responsibilities. Following her divorce, weekday caregiving duties became entirely hers. This made it difficult for her to maintain a job with fixed hours, so she began working freelance shifts in a jewelry factory in the afternoons. As noted by Gomes et al. (2015), it is common for mothers of children with ASD to encounter challenges in continuing their careers due to the demands of caregiving. In her interview, it became clear that Mother A had to give up aspects of her social, professional, and personal life to fully dedicate herself to motherhood, resulting in changes in her own identity as a woman.

Both mothers who participated in the study have been diagnosed with depression and are undergoing psychological treatment.

4.3 Therapeutic Practices and Coping Strategies in Atypical Motherhood: A Perspective on Multidimensional Care

Based on the interviews with two mothers of children diagnosed with Autism Spectrum Disorder (ASD), referred to in this study as Mother A and Mother B, this section aims to understand the therapeutic approaches adopted for their children, the frequency and types of interventions used, as well as the coping strategies mobilized by the mothers in their daily lives. The analysis of the narratives revealed both the investment in clinical and educational care for the children and the attention directed toward the emotional health of the mothers themselves.

Both mothers demonstrated active involvement in their children’s therapeutic processes, adopting multidisciplinary strategies. Mother B emphasized the use of Applied Behavior Analysis (ABA) as the central approach, in conjunction with occupational therapy, psychopedagogy, and physiotherapy. ABA has proven effective in supporting the development of children with ASD, as it structures interventions around each child’s specific needs, contributing to improvements in social and behavioral skills and promoting inclusion in various environments, including schools (Dias et al., 2023). Mother A reported regular sessions with a speech therapist, psychologist, psychopedagogue, and occupational therapist.

Speech therapy is especially important when working with children on the autism spectrum, as communication difficulties are common in this population. The speech therapist aims to support both verbal and nonverbal language development, not only improving speech but also fostering meaningful social interactions and autonomy for individuals with ASD (Moraes et al., 2022). Occupational therapy, the second most mentioned intervention in this study, focuses on developing autonomy through sensory, motor, and cognitive skills training. These findings emphasize the importance of interdisciplinary collaboration in supporting children with ASD (Fagundes et al., 2024).

In addition to the therapeutic care provided to their children, both mothers also participate in psychotherapy. Mother B expressed deep appreciation for this process, highlighting the value of being heard and emotionally supported. Mother A emphasized not only the importance of psychotherapy but also the role of self-care, made possible through the involvement of the child’s father, which allowed her some time to rest and emotionally recover.

To better illustrate the therapeutic routines of each family, a table was created detailing the frequency and types of therapies received by both the mother and the child with ASD.

Table 1: Frequency of Therapies for Mother and Child

	Mother A	Child of Mother A	Mother B	Child of Mother B
Psychotherapy	X		X	X
Psychiatry	X			
ABA Therapy		X		
Occupational Therapy		X		X
Psychopedagogy		X		X
Physiotherapy		X		
Speech Therapy				X

Source: Developed by the researchers.

The mothers who participated in the study described in detail how their daily routines are organized, especially in their role as primary caregivers of children with ASD. The therapies are scheduled throughout the week, highlighting the total dependence on the mother to ensure the child's ongoing development.

- **Child of Mother A:**

ABA therapy: three times a week (Mondays, Tuesdays, and Fridays).

Occupational therapy: Wednesdays.

Psychopedagogy: Wednesdays.

Physiotherapy: Thursdays (due to motor difficulties).

- **Mother A:**

Psychotherapy and psychiatric follow-up.

- **Child of Mother B:**

Speech therapy, psychology, psychopedagogy, and occupational therapy: once a week each, from Tuesday to Friday.

- **Mother B:**

Weekly psychotherapy: Mondays in the morning.

Self-care activities on the days the child is with the father.

It is understood that ASD requires a multidisciplinary support network to foster both psychological and physical development. Regardless of the specific characteristics of the disorder, a neurodivergent diagnosis demands specific care and treatment, and families must adapt and reorganize their routines to meet these needs effectively (Pastorelli et al., 2024). In this context, the interviewed mothers embraced these adjustments, recognizing the importance of seeking ongoing professional support such as psychologists, speech therapists, occupational therapists, and others (Lowenthal, 2021).

The coping strategies mentioned by the participants involved both professional and emotional support. Mother B emphasized the value of therapeutic follow-up, particularly personal psychotherapy, which she has engaged in since her pregnancy, and the presence of a support network. For her, being heard and having space for emotional expression are essential for managing everyday challenges. Contini, Costa, and Amaral (2023) emphasize the importance of therapeutic listening during pregnancy, noting its contribution to emotional well-being and to a healthier gestational experience.

Mother A, on the other hand, highlighted the importance of rest and the opportunity to share experiences with other mothers through a monthly support group offered by her child's school. Participating in this group allows for the exchange of experiences and the collective construction of practical solutions. As noted by Júnior, Araújo, and Rocha (2021) in their reflection on "Who takes care of those who care?", it is crucial to create welcoming and listening spaces for individuals who live similar realities – in this case, mothers of children with ASD –. These spaces foster mutual learning and the development of new coping strategies. Psychological intervention in such environments proves effective, as the professional perspective helps broaden understanding and generates new interpretations of lived experiences.

Furthermore, the mothers' reports reveal motherhood as a powerful source of strength and motivation, in which the care of their children is central to their emotional coping process.

5. Recommendations

The participants' narratives reflect what Souza and Silva (2025) describe as the emotional overload caused by the weight of responsibilities, whether physical, emotional, or financial. The authors emphasize that self-care is essential and helps with stress management and the development of strategies to preserve mental and emotional well-being. They stress the importance of mothers setting aside time for themselves and seeking support when needed.

It is equally important to highlight the significant role that relationships play in family dynamics, where challenges and adjustments may arise to sustain a resilient support network. This network should include family, friends, professionals, and the support found in groups where experiences are shared and guidance is provided by qualified professionals (Souza & Silva, 2025).

The convergence between therapeutic practices, emotional support, and support networks is a fundamental pillar in the experience of atypical motherhood. Moreover, it is essential for mothers of children with ASD to raise awareness within their families about the importance of self-care, as these women often give up their social and personal lives in order to meet the demands of caregiving.

The continuation of this research will allow for a broader understanding of the challenges faced and the resources mobilized by these mothers, contributing to the development of strategies that consider both the child's care and the preservation of family well-being.

6. Conclusion

This qualitative study aimed to understand the dimensions of the psychological suffering experienced by mothers of children diagnosed with Autism Spectrum Disorder (ASD) through the attentive listening of their subjective experiences, daily challenges, and coping strategies. The choice of centering this study around the mothers' narratives was guided by the understanding that atypical motherhood cannot be comprehended solely through diagnostic criteria or societal expectations, but rather as a complex experience marked by contradictory emotions, support networks (or lack thereof), and ongoing processes of adaptation.

The participants' narratives revealed intense and recurring feelings such as guilt, frustration, loneliness, fear, and exhaustion. These emotions emerge in response to the rupture of socially constructed expectations of what "ideal motherhood" should be — expectations that often overlook the specificities of atypical experiences —. As highlighted by Rios (2018), societal discourses and expectations placed on mothers are continuously reinforced by ideals of completeness, unconditional dedication, and personal fulfillment through motherhood. In the case of atypical motherhood, these ideals clash with a reality shaped by persistent challenges, physical and emotional exhaustion, and difficulties accessing healthcare and support services. As a result,

mothers of children with ASD frequently experience emotional overload, which can impact their identity, mental health, and autonomy, especially in a society that continues to demand an idealized and often unattainable maternal performance.

The data analysis showed that the psychological suffering of these mothers does not stem solely from the child's diagnosis but is closely related to the lack of emotional, social, and institutional support. In a context where caregiving responsibilities fall almost exclusively on mothers, there is an often-invisible burden that significantly contributes to emotional and physical exhaustion. The absence of effective public policies, the fragility of mental health services, the lack of safe listening spaces, and the moral judgment imposed on mothers who express suffering constitute a scenario of structural neglect.

Despite these adversities and the particularities of each narrative, the interviewed mothers demonstrated the active construction of coping strategies. Among these are seeking psychotherapy, forming formal and informal support networks, engaging in self-care, and sharing experiences with other mothers in similar situations. These strategies reflect both resilience and the importance of collective support and shared experiences as a form of resistance to isolated suffering. In this context, motherhood becomes a space of constant resignification, where suffering is not erased, but can be welcomed, worked through, and transformed through listening and support.

Atypical motherhood, therefore, demands not only practical adaptations — such as reorganizing family routines, attending therapy sessions, or facing social prejudice — but also profound subjective transformations. Mothers go through a process of identity reconstruction, in which the idealized figure of the mother gives way to a real, human mother who suffers, feels, and rebuilds herself every day. This resignification is only possible when there is room for suffering to be legitimized and supported, rather than silenced or blamed. As the narratives showed, what mothers often lack is not love for their children, but the basic conditions and support to continue caring without completely erasing themselves in the process.

In conclusion, there is an urgent need to expand public policies focused on maternal mental health, creating specific psychosocial support programs for mothers of children with ASD, as well as increasing the availability of free and accessible psychological care. It is also essential to invest in interdisciplinary training for professionals who work with these families, so that care goes beyond the technical dimensions of child development and also addresses the emotional and relational aspects of mothers and caregivers.

From an academic and scientific perspective, this research reinforces the importance of listening to mothers as protagonists of their stories, not merely as supporting figures in the caregiving process. Clinical listening — ethical and sensitive, grounded in the recognition of subjectivity and the value of lived experience — is a fundamental tool for building more humane and effective practices in mental health and social care.

Finally, the continuation of this study, with the inclusion of more participants and the expansion of analyzed contexts, may contribute to a more comprehensive understanding of the many forms of suffering and resistance that shape atypical motherhood. By giving voice to these women, this study aims not only to understand their experiences, but also to propose possible pathways for the integral care of mothers who face, with courage and vulnerability, the challenges of motherhood in the context of ASD.

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Conflict of Interest Statement

The authors declare no conflicts of interest.

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