

## Maternity experience experienced by mothers of children with autistic spectrum disorder: integrative review

Experiência da maternagem vivenciada por mães de crianças com transtorno do espectro autista: revisão integrativa

*Experiencia de la maternidad vivida por madres de niños con trastorno del espectro autista: revisión integradora*

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### Abstract

**Objective:** This study aimed to identify mothers' experiences of children with Autism Spectrum Disorder in the exercise of motherhood. **Method:** An integrative review, carried out between July and August 2023, during six stages: identification of the theme and selection of the research question; literature search; data extraction and categorization; critical analysis of the studies included; interpretation of the data; presentation of the review; synthesis of knowledge. **Results:** A total of 1946 studies were identified, with the final sample comprising nine articles. The mothers used a variety of strategies to establish an emotional bond with their children, made possible by the learning they gained from their constant and often exclusive daily dedication. **Conclusion:** The exercise of motherhood by mothers of children with Autism Spectrum Disorder is revealed through the development of the ability to reinvent themselves as mothers, during and after the diagnosis, to assume a new identity.

**Descriptors:** Mothers; Autism Spectrum Disorder; Child; Mother-Child Relations; Maternal Behavior

### Resumo

**Objetivo:** identificar as experiências vivenciadas por mães de crianças com Transtorno do Espectro Autista no exercício da maternagem. **Método:** revisão integrativa, realizada no período de julho a agosto de 2023, durante seis etapas: a identificação do tema e seleção da questão de pesquisa; busca na literatura; extração de dados e categorização; análise crítica dos estudos incluídos; interpretação dos dados; apresentação da revisão; síntese do conhecimento. **Resultados:** identificaram-se 1946 estudos, com a amostra final composta de nove artigos. As mães lançaram mão de várias estratégias para estabelecer vínculo afetivo com os seus filhos, oportunizado pelo aprendizado construído a partir da dedicação diária constante e muitas vezes exclusiva. **Conclusão:** o exercício da maternagem de mães de crianças com o Transtorno do

Espectro Autista revela-se por meio do desenvolvimento da capacidade de se reinventar como mães, durante e após o diagnóstico, a fim de assumir, assim, uma nova identidade.

**Descritores:** Mães; Transtorno do Espectro Autista; Criança; Relações Mãe-Filho; Comportamento Materno

## Resumen

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**Objetivo:** Identificar las experiencias de madres de niños con Trastorno del Espectro Autista en el ejercicio de la maternidad. **Método:** revisión integradora, realizada entre julio y agosto de 2023, en seis etapas: identificación del tema y selección de la pregunta de investigación; búsqueda bibliográfica; extracción y categorización de datos; análisis crítico de los estudios incluidos; interpretación de los datos; presentación de la revisión; síntesis del conocimiento.

**Resultados:** se identificaron 1946 estudios, y la muestra final se compuso de nueve artículos. Las madres utilizaron diversas estrategias para establecer un vínculo afectivo con sus hijos, posibilitado por el aprendizaje obtenido en la dedicación diaria, constante y muchas veces exclusiva. **Conclusión:** el ejercicio de la maternidad por las madres de niños con Trastorno del Espectro Autista se revela a través del desarrollo de la capacidad de reinventarse como madres, durante y después del diagnóstico, para asumir una nueva identidad.

**Descriptores:** Madres; Transtorno del Espectro Autista; Niño; Relaciones Madre-Hijo; Conducta Materna

## Introduction

Autism Spectrum Disorder (ASD) is defined as a neurodevelopmental disorder that presents as characteristics of communication, social interaction, and socio-emotional reciprocity. In addition, ASD has restricted and repetitive patterns of behavior, interests, or activities, such as repetition of speech, movement, or use of objects, manifested in the first years of life.<sup>1</sup>

Mothers of children with ASD are generally the primary caregivers for the demand for constant care with their children, which can result in physical, mental, and emotional exhaustion, and progress toward the emergence of depressive disorders, which potentially influence the development of their children.<sup>2-3</sup> The well-being and mental health of the mother compromise the relationship between mother and child, i.e., the establishment of maternity, since the fragility of this bond can bring damage to the improvement of the cognitive, motor, emotional, and social abilities of the child, especially those who have the disorder.<sup>4</sup>

The exercise of maternity is defined as the process by which the relationship between mother and child is strengthened, exercised through the daily care, welcoming, love, caring, and care applied to the child.<sup>5</sup> It is therefore built from the womb, in such a way that this bond will be strengthened as the mother provides her child in all aspects,

whether physical or psychological. Thus, the development of a good motherhood is decisive for constructing the child's personality, as it builds in it the feelings of confidence, independence, and security.<sup>6</sup> It should be noted that this process is unique; each mother will individually play out their way of motherhood.

The Winnicottian perspective leads to the understanding that in early childhood, the child is completely dependent on the mother, and that it is up to her to commit time, affection, and dedication to meet needs in a satisfactory way. At this stage, the child also begins the process of independence, when the mother returns to perform her daily activities and ceases to be available full-time, so the child begins to build himself internally and to identify the external world, which enables her to take possession of her care and build her social relationships.<sup>5</sup>

But considering that the identification of ASD symptoms occurs in the first years of age – corresponding to the first and early second childhood – it is understood that the mother of a child with ASD will have to face a series of challenges to be able to develop their maternity in a satisfactory way, as the stages of childhood development of their children will take an atypical form, mainly due to the limited autonomy of autistic children and the difficulty of their interactions with the world.<sup>1</sup>

Maternity, in this context, will involve the practices and adapted strategies that demand sensitivity, patience, and knowledge about ASD. In this sense, it is necessary to carry out studies<sup>7</sup> that aim to identify the common barriers and challenges faced by atypical mothers (a term used to refer to mothers exercising a maternity outside of normative standards),<sup>8</sup> and that point out the paths for effective interventions, to promote support, both for children with ASD and for their families, to strengthen emotional ties and improve the quality of life of all involved.

The study of this theme is justified by being of collective interest and presenting a political-social character, which considers the complexity and singularity of the atypical maternal experience. By giving voice to the experiences of mothers, it is possible to combat stigmas and prejudices related to autism, as well as promote greater awareness and inclusion.<sup>9</sup>

In this way, the objective was to identify the experiences experienced by mothers of children with ASD in the exercise of maternity.

## Method

This is an integrative review of the literature carried out in six stages: identification of the topic and selection of the research question; search in the literature; extraction of data and categorization; critical analysis of the studies included; interpretation of the data; presentation of the review/synthesis of knowledge.<sup>10</sup>

It was established as the theme: "Children with ASD". From there, the object of the study was defined, the interest in the maternity experience of mothers of children with ASD was specified, through the following guiding question: "How did mothers of children with ASD experience maternity?". The PICO strategy was used (P- mothers of children with ASD; I- maternity experience; Co-indetermined).

The search took place from July to August 2023. Two researchers operationalized the collection in a pair of ways. The search strategy used the combination of descriptors registered in Descriptors in Health Sciences/Medical Subject Headings (DeCS/MeSH) with the use of the *Boolean AND* and *OR* operators. The combination established was: (*autistic child OR autism spectrum disorder*) *AND* (*experience OR mother-child relations*) *AND* mothers.

The review was carried out in the databases integrated into the Virtual Library of Health (BVS): the Latin American and Caribbean Literature in Health Sciences (LILACS), the Medical Literature Analysis and Retrieval System Online (MEDLINE), the Nursing Database (BDENF), the Index Psychology, plus the PubMed, Scopus and the Web of Science. The databases were accessed through the Federated Academic Community (CAFe) in the Journal Portal of the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES).

Complete articles were included in any language with the 2018 time cut. After the search, the studies were exported to the *Rayyan® Software*, which enabled the verification of duplicates, the reading of the title and the summary of the publications, to select the articles for the reading of the full text, and thus include the publications that would make up the final sample. It is highlighted that this

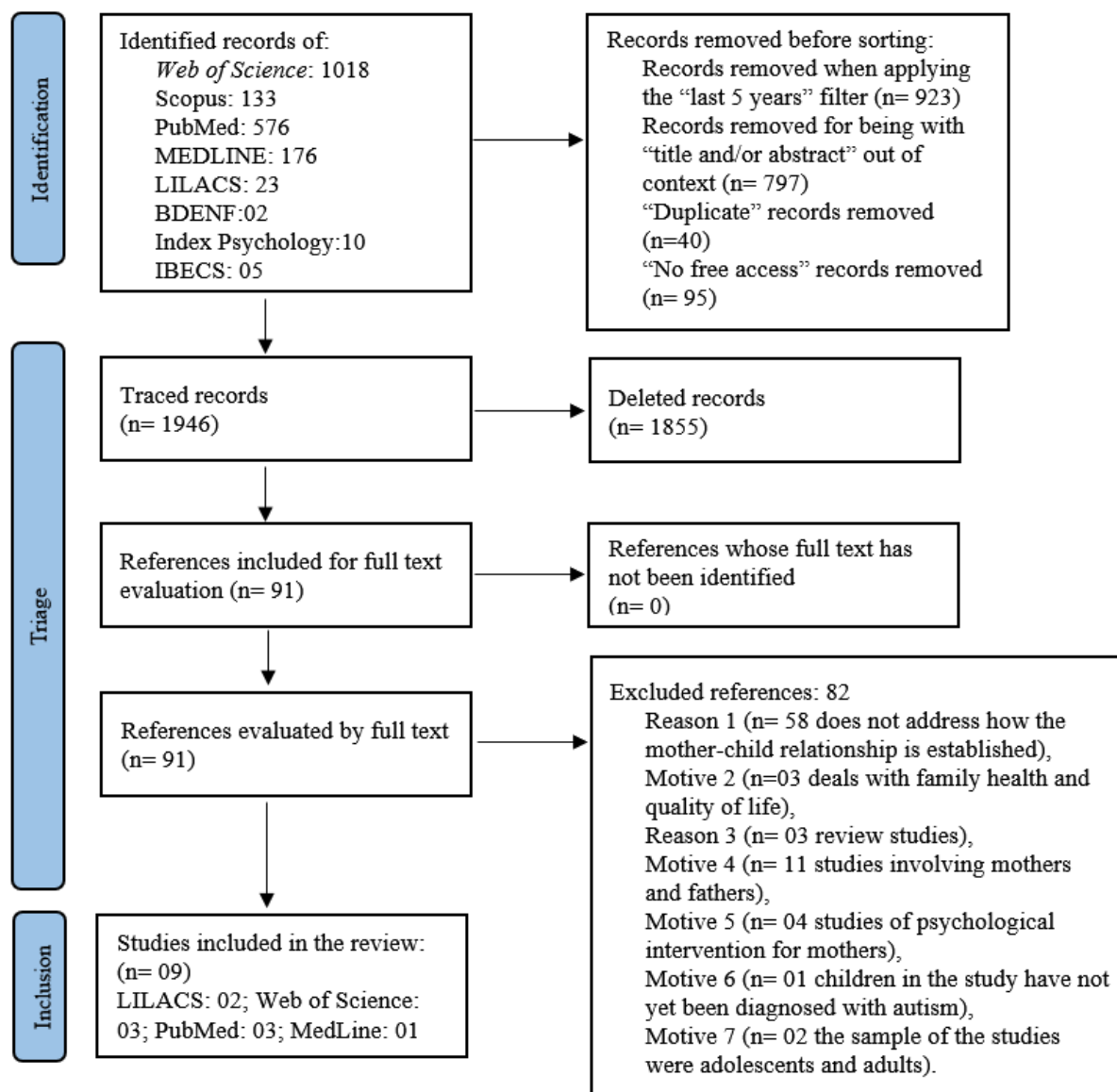
stage was carried out blindly to avoid biases, and there was the participation of two researchers from the graduate program in Nursing of the Universidade do Estado do Pará (UEPA) and the Universidade Federal do Amazonas (UFAM). There were no differences.

After defining and extracting the information from the articles included, a chart was prepared in Microsoft Office Excel 2019, with the identification of the study according to: year, area of knowledge, country where the research was conducted, Evidence Level (EL), type of study, objective and synthesis of the results. As for EL, the studies were classified into the following levels: Level 1: evidence resulting from the meta-analysis of multiple controlled and randomized clinical trials; level 2: evidence obtained from individual studies with experimental delineation; level 3: evidence from quasi-experimental studies; level 4: evidence from descriptive (non-experimental) or qualitative approach studies; level 5: evidence from case reports or experience; level 6: evidence based on expert opinions.<sup>11</sup>

It should be noted that the information analyzed in the selected studies was presented unchanged, i.e., the original production was followed. For the organization of the review, the article was translated into Portuguese when it was in Spanish or English.

## **Results**

The sample of this review study comprises nine articles. Figure 1 shows the flowchart of the selection path of the articles.<sup>12</sup>



**Figure 1** - Fluxogram of identification, selection, and inclusion of studies

When analyzing the studies by year of publication, we highlight the period from 2019 to 2023, in which the majority were published in the year 2021 (four), followed by the year 2020 (two), and 2019, 2022, and 2023 (one each year). As for the area of knowledge, they are predominantly linked to health, more specifically to Psychology, Psychiatry, and Neuroscience, with only one study published in the Journal of Nursing. As for the country of publication, Brazil was highlighted (three), followed by Greece, Nepal, Ethiopia, Iran, Pakistan, and the United States (one in each country). All studies present level 4 as qualitative approach studies.<sup>6</sup> (Chart 1)

**Chart 1** - Characterization of the study sample included

Year	Country of publication	Area of Knowledge	Type of study/ Participants	Objective	Summary of results
2019 <sup>13</sup>	Brazil	Nursing	Qualitative research, anchored in heideggerian phenomenology/ Interviews with 14 mothers of children diagnosed with ASD	To reveal the senses of mothers in cohabitation with the children affected by ASD.	The mothers report that living with their children generated a lot of learning.
2021 <sup>14</sup>	Brazil	Psychology	Qualitative research, supported by the construction of categories/ interviews with nine mothers of children with ASD.	Understand the perceptions and feelings of the mothers of children who present ASD and identify what internal resources and social support they use.	The mothers report that they are fully dedicated to their children because they saw the need to protect them. They also highlighted the daily learning with the children and the tightening of their bond through various mechanisms.
2022 <sup>15</sup>	Brazil	Collective health	Qualitative research, with narrative reconstruction/narratives produced by mothers of children with ASD, available on <i>YouTube</i> .	Analyze the narratives of autistic mothers about their experiences with their children.	It was identified that, along with the diagnosis, a mother emerged with a new identity, "a mother of autism". Subjectively, these mothers construct a new way of maternity, made possible through the daily

					relationship with their children.
2021 <sup>16</sup>	Greece	Neuroscience	Qualitative exploratory method with interpretative phenomenological analysis/ interviews with nine mothers of children with ASD.	Investigate the experiences experienced by mothers of children with ASD in Greece.	The mothers report that their children need support 24 hours a day, and that it is frustrating to feel that they are unable to meet their care demands, especially in times of crisis.
2021 <sup>17</sup>	Nepal	Research and treatment of autism	Qualitative phenomenological research/ interviews with nine mothers of children diagnosed with ASD.	Explore the experiences experienced by mothers raising children with autism.	In this study, mothers needed to make some changes in their parenting style to meet the demands of their children, in addition to having more patience and know how to deal with crisis moments.
2023 <sup>18</sup>	Ethiopia	Behavioral and mental health	Qualitative research / semi-structured interviews with 20 mothers of children diagnosed with ASD.	Examine the experiences of mothers in Ethiopia who raise a child with ASD.	The mothers report that the first step to adopting the new maternal practices is to accept the diagnosis of the child. They reinvented themselves as mothers to meet the needs of their



					children. Even with some difficulties in creating a bond with their children, over time they struggled to create other ways to relate to them.
2021 <sup>19</sup>	Iran	Pediatric psychiatry	Qualitative study using the conventional content analysis/interviews approach with 27 mothers of children with ASD.	Identify the perceptions of mothers about the stress caused by the lifelong care of a child with ASD.	According to the reports of the mothers, a number of factors can lead to the rupture of the mother-child relationship, such as concerns, psychological suffering and even the child's behavior.
2020 <sup>20</sup>	Pakistan	Psychology	Qualitative research with the interpretative phenomenological approach / Interviews with 15 mothers of children with ASD.	Explore how mothers experience and navigate their experiences with their children with ASD and investigate how the diagnosis process began and how the ASD dealing changed	In this study, the mothers affirmed that when they received the diagnosis, they engaged in an extra love and affection for their children, that acceptance and establishment of a routine helped them over the years, and that there were many changes in the family routine

				over time.	to adapt to the demands of the children.
2020 <sup>21</sup>	<i>United States</i>	Psychology	Qualitative research with the phenomenological approach / Interviews conducted with 13 mothers of nonverbal children diagnosed with ASD.	Understand the factors that contribute to the positive feeling of connection that some mothers feel with their nonverbal autistic children.	The mothers described the various ways of communicating and understanding their children. The connections are established through singular and unconventional gestures, which expresses the bond between them.

As for the type of study, the predominance of the phenomenological approach (five) and the use of semi-structured interviews as the tool for data production is observed.

As regards the objectives of the studies, the intention is to understand the daily experiences of mothers of children with ASD and the senses that they attribute to maternity, as well as to reveal the feelings that emerge after the diagnosis and the ways of dealing with the difficulties encountered. As for the synthesis of the results, it was possible to show that the mother-child relationship occurs in various ways, but essentially through daily communication with the children, reinventing each day new ways of interacting, learning to deal with their demands by adapting their routine to the needs of the children. Thus, there is a narrowing of the maternal bond through all learning generated in everyday life.

## Discussion

The integrative review brought, through the account of the experiences experienced by mothers, much evidence about the establishment of the mother-child bond and the

challenges faced in the exercise of this relationship amidst the exhausting routine of an atypical mother. In most cases, mothers devote themselves to integrally caring for their children, so that they are unable to develop other activities and therefore satisfy their own needs and desires.<sup>22</sup> In this scenario, the high overload rate results in high levels of stress and anxiety, especially in cases where the children do not have autonomy, i.e., they are more dependent on the mothers, and, associated with this, the lack of necessary support, whether financial or family support in the division of tasks.<sup>18,23</sup>

The research has been conducted in various contexts, including in countries where culture is a challenge to face, as there are the roots of social stigma about people with disabilities and/or developmental disorders, including the responsibility of the child being autistic falls on the mother.<sup>18,20</sup> Religious belief also stands out in some scenarios of conducting the studies, in which the child is seen as a divine blessing and a punishment for the sins of the mother, as a lack of faith or as something capable of "healing".<sup>17-18,20</sup>

In addition, among the various contexts, some convergent points emerged as regards the results found. Thus, based on the themes addressed in the articles, the categories for discussion were listed: a search for new learning to better care; reinventing new ways of maternity; and daily care that requires exclusive dedication.

#### A search for new learning to better care

Regarding the topic of "learning," it was possible to identify that mothers needed to acquire a range of knowledge about autism and how to adapt to their child's demands, especially to its characteristics. They showed that cohabiting with the child with autism brings much more learning to the mother than the opposite, as she seeks to understand the child's behaviors, be more patient and even identify new ways to interact with him, to narrow the maternal ties, which can often be compromised if the mother does not obtain the understanding necessary to deal with situations that require more knowledge about the child's personality.<sup>13</sup> Regarding the interaction between mother and child, it is noticeable that there has been a change in the parental style of mothers, as they have started to rethink the ways of caring for their children, such as how to use visual resources to entertain them, teach them and encourage them to develop their daily activities.

In addition to the learning facilitated by routine dealings with the child, mothers generally seek to participate in courses, lectures, and events aimed at carers of autistic children, which contributes to their learning.<sup>13</sup> The internalization of this knowledge serves as a foundation for the construction of their own way of motherhood, which will be shaped to the needs of the child and the senses that she will attribute to this process. In this sense, it is well understood that maternity is permeated with learning, from the birth of the child, when she is completely dependent on the mother, to independence that, in the case of children with neuroatypical development, may be in a slower manner.<sup>24</sup>

Meanings surround the daily routine of the autistic child, and it is up to the mother to interpret them and adapt them. For this, it is necessary to dive into a world of new knowledge that allows them to understand, in the smallest details, each gesture and behavior of the child. For a mother of a child with typical development, these minutiae can go unnoticed, as the narrowing of the bond can occur more naturally, unlike a mother of an autistic child, who needs to engage additional effort for this to occur.<sup>25</sup>

### Reinventing New Ways to Maternity

In this perspective, the category “New ways of maternity” was identified in most studies analyzed.<sup>15,17,21</sup> This new way of exercising maternity was developed some time after accepting the diagnosis of the child, because, in most cases, there was an initial resistance to admitting the diagnosis of ASD.<sup>20</sup> The acceptance phase is permeated with feelings of frustration, anguish, and even rejection, and it is essential to look for professionals and institutions that can help in understanding the characteristics of the disorder and, thus, direct the family to deal with the child and seek the appropriate treatment.<sup>26</sup>

Following the mourning period characterized by the loss of the idealized child, mothers, albeit with considerable difficulty, began a process of self-reconstruction, seeking diverse strategies to establish a bond with their child – including through subjective forms of communication, such as distinctive and non-normative gestures.<sup>17-18,21</sup> In the case of nonverbal autistic mothers, the connection between mother and child can suffer more ruptures, so mothers use rich interpretations of the behavior of their children to understand them and assign meaning to the gestures produced.<sup>21</sup> Gradually, mothers construct

themselves and reconstruct each experience, words not spoken, looks, and unique signs expressed by their children daily.

According to the results of the study,<sup>15</sup> the emergence of a new identity as “autistic mother” is marked by the breakdown of expectations of maternity created since pregnancy, and the construction of this maternity is developed, daily, filled with subjectivities and numerous barriers to coexistence, due to the child's atypicalities. The stereotyped behaviors of the child have been cited as one of the difficulties in establishing the mother-child bond, as well as the concerns and psychological suffering, which are intrinsic to the exhausting routine of these mothers.<sup>19</sup> Still, the mothers report that it is compensatory to see the development of the children, even within their limitations, because each step is an achievement resulting from all the effort, dedication, and overcoming daily challenges. It is notorious that, despite being exhausting, this process of new maternity has changed the worldview of mothers.

#### A daily care that requires exclusive dedication

In this sense, it penetrates the theme of “exclusive dedication”, pointed out in several studies included in this review, in which mothers report dedicating 100% of their day to the demands of caring for the child.<sup>14,16,20</sup> Given the new circumstance, after accepting the diagnosis, there is a complete restructuring of the family routine, coupled with the adoption of habits based exclusively on the needs of the child, and that mainly reach the mothers. At this point, in the search for solutions that best adapt to the new reality of the family, mothers choose, in many cases, to abandon the profession and/or studies for the exclusive dedication to their children.<sup>26-27</sup>

Thus, it is inevitable that this sudden change will bring stress, overload, and compromise the physical and mental health of mothers, as they find themselves in a cycle of going and coming to psychiatrists, psychologists, physiotherapists, phonoaudiologists, and nutritionists, with little time available for their self-care and their demands.

Through the analysis of the studies, it was also possible to identify that, in addition to the need for a comprehensive follow-up to the child during their activities, the mothers themselves feel that their children need constant additional protection, commitment of love, affection, and attention. Therefore, the affective bond between mother and child becomes

narrow.<sup>13,19</sup> It should be noted that mothers use these strategies to establish a close affective relationship, because they understand that the greater the dedication to the children, the better their development will be and the stronger the maternal connection with them will be. In fact, the exclusive dedication of the mothers can positively influence the increased abilities of the children, however, too much protection can cause the child to depend on the mother, which undermines their autonomy.<sup>28</sup>

In addition, mothers also experience feelings of frustration and guilt when they believe that they do not do enough or that they are unable to meet all the needs required by the disorder, especially in times of crisis when they are unable to cope with the situation.<sup>16</sup> Amidst these thoughts, the feeling of powerlessness and inability arises when they feel that they will not be able to provide the help that their children need, especially because they are most often completely dependent on the mothers, since they are the holders of all responsibility for their creation.<sup>28-29</sup>

The findings mostly dealt with the stress overload of mothers, their quality of life, and the experiences after the diagnosis, without pointing out how the exercise of maternity actually occurred. All studies used interviews as the means of producing data. Therefore, it is necessary to use other instruments that provide to address the topic, to bring other perspectives to the discussion.

This study shows itself as a tool with the potential to bring greater visibility to the mothers of children with ASD, to provide, to this reality, a more attentive and holistic look, not centered on the consequences of the disorder for children, but also for mothers. In addition, it is hoped to contribute to the development of more research on the subject, especially as regards Nursing, which has few productions in this field of research, given the indispensable role of these professionals in supporting atypical mothers, which is inserted from the diagnosis of the child, to the configuration of a solid support network that orients and assists them in the demand for intrinsic care to the emerging routine.

The understanding of the challenges these mothers face enables the identification of effective care strategies to assist in the development of interventions that promote the well-being of both children and their relatives, as well as the creation

of a support service that addresses the needs of these families in an integral way. In addition, this study can inform professional practices that recognize and value neuropsychological diversity to promote inclusion and equity.

## Conclusion

Several aspects were raised in this review of the literature on the subject addressed, such as the strategies used by mothers to narrow the relationship with their child, the ability to build their identity as a mother of an autistic child, and to redefine the maternity process from their daily experiences. The analyzed studies reveal challenges such as emotional overload, feelings of frustration, and the need for continuous adaptation to meet children's demands. Despite the difficulties, these mothers demonstrate resilience and seek strategies to strengthen the bond and promote the development of their children.

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