# "Until I had my son, I did not realise that these characteristics could be due to autism":

# Motherhood and family experiences of Spanish autistic mothers

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## Short running head: Motherhood and family

**Keywords**: *motherhood, maternity, pregnancy, family relationship, sensory processing* **Words:** 4963 words for main text + 255 for the Abstract + 414 for the Community Brief

#### Abstract

**Background**: Knowledge is sparse regarding the motherhood experiences and family relationships of autistic women. Few studies use a qualitative approach to afford autistic mothers (and want-to-be-mothers) a voice. This is an analysis of the experiences of Spanish autistic mothers presented from their perspectives.

**Method**: Nine autistic mothers responded to open-ended questions and verbalised their experiences of maternity and family relationships in writing or orally. Data obtained were analysed using a qualitative thematic analysis.

**Results**: We developed four main themes about the participants' experiences: 1. Autistic mothers were diagnosed after their autistic children (or close relatives) received their diagnosis; 2. Role of the nuclear family (partner and children); 3. The influence of sensory processing on coexistence with the partner, and upbringing of the children, of autistic mothers; and 4. The influence of anxiety on coexistence with the partner, and upbringing of the children, of the children, of autistic mothers. Their experiences showed that the mother's autism diagnosis can follow the diagnosis of an autistic child, and highlighted the importance of a good relationship with their partners and children during the process, increasing their self-acceptance (Themes 1 & 2). Also, the influence of sensory reactivity and anxiety intensified many aspects of their maternity and relations, from pregnancy to intimate experiences (Themes 3 & 4).

**Conclusion**: In conclusion, there is a need for greater understanding and awareness about the characteristics of autistic mothers in the Spanish context, so that family members or healthcare professionals could provide better individualised care for them – from their pregnancy to the upbringing of their children.

Keywords: motherhood, maternity, pregnancy, family relationship, sensory processing

#### **Community brief**

#### Why is this an important issue?

Previous research examining mothers' experiences regarding autism has tended to focus on mothers who were not autistic themselves, just their children. There is literature regarding autistic mothers from other countries, however, culture is an important consideration. We are not aware of any research about the experiences and needs of Spanish autistic women who are, or want to be, mothers, and their relationships with their children.

#### What was the purpose of this study?

We wanted to understand and identify the maternity experiences of Spanish autistic women and their family relationships, allowing them to tell their stories and experiences in their own words.

## What did the researchers do?

We asked autistic mothers about their experiences, which included questions regarding their diagnoses, partners, and children. We collected responses from nine autistic mothers related to their motherhood and family relationships. We identified patterns in the data that were important or interesting (themes, subthemes). Finally, we chose some example quotes to help the reader understand the analysis.

## What were the results of the study?

We found that many women related common experiences: (1) most mothers were diagnosed after their child was; (2) the mothers reported how important it was that their partner and children could understand them; (3) the sensory overload that many mothers had could affect experiences like taking their child to school; and (4) the anxiety that many mothers felt could affect things like how they experienced the pregnancy.

#### What do these findings add to what was already known?

There is no similar study in a Spanish population, and there is a limited understanding of motherhood and cultural diversity. This study reflects the need for additional support for autistic mothers in the Spanish context. For example, there is a need for professionals with updated knowledge who can identify autism and provide better individualised care, greater awareness about the characteristics of autism in women, and adaptation of hospital protocols for pregnant and autistic mothers.

## What are potential weaknesses in the study?

With the small number of participants, we cannot assume that these results represent the wider population.

### How will these findings help autistic adults now or in the future?

This study contributes to a greater understanding of how Spanish autistic mothers experience motherhood and family relationships. We hope this provides the foundation for future research and

helps autistic mothers receive the support they need, including from healthcare services. We encourage research that empowers autistic mothers to share experiences from their viewpoints.

#### Background

There is a large body of literature regarding women who have autistic children and how this affects family dynamics, interactions, and mental health.<sup>1–4</sup> However, little is known about the experiences and needs of autistic women who are, or want to be, mothers, and their relationship with their children, even though it is a topic of special interest to the autistic community - <sup>5–7</sup> and, specifically, none of these studies consider the experiences of Spanish autistic mothers.

The starting point is the woman's own diagnosis. Due to gender bias, even if women meet the criteria for Autism Spectrum Disorder (ASD), they have a high risk of not receiving a clinical diagnosis or obtaining a late diagnosis.<sup>8</sup> Often, this tends to coincide (in time) with having a child on the spectrum, which can help mothers feel a special and intense connection with their children and understand them and themselves better.<sup>5,9</sup> In fact, many mothers consider that such a relationship comes about by openly talking about being autistic with their children.<sup>10</sup> Nevertheless, Talcer et al., noted that some mothers experienced a delay in developing an emotional connection with their infant compared with other neurotypical mothers, being less likely to find motherhood a rewarding experience.<sup>11</sup> Similarly, there are quantitative studies that found that some autistic women experienced aspects of pregnancy and motherhood as much more challenging than non-autistic women; including higher rates of pregnancy complications, changes during pregnancy, sensory sensitivity, and difficulty with breastfeeding.<sup>12</sup> Pohl and colleagues found that autistic mothers were more likely to have experienced co-occurringmental health conditions, including pre- or postpartum depression, anxiety, selective mutism, feelings of misunderstanding by professionals, and living through motherhood as if in isolation. These problems were found also in McDonnel and DeLucia's systematic review; also, autistic parents reported difficulty communicating with healthcare professionals about their children.<sup>6</sup> To this equation, we can add the findings of other qualitative investigations which highlighted important issues for autistic mothers during pregnancy, childbirth, and parenting: heightened sensory experiences during the prenatal period, childbirth, and the postpartum period - including breastfeeding; not receiving clear guidance from health professionals and the family; the stress that stems from the perceived pressure to be the perfect and patient mother; and the stigmatisation of autistic mothers as 'bad mothers' by health professionals and society.<sup>13–17</sup>

These unique challenges described, along with the stigma associated with autism, may further exacerbate communication difficulties,<sup>13</sup> making them unable to ask for help or to hide their diagnosis,

not only from professionals but also from family and close friends.<sup>5,6,18</sup> Autistic women need to feel heard and understood by their relatives and the people closest to them, as well as by professionals. Having a support network would make the transition to motherhood easier and their experiences more positive.<sup>17,19,20</sup> In fact, a preliminary study suggests that autistic mothers could develop stronger support networks compared with non-autistic mothers. However, this finding should be interpreted with caution, both groups reported equally high levels of parenting stress when controlling for factors associated with maternal well-being (e.g., child's challenging behaviours) – meaning parenting stress should not be assumed only based on a maternal autism diagnosis.<sup>7</sup>

A very interesting line of research - and little explored -<sup>21,22</sup> is sensory processing during motherhood, as the sensory demands of parenthood may be especially challenging for autistic mothers. In Talcer and colleagues' study, autistic mothers reported difficulty in adjusting to the experiences of motherhood — including caregiving, social interaction, employment, and organizational skills resulting in higher-than-expected levels of fatigue, stress, feeling overwhelmed, and anxiety.<sup>11</sup> All autistic women reported a significant increase in their auditory and tactile sensory reactivity; e.g., breastfeeding was very painful and unpleasant, yet they breastfed successfully - even for years because they felt it was the best for their child.<sup>11,16,23</sup> Nevertheless, this sensory processing can affect not only the bond with the child but also the relationship with their partners, both at the level of shared care and the affective-sexual relationship.<sup>24-26</sup> We must bear in mind that autistic women can face a variety of life challenges, which can be exacerbated in times of stressful life changes, such as motherhood. Thus, the role played by partners, close friends, and family is crucial.<sup>20</sup> In summary, the current literature on motherhood is sparse and few studies use a qualitative approach to afford autistic mothers (and mothers-to-be) a voice, to better understand and identify the maternity experiences of Spanish autistic women and their family relationships. This is, therefore, the first approach to a similar study in the Spanish population.

#### Method

#### **Participants**

We recruited nine autistic women (age range = 29 - 58 years; M = 42.3, SD = 11.17) via five of the largest autism foundations in Spain. Inclusion criteria were: (a) identify as female, (b) formal diagnosis on the autism spectrum (including variants such as Asperger's syndrome, or high-functioning autism,

or self-identifying as autistic and awaiting assessment for a formal diagnosis); (c) mother (or wantedto-be); (d) over 18 years of age; and (e) Spanish-speaking. We included want-to-be-mothers as their responses could help us understand important aspects of motherhood that possibly mothers would not mention (such as fears of pregnancy).

To limit group heterogeneity, we excluded participants if they had (a) a co-occurring intellectual disability, (b) known brain injury, or (c) cognitive impairment.

Of the nine participants, eight had a formal autism diagnosis and one had been referred for formal diagnosis assessment and self-identified as autistic (appearing to meet all diagnostic criteria). The other eight women had a late confirmed diagnosis at that time (age range = 27 - 55; M = 39.3, SD = 10.93). Their reported diagnoses were: ASD (n=4), Asperger's (n=2), and 'high-functioning autism' (n=1). They were diagnosed between 0 and 4 years before the study (M = 1.71), except for one woman who was diagnosed at an early age (6 years old with ASD, and again at 48 years with Asperger's; M = 2.75). Seven participants were mothers and two wanted to be mothers. See Table 1 for additional information regarding the participants. All names are pseudonyms to protect confidentiality.

[TABLE 1 NEAR HERE]

#### Material

The structured interview used for this research was developed specifically for this work (the Autistic Women project), via a process of consultation with autistic women, expert clinicians, Master's students, and researchers. The topics reflected the research aims, previous research, clinical insights, and the priorities of members of the autism community. The interview consisted of 30 questions regarding different topics: (i) *diagnosis* (e.g., [when you were seeking the diagnosis] did someone [family, friends...] help you?); (ii) *partner-family* (e.g., do you feel that your partner supports you?); (iii) *motherhood-children* (e.g., do you have (or want to have) children?); (iv) *relationships* (e.g., do you have a friend with whom you share hobbies or common interests?); and (v) *camouflage* (e.g., do you feel the need to act differently to adapt to social interaction?). The responses were all open-ended and participants could verbalise and explain their experiences with no time or word limits. Although we asked questions more directly related to love, bonds, and parenting, we focused the analysis on experiences concerning motherhood. A copy of the interview schedule is available by request from the first author (IM).

## Procedure

The Ethics Commission of the Universitat Jaume I provided ethical approval for this research. We contacted potential participants through five associations that agreed to support the study. These organisations gave their informed consent via e-mail, and our first contact with the participants was via an anonymous form. The beginning of the form included the contact information of the principal researcher (IM) in case the women needed it. The women could choose their preferred modality to express themselves. Eight participants contacted the researchers to answer the questions in writing. The questions were conducted via video call (n = 1), online form (n = 7), and e-mail (n = 1) according to the participants' preferences. We provided these options to make the study as inclusive as possible. The video call lasted one hour. The online form could be answered in 45 minutes via Google Forms. There were no notable differences in the length of responses depending on the modality.

#### Data analysis

We transcribed verbatim the responses from the video call and analyzed them alongside the written responses received online. We analyzed the data following the model for thematic analysis of Braun and Clarke<sup>27</sup> to develop themes directed by the data content (inductive approach). This is a useful method to examine the different participant's perspectives, highlighting similarities and differences, and generating unanticipated insights.<sup>27–29</sup>

First, the second author of this study (MC) familiarised herself with the data, observing patterns and potential categories. Second, via a first reading, the initial coding was created, and interesting extracts were identified, applying the appropriate code to them. Excerpts representing the same meaning had the same code applied. Third, we exported information to the online software *Taguette* by Rampin & Rampin,<sup>30</sup> an open-source qualitative research tool to develop the coding framework by creating topics from text excerpts and subsequently developing themes and then refining these themes into multiple sub-themes. Once we developed the initial set of themes and sub-themes, MC ensured that each theme had sufficient data to corroborate it. Through the initial coding, we identified several patterns in the responses, corresponding to four large categories related to the phenomenon of motherhood in autistic women. Subsequently, IM reviewed the analysis. Both researchers met seven times during the process to discuss the selected themes and their relationship to the answers obtained. A third researcher, outside the investigation (JM), carried out their classification, with a 90% agreement for sub-themes ( $\kappa = .86$ , a near-perfect agreement). We used researcher triangulation to

address credibility<sup>31</sup> and resolved disagreements through discussion (although extracts were not restructured after the triangulation).

Finally, we organised the narrative of the participants' examples to support a coherent narrative of the results. We provided direct quotes regarding related experiences and an interpretive analysis to help the reader understand the analysis.

## Results

The data analysis produced four themes, each with two sub-themes, making a total of eight (Table 2). Each sub-theme is discussed along with illustrative quotes from the participants.

## [TABLE 2 NEAR HERE]

# Theme 1: Autistic mothers were diagnosed after their autistic children (or close relatives) received their diagnosis

This theme reflects the isolation of autistic women and their underdiagnosis. The participants reported obtaining a formal diagnosis or having started a self-diagnosis, (1.1) after their children or close relatives received an autism diagnosis, or (1.2) they found they shared very similar characteristics to their child or other family members. Thus, maternity would, in many cases, be the starting point of a long process of differential tests for both the children (mostly males) and their mothers.

# Sub-theme 1.1: Autistic mothers were diagnosed by a professional as a result of the child's diagnosis (or close relative)

Some children (parents or relatives) of the participants were diagnosed as autistic. Three women (two of them mothers of an autistic child) reported not being aware that they were autistic until their children or relatives (males) received the diagnosis:

"[The professional] suspects due to being the mother of an autistic child" (Melissa);

"the doctor who diagnosed my brother suggested that I could be autistic" (Sienna),

They stated that it was at this moment that the professional usually investigates the origins and becomes interested in the parents:

"[I imagined something during those months... (1.2)] My son received his diagnosis at 18 months, once we went to his therapy and they suggested that I could be on the spectrum" (Laura). Nevertheless, the fact that inquiring and making the possible diagnosis known at the same time as their child's (usually young) could cause relatives to not believe the mother or think that she wants to attract attention:

"My maternal family did not believe me, they thought that I had become obsessed with the topic because of my boy" (Melissa);

"[When I told them] my brother and nephews did not react. My friends did not believe me" (Olivia).

Sub-theme 1.2: Autistic mothers recognise themselves in the characteristics of their children (or other family members) and have initiated their own diagnosis

Self-diagnosis is often the only accessible and feasible alternative, and most often it is accurate. Three women (two of them mothers of an autistic child) reported that they were the ones who began self-diagnosing by observing the characteristics they shared with their children or close relatives. It was later that they received an official diagnosis, not without having previously investigated: *"Until I had my son, I did not realise that these characteristics could be due to autism, but once I investigated myself, I felt identified" (Laura);* 

"My son was diagnosed with Asperger Syndrome at the age of six, after a process that started when he was two years old. In those years, I realised that I thought and acted very similar to him when I didn't pretend to fit in" (Chloe);

"My niece, who is autistic, and I always acted very similarly. I have a very special bond with her" (Anna). Women tend to differ from men, however, in the narrative most agree in terms of routines, sensory processing, and anxiety, and it is here where mothers can recognise themselves: "I felt identified by my repetitive routines, how meticulous and how perfectionist I was, we were. Now I know that my "hobbies" are a necessity, all that unresolved anxiety, my sensory profile, and the constant need to move, my "social anxiety", not understanding double meanings or jokes" (Laura). Or it has been their partners who have identified these characteristics:

"The first person who suggested it to me was my partner" (Chloe).

However, other mothers reflected on the differences in characteristics regarding their children: "I understand my son but at the same time there are aspects that differ from me" (Helen).

Theme 2: Role of the nuclear family (partner and children)

This theme relates to the participants' shared experiences with their nuclear family when it comes to receiving support, or not. Thus, the interest of family and friends in learning about autism is described as a key factor for understanding and acceptance.

## Sub-theme 2.1: The partner and children as a guide or pillar for autistic mothers

A true understanding and acceptance of the differences by friends, family, and partners can contribute to considerably reducing possible meltdowns or derived disorders (e.g., post-traumatic stress), which usually worsen in adolescence or youth:

"My youth was good because I met my husband, and he afforded me great security and I began to feel valued" (Helen).

Thus, couples and children are a fundamental pillar in their day-to-day lives, to feel understood and valued, since they seem to have been informed and knew about autism:

*"I have another older daughter who is studying Medicine. As she has seen everything, as she says, "to contribute her tuppence worth, to help." (Helen).* 

For other women, feeling recognised and understood by their relatives when they received their diagnosis meant revealing their true identity and increasing their self-acceptance:

"I read my report with my partner and his son, they recognized me in everything, and there was a session with the professional for my partner to answer all his questions. In general, the diagnosis and visibility have been a relief since it was the explanation for many daily problems and misunderstandings" (Olivia).

In addition, the mothers reflected on how adapting and meeting the needs of their children was a positive experience,

"My (autistic) boy is a gift. He has done a lot for this family. He has rediscovered us" (Helen).

Sub-theme 2.2: Lack of understanding by the partner and children of autistic mothers More than half of the participants reported not feeling supported or understood by their families. They reported having limited relationships with their families, and some of them even highlighted:

"I am independent of my sons, and I have scant relationship with them" (Thea).

In addition, they reported that their partner (and those with older children) sometimes did not help them progress in all their qualities and/or potential:

"Yes and no... there are things that they enhance and others that do not interest them" (Melissa). Many reflected that sometimes the partner does not understand some of the externalising characteristics of autism, such as meltdowns and that, above all, many family members do not have the appropriate tools to understand them:

"My daughter and my husband know how I am, but they don't know what to do" (Helen); "I don't know if they understand that I am more prone to meltdown in moments of anxiety and frustration. At those times no, I don't feel supported by my husband and sons (Leah). All of this has an impact on communication, making it a great challenge to find a partner who can adjust, understand her needs, and accompany her on the adventure of motherhood: "It is difficult for me to find the right partner" (Sienna).

# Theme 3: The influence of sensory processing on coexistence with the partner. and upbringing of the children, of autistic mothers

This main theme reflects how participants often described the experiences of relationships and motherhood as complicated processes, particularly due to tactile sensory reactivity and the acceptance of their condition by their partners.

Sub-theme 3.1: How sensory processing affects sexuality and coexistence with the partner Most of the women stated that they had and lived with a partner and referred to the need for a person who understands them and was aware that they were unique, who appreciated them for this reason and not despite it:

"I am asexual due to my sensory profile, but in my partner, I found the stability that I never had before. That is what I consider love, he accepts me as I am" (Laura).

Another phenomenon reported in this study is the internalisation of suffering due to sensory intensification, particularly tactile sensory reactivity, which can lead to overwhelming intimate experiences on the part of a partner (or even children):

"Related to my skin, I am delicate. Sometimes certain hugs or touches feel uncomfortable, certain smells cause rhinitis" (Sienna);

"I only have tactile hyposensitivity, I can't stand being touched gently, such as subtle caresses, they make me gag and feel nauseated. If I touch something, I have to do it with a certain force, if not, I don't feel it" (Chloe).

Sub-theme 3.2: How sensory processing affects the upbringing of children (or having children)

Some mothers reported finding the experiences of motherhood particularly stressful due to their predisposition to experience sensory overload; e.g., regarding pregnancy:

"I don't have children yet, and I would like to have them, but I'm terrified of becoming a mother due to hypersensitivity [...] I don't know what those feelings will be like..." (Anna).

Also, due to sensory overload, most participants would avoid social situations related to their children (e.g. parties, picking up from school, fairs). They highlighted the importance of this since they feel that their own difficulties sometimes get in the way of satisfying the needs and opportunities of their children:

"I am incapable of facing situations as common to others as, e.g., taking my son to school" (Laura); "They would like to, but I can't go to the fair or the shopping centre" (Melissa).

# Theme 4: The influence of anxiety on coexistence with the partner, and upbringing of the children, of autistic mothers

This theme described anxiety challenges that participants felt as directly related to having a partner and children.

## Sub-theme 4.1: How anxiety affects coexistence with the partner

Many women expressed a tendency to repress and internalise anxiety and suffering, which leads them to an emotional collapse:

"I suffer a lot, but I don't know how to express it. I keep it quiet or I lash out with some misplaced anger (towards her partner)" (Helen).

On the other hand, the participants reported that having the diagnosis did not prevent their partners or former relationships from thinking that their actions were intentional, and out of ignorance, they launched all kinds of hypotheses and labels:

"I have a low tolerance for frustration, which draws attention to me, and then, I tend to be classified as exaggerated or stressed (regarding her partner or relationships)" (Sienna).

## Sub-theme 4.2: How anxiety affects the upbringing of children (or having children)

Some participants reported experiencing heightened feelings and empathy for their autistic children and that having to think about their child's needs contributed to feeling overwhelmed:

"My son distorted me [my idea of what autism was] with his aggressive behaviours..." (Helen).

But these sensations were also triggered before having children, or long after, as women reported feeling a fear of possible sensory overload and even losing control over their bodies during pregnancy:

"If something happens to my [supposed] baby, I wouldn't be able to get over it... the feeling of having him inside me... causes me a lot of anxiety [...] the change and alteration in hormones and emotions, of my whole body, I'm afraid of ending up in a mental institution for not wanting to have my baby inside me during the pregnancy. I mean abortion after five months, I couldn't do it" (Anna) During another phenomenon such as perimenopause and/or menopause, which give rise to physiological, psychological, emotional, and cognitive changes that can affect their health and wellbeing:

"After everything we have been through... Now that my son is well ...Now, the one who needs the most help is me. At my age. Who knows why. Premenopause, emotional exhaustion due to the pandemic have set me off. It's like I'm already overflowing and sometimes I'm afraid of myself. I switch off" (Helen).

#### Discussion

This study examined Spanish autistic women's experiences regarding motherhood and family relationships. The open-ended responses (whether written or spoken) provided rich data for analysis, yielding four main themes.

The first main theme — Autistic mothers were diagnosed after their autistic children (or close relatives) received their diagnosis — highlighted the low probability that women have of receiving an early diagnosis. Rather, it is when they have an autistic child (mostly males) that they become aware of the possibility of being on the spectrum themselves;<sup>5</sup> at this point, we might ask ourselves whether this underdiagnosis seen in mothers might also exist in daughters. Thus, mother and child share diagnoses, which could be experienced as a 'double acceptance' for the mothers towards diagnoses (first their child's and then their own) but also as a deep bond between them. As described by Dugdale and colleagues,<sup>5</sup> autistic parents had an instinctive understanding to meet their child's needs, and their child also turned to them for support. Nevertheless, not everything should be left to 'instinct'. Support is required for autistic mothers, e.g., a peer group (of autistic mothers) available to share their experiences, led by a professional who can help them (e.g., regarding pregnancy or child

rearing).<sup>17,32</sup> In addition, it should be noted that those women who did not receive a diagnosis after the diagnosis of their children, received their diagnosis because of another person close to them (e.g., a niece ora brother).

In the second superordinate theme — Role of the nuclear family (partner and children) — the participants underlined the need for greater awareness about the characteristics of the autistic condition in women, as well as in maternity, so that family members could provide better individualised care. It is important that the support an autistic person receives is matched to their needs, or they can make things worse and increase stress levels.<sup>25</sup>. Participants highlighted that disclosing their true identity and having their partners and children participate in the process increased their self-acceptance.<sup>5,10</sup>

The third theme was: The influence of sensory processing on coexistence with the partner and upbringing of the children of autistic mothers. In terms of specific difficulties, the present study indicated that sensory changes and problems associated with motherhood were particularly difficult.<sup>12</sup> This seemed more salient and difficult during pregnancy, with greater reference to tactile or proprioceptive sensory reactivity, as suggested by Talcer et al.,<sup>11</sup> due to internal sensations that could be very difficult to cope with. Sensory hyperreactivity affected many aspects of their maternity, and participants reported not being able to adapt to the change to fulfil their children's needs. In this way, sensory features affect not only pregnancy, labour, or birth<sup>33</sup> but also the upbringing of their children, as motherhood involves a high level of tactile input (e.g., skin-to-skin, breastfeeding)<sup>11</sup>.

Regarding social relationships, participants emphasised how, due to the sensory intensification that can lead them to experience overwhelming intimate experiences, they can avoid sexual activity. Along this line, it is important that they can feel comfortable when they find a partner who is aware of their singularities, and who understands and accepts them.<sup>20,24,26</sup>

Finally, regarding the fourth main theme — The influence of anxiety on coexistence with the partner. and upbringing of the children, of autistic mothers — we can see how motherhood experiences could be viewed as stressful due to their propensity for emotional meltdowns, usually from sensory overload. This study highlighted empathy as an overwhelming factor, which concurs with other research findings indicating that autistic people, contrary to popular beliefs that classify them as insensitive, can experience empathy so great that it can make them feel overwhelmed and upset. In fact, recent studies suggest that the autistic manifestation of empathy might not only be more intense but also more all-encompassing than in the neurotypical model (see <sup>34,35</sup> for more information). On the other hand, participants indicated physical changes and sensations leading them to feel they were losing control over their bodies at certain stages of motherhood, such as kicks or movements from the foetus during pregnancy.<sup>11,12</sup>. In addition, a participant mentioned menopause as the cause of her exhaustion, which is similar to the findings of Moseley et al., who found that perimenopause and menopause were associated with greater stress and amplified autistic traits.<sup>36</sup>

## Limitations

This study is not without its limitations. First, the interview did not always explore specific issues in this context as, there was no standardised instrument for this subject. On the other hand, the sample may not be representative of the general population of mothers, due to the small number of autistic women who participated, and which comprised females from white ethnic backgrounds. In addition, the participants were recruited largely via autism associations, which may have biased our sample towards those women more accepting of their autistic identity. For future studies, researchers should be cautious when including mental health problems in the participants' exclusion criteria since, as mentioned in the study, mothers could report mental health issues, such as anxiety or depression, even if they are not diagnosed. Regarding the procedure for future studies, we recommend using an online live chat to gather more information and to be able to conduct a semi-structured interview in the preferred written communication route for some participants.

#### Implications

Research is required in the area of health and care for autistic mothers, and to break down the barriers that already surround the intersection of motherhood and diversity. Given the absence of a substantial body of research on the field in the Spanish territory and the literature's usual focus on autistic children (even when perhaps their mothers were autistic but not diagnosed), this analysis challenges us to reflect on the poor understanding of autism in adulthood and, specifically, on autistic women, who may fall outside the neurotypical expectations of motherhood within a Spanish context. Therefore, it is important to have a greater understanding and acceptance among people who interact with autistic mothers (e.g., midwives, nurses, doctors), who would benefit from autism informed additional support and better adaptation. Specifically, there may be a need to adapt hospital protocols

and provide healthcare professionals with information about sensory reactivity. For example, during breastfeeding the healthcare professional should ask for permission before touching the mother, and environmental stimuli (including visual, auditory, smell, taste, and/or touch) must be taken care of so that the woman is not subjected to overstimulation during breastfeeding, or provide opportunities to breastfeed their baby calmy, with privacy, and without interruptions.<sup>17</sup> Thus, autistic mothers could experience motherhood in a way that is more comfortable. Therefore, we encourage additional studies based on their personal experiences, allowing autistic mothers to explain their perspectives so that they do not feel like 'the only female in the spectrum ever to become pregnant' as Grant<sup>32</sup>reported. We hope this provides the foundation for future research and helps autistic mothers get the support they need.

#### Acknowledgements

We thank all the autistic mothers who kindly participated in this work. We also thank EC for reviewing the questions of the present interview. This study began when my son was born, and was written with my right hand on the keyboard and my left on his shoulders.

## **Authorship Confirmation Statement**

**Author 1** engaged in the conceptualization, data analysis, and funding acquisition, conducted the research, provided the analysis tool, supervised Author 2, and wrote the final manuscript. **Author 2** engaged in the analysis of the data and wrote the initial draft. All authors revised the article and approved the final version for publication. The article has been submitted solely to this journal and is not published, in press, or submitted elsewhere.

## **Conflict of interest**

We have no conflicts of interest to disclose.

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Pseudonym	Current	N⁰ of	Are the	Method of	Do the	Is any other
	age	children	children	becoming a	women	family
	(diagnosis	(age of	diagnosed	parent	have a	member
	age)	children)	as		partner?	autistic?
			autistic?			
Laura	29 (27)	1 (5)	Yes	Birth	Yes	No
Anna	32 (31)	Want-to-be-	-	-	No	Yes, niece
		mother				
Melissa	34 (34)	3 (10, 5, 5)	Yes, the	Birth	Yes	Yes, father
			first			(but no formal
						diagnosis)
Sienna	36 (33)	Want-to-be-	-	-	No, she	Yes, brother
		mother			would like	
					to	
Chloe	37 (33)	2 (11, 1)	Yes, the	Birth	Yes	Yes, many
			first			members of
						her family
Helen	45 (No	2 (23, 13)	Yes, the	Birth	Yes	Yes, nephew.
	formal		last			Suspicion of
	diagnosis)					brother,
						father, and
						grandmother
Leah	54 (53)	2 (23, 20)	No	Birth	Yes	Yes, ND
Olivia	56 (55)	1 (ND)	No	Adopted her	Yes	Yes, many
				partner's		members of

# Table 1. Demographic information

				child		her family
						and friends
Thea	58 (6, 48)	2 (37, 23)	No	Birth	Yes	No
ND = no data						

Themes	Sub-themes
Theme 1. Autistic mothers were diagnosed	Sub-theme 1.1 Autistic mothers were
after their autistic children (or close relatives)	diagnosed by a professional as a result of
received their diagnosis	the child's diagnosis (or close relative)
	Sub-theme 1.2 Autistic mothers recognise
	themselves in the characteristics of their
	children (or other family members) and
	have initiated their own diagnosis
Theme 2. Role of the nuclear family (partner	Sub-theme 2.1 The partner and children
and children)	as a guide or pillar for autistic mothers
	Sub-theme 2.2 Lack of understanding by
	the partner and children of autistic mothers
Theme 3. The influence of sensory processing	Sub-theme 3.1 How sensory processing
on coexistence with the partner, and upbringing	affects sexuality and coexistence with the
of the children, of autistic mothers	partner
	Sub-theme 3.2 How sensory processing
	affects the upbringing of the children (or
	having children)
Theme 4. The influence of anxiety on	Sub-theme 4.1 How anxiety affects the
coexistence with the partner, and upbringing of	couple's coexistence
the children, of autistic mothers	Sub-theme 4.2 How anxiety affects the
	upbringing of the children (or having
	children)

# Table 2. Themes and sub-themes