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A systematic review

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The childbearing and mental health experiences of autistic mothers: a systematic review

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The childbearing and mental health experiences of autistic mothers: a systematic review

It is recognized that diagnostic rates of autism in women is increasing and with this, areas such as pregnancy and childbearing need to be viewed through a neurodivergent lense. As autistic women have children and take on the challenges of motherhood, systematic reviews are needed to provide an orderly and up-to-date base highlighting the existing research gaps. This study aims to identify and analyze research that has addressed the childbearing experiences and mental health of autistic mothers, delineate trends in research, and identify areas for future studies. The protocol of this systematic review was registered in the international database of systematic reviews PROSPERO (registration number: CRD42022368244). In this work, the guidelines of standards for systematic reviews and meta-analyses (PRISMA) were followed at all stages. The review identified 15 studies that explored the childbearing experiences and mental health of autistic mothers. Results indicate that autistic mothers are more likely to experience parenting difficulties, intense sensory experiences during prenatal, perinatal and postnatal periods, and mental health problems. However, there are studies that highlight that autistic mothers can receive the same social support and experience marital satisfaction. The findings of this review suggest that, to improve our understanding of the childbearing and mental health experiences of autistic mothers, studies should include multiple informants and mixed methodologies. Additionally training programs need to be co-produced to raise awareness in health care personnel.

Keywords: Autism; autistic Mothers; motherhood; systematic review

Introduction

Autism spectrum disorder (ASD; here on referred to as autism in line with community language preference – see Monk, Whitehouse and Waddington, 2022) is a neurodevelopmental disorder characterized by qualitative deficits in communication and reciprocal social interaction, repetitive and restricted behavior patterns, and sensory-motor and perceptual difficulties (APA, 2013). In recent decades, the prevalence of autism has markedly increased (Baio et al., 2018). This could be explained by changes in autism diagnostic criteria in recent years, increased public and professional awareness and knowledge, as well as improved screening practices (Elsabagh et al., 2012; Alcantud et al., 2016). According to the criteria of Zeidan et al. (2021), the worldwide prevalence is 65 per 10,000 children. Although earlier research reported that autism was predominantly in males, recent research shows that females are just as likely to have autism, however the autistic characteristics are different, leading to women being under-diagnosed (Bargiela, Steward and Mandy, 2016). Increased understanding of autistic characteristics in women has led to increased UK based diagnosis rates (Russell et al., 2022), as well as increased numbers of research projects to exploring autistic women's experiences (Harmens, Sedgewick, and Hobson, 2022; Kock, Strydom, O'Brady, and Tantam, 2019; Seers, and Hogg, 2021).

One research area that is gathering increased attention is the experience of pregnancy, child birth and parenting in Autistic women. The qualitative sensory and communication differences inherent in autism (He, et al., 2023; Milton, Waldock, and Keates, 2023) coupled with a health system designed and implemented via a neurotypical framework, can make childbirth and postnatal health care in autistic groups complex (Hampton et al., 2022). Reactivity to sensory stimuli (such as pain, touch, and internal changes) are more intense in autistic people and they often show difficulties adapting

to sensory stimuli (Sundelin, 2018). Thus, it is possible that the experience of motherhood is somewhat different for autistic women compared to non-autistic women. In addition, autistic women have to deal with a greater amount of negative experiences in socio-cultural environments compared to neurotypical women increasing the risk of poor mental health outcomes (Morgan, 2020; Rumball et al., 2020; Sala et al., 2020). Autistic women experience a higher burden of chronic mental health co-occurrences (Croen et al., 2015; Weir et al., 2021), that can negatively mark their cognitive, emotional and social experience of motherhood (Leedham et al., 2020) such as, frequent psychological distress, suicidal ideation, and daily functional challenges (Beck et al., 2020).

Although in recent years there is increasing research reporting that autistic mothers face unique challenges in the prenatal, perinatal, postnatal and parenting periods (Pohl et al., 2020), motherhood in autistic women is a neglected area in need of further dedication. To date, there have been two reviews of the literature linked to autistic mothers focusing on very specific areas; the first linked to autistic women's experiences of infant feeding (Grant et al., 2022); and the second linked to sensory challenges experienced by autistic women during pregnancy and childbirth (Samuel et al., 2022). The present review complements the previous ones from a methodological-conceptual point of view, since it is not limited to the review of qualitative studies and sensory experiences only, but also includes quantitative studies and explores other extraneous variables that impact parenting experiences, offering a more holistic view.

The aim of this study was to identify and review research on the childbearing experiences and mental health of autistic mothers, delineate trends in research, and identify areas for future studies. The following questions were posed: 1) What are the characteristics of research that has explored the childbearing experiences and mental health of autistic mothers? 2) What are the main findings

of the studies that have explored the experiences of motherhood and mental health of autistic mothers?; 3) What is the quality of existing research that has explored the experiences of motherhood and mental health of autistic mothers?

Method

Protocol and Registration

The protocol of this systematic review was registered in the international database of systematic reviews PROSPERO (registration number: CRD42022368244). In this work, the guidelines of standards for systematic reviews and meta-analyses (PRISMA) (Page et al., 2021) were followed at all stages.

Eligibility criterion

The PRISMA methodological guidelines (Page et al., 2021) stress the importance of using inclusion criteria to identify clear and well-defined outcomes. The following inclusion criteria were used: (1) articles addressing the childbearing and/or mental health experiences of autistic mothers; (2) empirical studies; (3) articles that are published in English in peer-reviewed journals. Articles were excluded if they; (1) addressed the childbearing and mental health experiences of neurotypical mothers of autistic children; (2) were systematic reviews, meta-analyses, opinion articles, narrative reviews, dissertations, editorials, book chapters, gray literature (e.g., doctoral theses), and conference proceedings; and (3) were articles published in languages other than English.

Search strategy

In March 2022, Scopus, Web of Science (WoS) which are platforms for scientific research and citation data and google scholar databases were searched for studies related to the childbearing experiences and mental health of autistic mothers. The search was conducted again in August 2022 to update the results of the initial search. Filters were applied to only archive peer-reviewed journal articles written in English that were published between between the start of the Scopus and WoS databases and August 2022. The following keywords strategically combined with booleans operators (“autism spectrum disorder” OR “autism” OR “autistic” OR Asperger’s Syndrome AND “mothers” OR “mother-child interaction” OR “maternity” OR “motherhood”) were used to navigate the databases. These words were used in the same order in both databases and in similar categories. For example, in the Scopus search through Elsevier the TITLE-ABS-KEY field label and the Web of Science search through Clarivate Analytics the TS field label was applied. The snowballing technique was used to access relevant studies that could have been published in other databases.

Study selection process

The search yielded 8383 records. Duplicates were then removed manually using Excel. The principal investigator reviewed the titles and abstracts of the articles for inclusion in the full-text evaluation. A second evaluator carried out this process in parallel and blinded to the evaluation of the first evaluator. Any articles that met the inclusion criteria were included in the full-text selection. The same reviewers independently and in parallel evaluated the articles identified for full-text review. Interrater reliability was calculated using Cohen's Kappa, which was 0.85. The articles on which the reviewers disagreed were discussed with the rest of the authors of the manuscript, finally reaching a consensus. Finally, 15 studies were recorded in the qualitative synthesis of information (see Figure 1)

Insert Fig 1

Data extraction

For each article, the extracted information included the details of the research team (including the name of the authors and the geographical location of the study), the details of the study (year of publication, journal, type of design of the study, measures used), the characteristics of the study participants (sample number, age, gender and ethnicity of both samples), the results (main findings of the studies). To eliminate potential bias, two authors independently extracted data from each article and data was inserted into an excel sheet. Agreement of the extracted data between the two researchers was strong (94%). Any disagreements in the extracted data were discussed with the other authors and consensus was reached in all cases.

Quality assessment of the studies

The quality of the articles included in the qualitative synthesis of information was evaluated by the principal investigator using the Quality Assessment Tool for Studies with Diverse Designs (QATSD; Sirriyeh et al., 2012). This methodological tool has good inter-rater reliability (Sirriyeh et al., 2012) and has been developed to evaluate qualitative, quantitative, and mixed methods scientific research. It is composed of 16 items, of which 16 apply to mixed methods studies, 14 apply to qualitative studies and 14 apply to quantitative studies. The rating scale for each item ranges from 0 to 3, with a maximum overall score of 48 for mixed methods and a maximum overall score of 42 for qualitative and quantitative studies. The higher the score, the higher the quality of the studies. The items that generated doubts to the principal investigator were discussed with the rest of the authors of the manuscript and a final agreement was reached. The tool has been tested by health researchers with good inter-rater reliability (Sirriyeh et al., 2012).

Results

Methodology used

Of the 15 systematized studies, 7 used a qualitative methodology. Six studies collected data through semi-structured interviews (Rogers et al., 2017; Dugdale et al., 2021; Talcer et al., 2021; Hampton et al., 2022; Donovan, 2020; Hampton et al., 2022) and one used a face-to-face research questionnaire (Gardner et al., 2016). On the other hand, 8 articles used a quantitative methodology. Six studies collected data via Likert-type surveys and diagnostic tests in a face-to-face manner (van Steijn et al., 2013; Lau et al., 2016; Dissanayake et al., 2019; Dawn et al., 2021; Lau and Peterson, 2011; Hampton et al., 2022) and two collected data via an online survey (Lum et al., 2014; Pohl et al., 2020).

Characteristics of the study

The research teams of the systematized studies had an average of 3 authors. The articles were published from 2011 to 2022. The research was carried out in ten countries, the majority of which were in Australia (n=7 articles), the USA (n=5 articles) and the UK (n=5 articles). The journals that published most articles on childbearing and mental health experiences of autistic mothers were Autism (n=4 articles), Research in Autism Spectrum Disorders (n= 3 articles), and Nursing for Women's Health (n= 2 articles). Most of the journals are indexed in quartile Q1 as declared in the Scimago Journal and Country Rank database and only two are indexed in quartile Q3 (Autism in Adulthood and Nursing for Women's Health).

Characteristics of the participants

A total of 1823 people participated in the research reported in the 15 articles. Of the participants, 759 (41.6%) were autistic mothers and 631 (34.6%) were neurotypical mothers. On the other hand,

four articles (Lau et al, 2016; Lau and Peterson, 2011; van Steijn et al, 2013 and Dissanayake et al, 2019) also involved 133 (7.2%) autistic parents and 91 (4.9%) neurotypical parents, and only one article (van Steijn et al, 2013) involved 96 (5.2%) autistic children and 96 (5.2%) neurotypical children. The race/ethnicity of participants was only reported in seven articles (Talcer et al, 2021; Lau et al, 2016; Hampton et al, 2022; Dugdale et al, 2021; Donovan, 2020; Hampton et al, 2022 and Hampton et al, 2022), where 499 participants identified as white, 99 participants as non-white and 2 multiracial participants. The age of the study participants ranged from 18 to 65 years.

Insert Table 1

Data collection methods

Because of the multidisciplinary basis of the systematized studies, a wide range of measures were used to document the childbearing experiences and mental health of autistic mothers. Eight articles used interviews and questionnaires to assess childbearing experiences, such as, family behavior, sense of efficacy, attachment style, parenting style, emotional state, sense of competence, trust, and perception of health care experiences (Rogers et al., 2017; Pohl et al., 2020; Hampton et al., 2022; Gardner et al., 2016; Dugdale et al., 2021; Donovan 2020; Hampton et al., 2022; Lum et al., 2014). The measures used were: Family Outcome Scale (FOS-R) (Bailey, Hebbeler and Bruder 2006), Parenting sense of efficacy (PSOE) by Johnston and Mash (1989), Hazan and Shaver's Attachment Self Report (1987), Johnston and Mash's (1989) 9-item measure of parents' affective feelings of joy or disappointment with parenthood, Parenting Styles and Dimensions Questionnaire (PSDQ) by Robinson and Cols (1995), measure of Parental Style (MOPS; Parker et al., 1997), the Parent Sense of Competence Scale (PSOC; Johnston and Mash, 1989), the Parent-Child Relationship Inventory (PCRI; Gerard, 1994), the Parenting Needs Questionnaire (PNQ), Karitane

Parenting Confidence Scale (KPCS), Infant Parenting styles Questionnaire factors (IPSQ) of Arnott and Brown (2013).

On the other hand, four articles used interviews and questionnaires to assess sensory experiences (Rogers et al., 2017; Hampton et al., 2022; Gardner et al., 2016, Hampton et al., 2022). Nine studies assessed the mental health of autistic mothers (Dawn et al, 2021; Lau and Peterson, 2011; Hampton et al, 2022; Talcer et al, 2021; Pohl et al, 2020; Donovan, 2020, Dissanayake, 2019; Lum et al, 2014; Hampton et al, 2022). The instruments used for these variables were: Parenting Stress Index-Short Form (PSI-SF, Abidin, 1995); widely used marital satisfaction scale Quality of Marriage Index (QMI, Norton, 1983); Depression, Anxiety and Stress Scale – Short Version (DASS-21; Lovibond and Lovibond 1995); Perceived Stress Scale (PSS, Cohen et al., 1983); State-Trait Anxiety Inventory (STAI, Spielberger et al., 1983), Edinburgh Postnatal Depression Scale (EPDS, Cox et al., 1987), Satisfaction with Life Scale (SWLS, Diener et al., 1985), three interviews and two questionnaires.

Reporting Quality

The QATSDD ratings show the strengths and methodological limitations of the research included in the review. As a strength, the research reviewed has a theoretical basis that allows us to understand the context in which the study takes place. In addition, there are adequate descriptions of the evaluation instruments and justification of the analysis methods used. The research by Dissanayake et al. (2019) scored the highest, despite not including members of the autistic community in the research design. On the other hand, weaknesses center on three items. The lowest is related to autistic community involvement in the research design. Only the research by Talcer et al. (2021) and Pohl et al. (2020) involved autistic community members in their methodological

designs. The remaining items with low scores Rogers et al. (2017) study, along with Gardner et al. (2016), is due to the selection of the sample and its representativeness s

Insert Table 2

Main Findings

Fifteen articles were systematized in our review and their findings were organized along three related axes: (1) parenting experiences, (2) sensory experiences, and (3) mental health. Although some of the studies involved more than one of the different axes mentioned above. We believed for clearer synthesis each axes deserves to be examined separately..

Experiences in parenting

The current search identified twelve studies that examined the parenting experiences of autistic mothers. Dawn et al. (2021) studied autistic mothers of autistic children, revealing that achievement of family outcomes among autistic and non-autistic mothers is similar, and that autistic mothers reported good support systems. Rogers et al. (2017) studied problems and experiences of autistic women giving birth, across pregnancy, childbirth, and early motherhood. The results suggest that autistic women may face particular challenges in the role of motherhood such as, problems in breastfeeding and communication with public health personnel. In this regard, Pohl et al. (2020), reported that autistic mothers have greater difficulties in parenting due to the demands of multitasking, domestic responsibilities, and creating opportunities for socialization for their child. They also noted that autistic mothers are more likely to find motherhood an isolating experience and felt that their parenting was being judged. However, Lau et al. (2016) found that autistic mothers had comparable levels of parental efficacy to neurotypical fathers in the same family indicating that parental efficacy does not differ between neurotypes.

Gardner et al. (2016) explored the childbearing experiences of autistic women. The findings of this study indicate that adjustment to motherhood and childcare was a challenging experience for autistic mothers. Understanding their babies' behaviors and needs, connecting emotionally with them, and difficulties with social interaction, proved to be common problems during the postpartum period. Autistic women felt their parenting skills and decisions were judged. Dugdale et al. (2021) reported the following issues of autistic mothers: 1. Autism fundamentally impacts parenting; 2. Struggle for appropriate support; 3. Development and acceptance; and 4. The ups and downs of parenting. A look at these results highlights that while motherhood may generally be a joyful experience for autistic mothers (Themes 1 and 4), it is in turn related to specific problems that are not very common in neurotypical mothers (Theme 1), such as negotiating misunderstandings from others (Theme 2). A key concern was the need for self-care and self-acceptance (Theme 3), with parenting as an outcome of personal growth and adaptation (Theme 3). They also experienced feelings of intense connection and closeness (Theme 4), although managing the children's needs had a profound personal impact (Themes 2 and 4).

In this regard, Van Steijn et al. (2013) explored the parenting styles of mothers who had both ADHD and autism diagnosis and/or traits. Mothers with a diagnosis and/or high autistic traits used a more permissive parenting style when dealing with neurotypical children. For their part, Dissanayake et al. (2019) found that autism traits did not solely contribute to mothers' self-esteem, but were associated with parenting difficulties and some aspects of the mother-child relationship (e.g., lower perceived enjoyment and satisfaction in the mother-child relationship and level of interaction with the child); however, they were not related to parenting efficacy. A study conducted by Lau and Peterson (2011), with autistic mothers, explored romantic attachment, marital satisfaction, and satisfaction with motherhood in four groups: 1 (autistic mother and autistic child),

2 (autistic spouse and autistic child), 3 (autistic child only) and 4 (control: not autistic). The results showed that mothers' autism diagnosis (either in self or spouse) did not significantly decrease the satisfaction and pleasure of parenting roles. Regarding attachment style, the autistic mothers reported that most of them had an avoidant attachment style. On the other hand, Donovan (2020) reported that the experience of pain and loss of control during labor made communication with health care personnel a more pronounced challenge. It was also observed that the direct and literal style of communication resulted in misunderstandings, and they also expressed difficulty in reading social cues. Hampton et al. (2022) reported that autistic mothers felt that lack of knowledge about autism from professionals was a barrier to meeting their needs, also lack of autism awareness in professionals led to a breakdown in trust. On the other hand, participants in both groups expressed concern about taking on the responsibility of motherhood, however autistic participants specifically were concerned about feeling isolated after birth, and were worried about the executive functioning demands of parenthood. Lum et al. (2014) reported that autistic mothers present greater challenges in communicating, acquiring information and support during pregnancy, childbirth and postpartum.

Sensory experiences

We found six articles that revealed specific results on sensory experiences. Talcer et al. (2021) identified that (1) the sensory experiences were more intense in the pregnancy period; (2) that the medical personnel did not understand the sensory challenges of the physical environment during the labor; and (3) in the postpartum period, there was an auditory and tactile sensory hyperreactivity that significantly impacted the maternal role, social, occupational and mental health areas. Rogers et al. (2017) also found that sensory problems exacerbated during pregnancy mainly occurred during medical examinations. Hampton et al. (2022) identified that during labor

sensory issues were very challenging, due to tactile stimuli and postpartum room stimuli. Gardner et al. (2016), showed that women report difficulties processing sensations associated with pregnancy (such as loud sounds and sensations inside the womb) during the prenatal period. Dugdale et al. (2021) reported that the changes and sensory issues associated with parenting were difficult mainly in the pregnancy period, despite this, participants adapted to change to meet the needs of their children, thus demonstrating their dedication and resilience in the face of challenges. Hampton et al. (2022) reported that sensory changes in the non-autistic group were limited to smell and taste, while the autistic group reported changes related to sound, lights, and touch, which were overwhelming, making everyday tasks more challenging. In summary, these studies report that autistic mothers had more intense sensory experiences (e.g., hyperreactivity), and these experiences impact on their relationship with health care personnel.

Mental health

We found nine articles that described findings related to mental health. In a recent study Hampton et al. (2022) explored stress, depression, anxiety, and life satisfaction during the third trimester of pregnancy in autistic women. The findings indicate that autistic mothers scored higher than non-autistic mothers on stress, depression, and anxiety, although there were no differences between groups for life satisfaction. However, in a study by Dawn et al. (2021), the stress levels of autistic mothers were found to be very similar to those of non-autistic mothers. For their part, Talcer et al. (2021) demonstrated that autistic mothers with sensory processing difficulties increased levels of stress and anxiety upon becoming mothers, due to increased sensory reactivity and difficulties in reducing sensory overload. In the same direction, Pohl et al. (2020) revealed that autistic mothers are more likely to experience prenatal and postnatal depression than non-autistic mothers. In

addition, 70% of mothers with or without a formal diagnosis of autism reported having psychiatric condition, such as anxiety and personality disorders.

On the other hand, Dissanayake (2019) reported that an increase in general parenting difficulties was associated with a decrease in psychological well-being. Also Lum et al. (2014) reported that challenges increase under emotional distress and during pregnancy and childbirth. For his part, Donovan (2020) emphasized that labor and birth are stressful for all women, but especially for autistic women. Difficulties in communicating with medical personnel during labor resulted in increased anxiety, inadequate pain relief, and feelings of frustration. The continuous presence of the nurses during labor, the recognition of the participants' anxiety, and the implementation of measures to relieve that anxiety helped the women to cope with their anxiety and stress. Conversely, when participants felt that nurses did not acknowledge their anxiety or when they did not communicate what was happening, participants felt significant levels of anxiety and fear. Hampton et al. (2022) reported that although both groups discussed positive emotions such as enjoyment and excitement, some participants felt that negative emotions intensified. Autistic participants mentioned increased anxiety and low mood, and reported that increased social attention was sometimes experienced as exhausting. Lau and Peterson (2011) reported that marital satisfaction was high regardless of the presence or absence of a diagnosis of autism within the family. In summary, the nine studies highlight that autistic mothers may experience higher levels of stress, emotional distress, anxiety, depression than non-autistic mothers. This increased psychological distress was reported to be due to increased sensory sensitivities and social demands on the autistic women, coupled with lack of awareness and understanding from healthcare professionals.

Discussion

This review aimed to identify and analyze research that has focused on the childbearing and mental health experiences of autistic mothers, to provide a comprehensive and up-to-date overview of the findings in this field of research. The results indicate that research on autistic women taking on the challenges of motherhood has grown in recent years, but remains limited, with only 15 published studies. The methods that were used were similar, with most research on pregnancy and childbirth being qualitative explorations (Donovan 2020; Gardner et al., 2016; Hampton et al., 2022a; 2022b; Rogers et al., 2017) and research on parenting being mostly survey based (Adams et al., 2021; Dissanayake et al., 2019; Lau et al., 2016; Pohl et al., 2020; van Steijn et al., 2013). In addition to this, the research did not consistently report participant demographics that could impact pregnancy and parenting experiences, with some not providing information on ethnicity (Adams et al., 2021; Dissanayake et al., 2019; Gardner et al., 2016; Lau et al., 2011; Pohl et al., 2020; van Steijn et al., 2013), socio-economic status (Gardner et al., 2016; Lau et al., 2011; Talcer et al., 2021) and the presence of existing mental health conditions (Dissanayake et al., 2019; Donovan 2020; Gardner et al., 2016; Lau et al., 2011; Lau et al., 2016; Pohl et al., 2020; van Steijn et al., 2013). Given the limited research carried out in this area it is important to consistently report demographics and also employ a wider range of innovative and inclusive methodologies to gain a more thorough understanding. For example blog-based studies and/or social media discourse analysis (e.g. Tamássy, and Géring, 2022) could allow researchers to analyse first-hand accounts of autistic pregnancies, births and parenthood across diverse autistic groups (including marginalized groups such as non-speaking autistic participants, ethnic minorities, LGBTQ+ groups). Ecological Momentary Assessment (EMA; Shiffman, Stone, and Hufford, 2008) could also be used to remove the need for retrospection and provide personal experiences of pregnancy, childbirth and postnatal experiences in real time.

In addition, the countries most engaged in research on maternal experiences and mental health of autistic mothers are Australia, USA and the UK. This high participation of Anglo-Saxon countries goes in the same direction of bibliometric analyses on research production in autism (Shekarro et al., 2021; Feng et al., 2022). However, the cultural similarities of the articles included in this review limit the generalizability of the results to other countries. For this reason, similar research needs to be carried out in developing countries, such as those in Latin America, to develop innovative studies that provide information about the socio-cultural impact on pregnancy and childbirth in autistic women. Most of the studies included both autistic and neurotypical mothers and to a lesser extent fathers and children. These findings indicate that multi-perspective research design should also be considered to triangulate information, in order to understand the experience of motherhood and mental health of autistic mothers from various perspectives.

Studies that addressed the parenting experiences of autistic mothers found that this population may face particular challenges in the role of mothering due to the demands of multitasking, domestic responsibilities, creating socialization opportunities for their child, understanding their babies' behaviors and needs, connecting emotionally with them, and difficulties with social interaction (Rogers et al., 2017; Pohl et al., 2020; Gardner et al., 2016; Dissanayake et al., 2019). Studies by Lau et al. (2016) and Dawn et al. (2021) highlighted that autistic mothers had comparable levels of parenting efficacy to neurotypical mothers, and further, autistic mothers reported having good support systems. This is most likely due in part to changes in contemporary societies for mothers in a general sense, as women now find more parenting options and support systems available (e.g., shared parenting responsibility, daycare). Therefore, the autistic mothers as well as other neurodivergent mothers not only benefit from these options, but also from the wealth of information, experience, and support empowering parenting responsibility (Shaul et al., 2018). The

sensory experiences of autistic women in the pregnancy period were reported as becoming more intense (Rogers et al., 2017; Talcer et al., 2021; Gardner et al., 2016; Hampton et al., 2022), and further amplified throughout delivery due to intense pain, tactile interactions and postpartum room stimuli (Hampton et al, 2022). The most common sensory issues participants reported throughout pregnancy and childbirth included hypersensitivity to touch, light and sounds (Gardner et al., 2016; Hampton et al., 2022a; 2022b; Rogers et al., 2017; Talcer et al., 2021). These reported findings around sensory issues are consistent with the wider literature, as it has been reported that autistic people show hypersensitivity to environmental stimuli such as unexpected sounds, bright and contrasting lights, strong odors, specific textures, touch, and temperature changes (Lane, 2019). Hypersensitivity and sensory overload were reported to lead to meltdowns and shutdowns in the autistic mothers (Hampton et al., 2022a). In addition to external environments causing aggravated sensory issues in pregnant autistic women, a study by Gardner et al (2016) reported that during the prenatal period women showed difficulties in processing or understanding internal sensations associated with pregnancy (such as fetal movement). Again this sensory difficulty in identifying introspective body cues is similar to previous literature that reports difficulties interpreting hunger and fullness cues (Nimbley et al., 2023). Further research is needed to understand the role of internal and external sensory issues in autistic groups and how this relates to mental health outcomes. Importantly, Burton (2016) asserts that more positive experiences in health care settings can still be achieved to minimize sensory related anxiety and stress such as greater staff consistency, staff taking the time to build relationships (and understand individual's sensory profiles), as well as using a collaborative approach. This highlights the need for further autism knowledge and awareness training in physicians and health care personnel specifically on sensory issues that can impact interpersonal interactions and clinical service delivery. Medical staff could

carry out sensory assessments with pregnant autistic women and discuss with them appropriate adaptations during prenatal, intrapartum and postpartum periods. In addition to increasing better staff awareness, there is a need to explore how prenatal and postnatal environments can be designed in a more autism friendly way to reduce external stimuli that can aggravate hypersensitivities.

Taken together, the difficulties and challenges presented by autistic mothers in daily parenting activities and in sensory areas negatively impacted their mental health. For example, studies reported higher levels of stress, emotional distress, feelings of frustration, anxiety, prenatal and postnatal depression in autistic mothers compared to non-autistic mothers (Hampton et al, 2022; Talcer et al, 2021; Pohl et al, 2020; Dissanayake, 2019; Donovan, 2020; Lau and Peterson, 2011). These stressful exposures during childbearing activity provide increased vulnerability to negative life experiences (Muniandy, 2021), and are likely to drive burnout over time (Raymaker et al., 2020). Therefore, research is urgently needed to prove the effectiveness of intervention programs that seek to enhance the quality of life of autistic mothers. However, the study by Adams et al (2021) based in Australia reported that the stress levels of autistic mothers were very similar to those of non-autistic mothers. To have a more complete understanding of the problem and to know if cultural variables are central to its explanation, more studies are necessary. In addition, Lau and Peterson (2011) emphasized that marital satisfaction was high regardless of the presence of an autism diagnosis. Highlighting that although the activity of motherhood is a challenge for autistic mothers, their main support system (i.e. partner) is still in place which may alleviate pre and post natal distress.

Limitations

It is possible to note some limitations of this study. It is recognized that our search is not completely exhaustive despite the fact that the main databases (Scopus and WoS) and the snowballing technique were used. For this reason, it is recommended that other databases such as PubMed and MEDLINE be used for new or different research. While this review provided a thorough review of the literature, the gray literature, which can provide a rich source of information, was excluded. Additionally, the current review did not involve a participatory design and is therefore limited by the lack of participation of autistic mothers.

Conclusion

The current review identified 15 studies that investigated the childbearing and mental health experiences of autistic mothers. This population is more likely to experience parenting difficulties, intense sensory experiences and mental health problems. However, two studies showed that these mental health problems were not significant when compared to non-autistic mothers and that autistic women were able to still maintain marital satisfaction despite the difficulties around pregnancy and birth. Further research into the experiences and psychological well-being of autistic mothers across different countries is needed (to better understand the cultural effects and the impact of different healthcare systems). The available literature also highlights that the experiences related to healthcare personnel during the prenatal, perinatal, and postnatal period are highly correlated with the negative experiences of autistic mothers. Therefore, more specialized training is required for health professionals who have the responsibility to assist autistic mothers. The current review also highlights the need for more autism informed adaptations to service delivery and healthcare environments to support autistic women experiencing sensory or social related issues. The small number of studies in this area highlights that more research is needed to help

us better understand the challenges of autistic mothers and more autism informed services need to be co-designed and co-produced with autistic people to help with these challenges.

Data availability The data generated or analyzed during the current study are available from the authors on reasonable request.

Declarations

Ethical approval This study used secondary sources and did not require approval from an ethics committee.

Conflict of interest

No conflicts exist among the co-authors

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Study	Title	Method	Sample	Measure of evaluation	Results	Country	Journal
Adams et al., 2021	Autistic Mothers of Autistic Children: A Preliminary Study in an Under-Researched Area	Quantitative	20 autistic mothers and 20 non-autistic mothers	DBC-P SCQ VABS-II FOS-R PSI-SF	<ul style="list-style-type: none"> - There were no differences in achievement of family outcomes between autistic and non-autistic mothers. - Autistic mothers can develop stronger support networks. - Autistic and non-autistic mothers report equally high levels of parental stress. 	AUS	Autism in Adulthood (Q3)
Talcer et al., 2021	A qualitative exploration of the sensory experiences of autistic mothers.	Qualitative	7 autistic mothers	Semi-structured interviews	<ul style="list-style-type: none"> - Auditory and tactile sensory hyperreactivity. - Low proprioceptive and vestibular sensory reactivity. - Sensory experiences impacted their maternal, social and work roles, and affected mental health. 	UK	Journal of Autism and Developmental Disorders (Q1)
Rogers et al., 2017	Perinatal issues for women with high functioning autism spectrum disorder	Qualitative	1 woman with ASD	Interviews, e-mail exchanges	<ul style="list-style-type: none"> - Communication and service difficulties with health professionals. - Sensory issues (hypersensitivity with touch, hallucinations) and 	AUS	Women and Birth (Q1)

					parenting challenges were very pronounced.		
Pohl et al., 2020	A comparative study of the maternity experience of autistic and non-autistic women	Quantitative	355 autistic mothers 132 non-autistic mothers	online survey AQ-10	- More likely to have experienced additional psychiatric conditions. - Greater difficulties in parenting and domestic responsibility. - More likely to feel misunderstood by professionals. - Motherhood as an experience of isolation.	UK USA AUS FR CAN	Molecular Autism (Q1)
Lau et al., 2016	Parents on the autism continuum: Links with parenting efficacy	Quantitative	Group 1 (29 fathers and 80 mothers) with ASD in the father/mother and in the child. Group 2 (31 fathers and 97 neurotypical mothers) with ASD in the child. Group 3 (22 fathers and 87 neurotypical mothers) of typically	AQ PSOE	- The total AQ score was highest in Group 1, followed by Group 2, then Group 3. - Male subjects scored higher on the Total AQ than female subjects. - Fathers with ASD had the lowest parental efficacy, mothers with ASD had comparable levels of parental efficacy to fathers without ASD in the family.	AUS	Research in Autism Spectrum Disorders (Q1)

			developing children.				
Lau y Peterson., 2011	Adults and children with Asperger's syndrome: exploration of adult attachment style, marital satisfaction and satisfaction with parenthood	Quantitative	Group 1 (7 fathers and 15 mothers with ASD)	seminal vignette instrument (Hazan and Shaver) QMI 9-item measure of fathers' affective feelings of joy or disappointment with parenthood, of Johnston and Mash (1989)	- Marital satisfaction was high in all four groups. - Respondents with SA were predominantly avoidantly insecure in romantic attachment, in contrast to predominantly secure attachment in all other groups. - Having a child with AS reduced parental (though not marital) satisfaction.	AUS	Research in Autism Spectrum Disorders (Q1)
Hampton et al., 2022	A qualitative exploration of autistic mothers' pregnancy experiences	Qualitative	24 autistic and 21 non-autistic women	Semi-structured interviews AQ	- The autistic group experienced increased physical and sensory symptoms (hypersensitivity with touch, light, and sounds) during pregnancy. - Autistic participants were sometimes reluctant to disclose their diagnosis to health professionals and felt that	UK USA IR	Autism (Q1)

					professionals lacked knowledge about autism.		
					- Autistic participants emphasized the need for detailed information and to be given time to process verbal information.		
					- Need for sensory accommodations in health care settings.		
Hampton et al., 2022	A qualitative exploration of the experiences of autistic mothers II: Childbirth and postnatal experiences	Qualitative	21 autistic and 25 non-autistic women	Semi-structured interviews AQ	- The sensory aspects of childbirth could be a challenge (i.e. hypersensitivity with touch and sounds). - Need for sensory adjustments. - Importance of clear and direct communication during childbirth. - Participants felt that professionals lacked knowledge about autism. - Both groups reported parenting strengths and challenges.	UK USA	Autism (Q1)
Gardner et al., 2016	Exploratory study of the maternity experiences of women with Asperger's syndrome	qualitative	eight women with Asperger syndrome	Research questionnaire	- Difficulties in processing sensations (during pregnancy - hypersensitivities with touch, light, sounds, smell and interactions; during birth – hypersensitivities with sounds and smells; after birth	USA	Nursing for Women's Health (Q3)

					<ul style="list-style-type: none"> - hypersensitivity around touch specifically breastfeeding). - - Feelings of little control over their actions or the environment. - Challenging experiences in adjusting to motherhood and child care. 		
Dugdale et al., 2021	Intense connection and love: the experiences of autistic mothers	qualitative	Nine autistic mothers	Semi-structured interviews	<p>Motherhood as a joyful experience with specific problems.</p> <ul style="list-style-type: none"> - Need for self-care and self-acceptance with parenting. - Feelings of intense connection and closeness were experienced. - Managing the children's needs had a profound personal impact. 	UK	Autism (Q1)
Donovan, 2020	Childbirth experiences of women with autism spectrum disorder in an acute care setting	qualitative	24 autistic women	Semi-structured interview	<p>Difficulty in communication and comprehension.</p> <ul style="list-style-type: none"> - Feeling stressed in an uncertain environment and being an autistic mother. 	USA UK AUS	Nursing for Women's Health (Q3)
van Steijn et al., 2013	Are symptoms of autism spectrum disorder and/or attention deficit/hyperactivity	Quantitative	96 families	PSDQ	<ul style="list-style-type: none"> - Higher scores for the permissive style with respect to affected children, and lower scores for the authoritarian parenting style and 	UE	European Child and Adolescent Psychiatry (Q1)

disorder in parents related to parenting styles in families with children affected by ASD (+ADHD)?

for affected and unaffected children.

- Mothers with high ASD symptoms reported using a more permissive parenting style with their unaffected child only

Dissanayake et al., 2019	An exploratory study of autism traits and parenting	Quantitative	58 parents with a blood relative with autism (9 fathers and 49 mothers) 4 autistic mothers 1 autistic father	Online survey. Demographic Questionnaire. AQ AQ Child DASS-21 MOPS PSOC PCRI PNQ	- Autism traits were associated with AUS parenting difficulties for their DT child and some aspects of this parent-child relationship. - Parents with high autism traits reported more parenting difficulties than parents with low traits.		Journal of Autism and Developmental Disorders (Q1)
Hampton et al., 2022	Autistic mothers' perinatal well-being and parenting styles	Quantitative	n = 27 autistic women; n = 25 non-autistic women), 2 to 3 months after birth (n = 24 autistic women; n = 26 non-autistic women) and 6 months	AQ PSS STAI EPDS SWLS KPCS	- Autistic mothers scored significantly higher on stress, depression, and anxiety at all time points. - There were no differences between groups for life satisfaction.	UK USA IRL	Autism (Q1)

after birth (n = IPSQ
22 autistic
women; n = 29
non-autistic
women).

- Anxiety scores decreased significantly over time for both groups.

- No differences were found between groups for parental confidence, parental anxiety, caregiving, parental involvement or routine.

Lum et al., 2014	Health communication: A pilot study comparing perceptions of women with and without high functioning autism spectrum disorder	Quantitative	n = 32 autistic females; 26 non-autistic females	self-prepared exploratory questionnaire	<ul style="list-style-type: none"> - Women with ASD experienced greater health care communication challenges. - Women with ASD reported greater anxiety related to health communication. - Challenges increase under emotional distress and during pregnancy and childbirth. 	AUS	Research in Autism Spectrum Disorders (Q1)
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Table 1: Extraction table detailing study and participant characteristics.

