Descriptive Study of the Sensory Experiences of Autistic Mothers as Occupational Beings

Scholarly Journal Article

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Abstract

Introduction: A majority of autistic individuals experience sensory processing challenges. Although sensory demands during parenting are high, little research exists on how difficulties with sensory processing impact autistic mothers' full engagement in meaningful occupations during parenthood. Objectives: The purpose of this descriptive study is to better understand the sensory experiences of autistic mothers, specifically related to parenting and self-care occupations. Methods: An online anonymous survey was developed to explore autistic mothers' personal and sensory experiences throughout early motherhood. Participants were recruited through autistic mother-specific Facebook groups. The sample was made up of 175 autistic mothers. Results: The results of the study gathered an international sample of individuals who identify as autistic mothers, almost all of whom had received a diagnosis post-parenthood. The data collected confirmed challenges for autistic mothers in several occupational areas: disrupted self-care routines, decrease in mental well-being, disrupted sleep, misalignment between their and their child's sensory needs, decrease in participation in leisure activities, and guilt and isolation associated with not participating in social situations related to their child. Conclusion: Most autistic women presenting to healthcare providers are undiagnosed/unidentified, meaning they do not know they are autistic until later in life, often after having children. The findings of this study can educate and support occupational therapists working in school-based, pediatric, and primary care settings to provide family-centered and neurodiverse-affirming care. Occupational therapists can also utilize this information to assist parents of their clients or the clients themselves with autism identification and access to services.

Keywords: autism, advocacy, motherhood

Descriptive Study of the Sensory Experiences of Autistic Mothers as Occupational Beings

Introduction

Autism Spectrum Condition (ASC) is a neurodevelopmental disability that impacts how people communicate and perceive sensory input (Bargiela et al., 2016). Historically, autistic people have been misidentified as a group that needs fixing, rather than understanding, accommodation, and support. For the purposes of this article, we have chosen to use identity-first language (autistic) rather than person-first language (person with autism), as this tends to be more widely preferred by the autistic community (Price, 2022). While not always being identified and diagnosed at an early age, autistic traits are experienced in childhood and persist throughout a person's lifetime.

Although all genders can present with autistic traits, men are more frequently diagnosed than women at a ratio of 3:1 (Pohl et al, 2020). There is more pressure from society for autistic women to be more social than autistic men, making some feel the need to hide their autism (Milner et al., 2019). Milner et al. report that the most commonly observed theme among autistic women is masking their diagnosis. Masking is hiding or suppressing autistic traits from others. This can potentially result in a misdiagnosis or no diagnosis at all. Over time, masking may contribute to mental health challenges such as anxiety and depression (Price, 2022).

An ASC diagnosis is a privilege for many individuals, women in particular, as there are many barriers to obtaining a clinical diagnosis. Some of these barriers include stigma, assessment tools that were developed with wealthy, white, gender-conforming boys in mind, a lack of specialists who are qualified to assess and diagnose autism in adults, an inability to afford

the assessment, and a difference in the presentation of autistic traits in women (Price, 2022; Talcer et al., 2021).

Despite the challenges stated above, many autistic women go on to have children. While autistic mothers can enjoy being parents, they often face specific obstacles. Even before the child is born, autistic mothers may experience sensory sensitivities during pregnancy (Talcer et al., 2021). As they care for their children, they often become dysregulated because of the sensory environment of their day-to-day activities. Moreover, with the multitasking demands that parenthood brings, autistic mothers compared to non-autistic mothers reported an increase in difficulty with multitasking (Pohl et al, 2020). Talcer et al. stated that as autistic women's children become more socially active, autistic mothers may find themselves in social situations that they would normally avoid. Many of these challenges can be managed if autistic mothers have the right kinds of support in place. Some strategies that have been successful for autistic mothers include scheduled downtime, creating a routine, utilizing sensory strategies, self-advocacy, and engaging with a group of other autistic mothers (Talcer et al., 2021). With the right strategies in place, autistic mothers can better navigate their unique experiences of motherhood.

The purpose of this study is to understand the experiences of mothers with autistic traits, specifically the impact of the transition to motherhood and their responses to sensory stimuli. The expected outcomes of this study include increasing the understanding of the lived experiences of autistic mothers. We also aim to understand the effects of autistic traits on mothers' activities of daily living (ADLs), their engagement in occupations, and their role as a parent. The findings of this study can educate and support occupational therapists working in school-based, pediatric, and primary care settings to provide family-centered and

neurodiverse-affirming care. Occupational therapists can also utilize this information to assist parents of their clients or the clients themselves with autism identification and access to services.

Methods

Research Design

This study was a quantitative, non-experimental design focusing on the sensory experiences of autistic mothers. This study was designed as descriptive research, focusing on autistic mother's occupations, specifically ADLs, leisure, sleep, and social participation (AOTA, 2020). A survey was created, specifically designed to elicit information about the participants' personal experiences with specific sensory stimuli in their daily lives to gain a deeper understanding of their sensory experiences as they navigate the journey of motherhood. An informed consent is included at the beginning of the survey with clear instructions to orient the participants through the process. Our study received approval from the IRB committee from Keck Graduate Institute.

Sample, Population, and Sampling Approach

The sampling population for this study was clinically and self-diagnosed autistic mothers. The recruitment process was through Facebook groups specifically for autistic mothers, such as “Autistic Women+ Living Authentically” and “Women with Autism/Autistic Women and Girls,” accessible through our faculty advisor and one group member. The inclusion and exclusion criteria were developed from several articles (Dugdale et al., 2021; Talcer et al., 2021). The inclusion criteria were women over 18 years of age, mothers, and a clinical or self-diagnosis of Autism Spectrum Condition, including both those who received their diagnosis before and after childbirth. The exclusion criteria were women under the age of 18 and non-autistic mothers. The recruitment material was a digital flyer that was shared in the Facebook groups.

Assessments or Measures

A 63-question multiple-choice survey was created, sourcing questions from three studies, Talcer et al (2021), Pohl et al (2020), and Dugdale et al (2021). The survey was categorized by occupational themes such as self-care, childcare, leisure, work, emotional wellness, socialization, birthing process, and sleep. Access to a computer with the Internet was required for participation.

Data Collection

Quantitative data regarding the sensory experiences of autistic mothers were gathered via an online survey. Data was compiled into an Excel spreadsheet and analyzed for patterns.

Data collection occurred from May 17 - June 21, 2023. Rebecca Rosenzweig, group member, and Dr. Kiley Hanish posted the flyer and link to the survey in the Facebook groups. Because the survey contained material that may be triggering to some of the participants, resources were provided. The participants were able to contact Dr. Kiley Hanish over email or the phone, and her contact information was located at the beginning of the survey in the consent form and the post-submission confirmation message.

Data Analysis

Descriptive Statistics

For the descriptive variables, frequency, percentage, and mode were analyzed.

Ordinal Data

The frequency, percentage, mean, and standard deviation were determined for variables categorized as ordinal data.

Data Analysis Process

The following tables are the results of the data analysis using descriptive and ordinal scales of measurements.

Results

Demographics

175 autistic mothers participated in the survey. The demographic information gathered was that 90% (n= 158) of participants identified as female, 70% (n= 122) were married, 69% (n= 118) had never been a single parent, 32% (n= 56) had a bachelor's degree, and 36% (n= 63) worked full-time. The sample included mothers mainly from the United States of America 63% (n=110), the United Kingdom 13% (n=23), Canada 9% (n=16), and Australia or New Zealand 8% (n=14) (See Table 16). The majority of the participants 56% (n=77) were self-diagnosed autistic and received their diagnosis after becoming a parent 93% (n=162). The average age for diagnosis among these mothers was 35-44 years old (n=72), and most participants became mothers by giving birth 97% (n=169). Almost half 42% (n=44) of the mothers had children in the newborn to 5 years-old age category, whether it be only one child in this category or one child in this category and another child(ren) in a different category.

Because autism is a heritable condition, there is a likelihood that other family members may also be autistic. When asked, 81% (n=142) of participants responded yes to having a family member with a diagnosis or suspected autism diagnosis, and 53% (n=93) had a child with an autism diagnosis. Because many autistic people typically have co-occurring conditions, it was important to ask if participants had other mental health conditions. The data demonstrated that out of the 175 participants, 95% had co-occurring diagnoses, the most common being anxiety, depression, and ADHD. (See Tables 1- 16 for demographic characteristics.)

Autism and Occupation

To gather further data about the sensory experiences of autistic mothers, additional questions asked were related to the impact of parenting on their occupations, such as the birthing process, sleep, self-care, emotional wellness, childcare, socializing, leisure, and work.

The Birthing Process

The birthing process can be overwhelming from a sensory perspective. Many of our participants, 41% (n=70), stated that they had the birthing process explained to them and felt knowledgeable going into labor and delivery or cesarean. However, almost half of the participants felt it was too loud during the labor process, 42% (n=72), and were touched too often by medical staff, 42% (n=73). Additionally, 36% (n= 63) of the participants experienced a meltdown or shutdown during the labor process (see Table 23).

Sleep

Sleep is the foundation for all waking occupations, and it is common for autistic people to experience challenges with sleep. Almost half of the participants, 40% (n=70), reported often experiencing a lack of or disrupted sleep due to their child(ren) not sleeping through the night, and almost half, 45% (n=79), of participants were rarely or not at all able to fall back asleep after being awoken by their child during the night (see Table 24).

Self-care

Mothers reported that they were not able to take care of their sensory needs at the same level as before having a child. Almost half of the participants, 44% (n=77) reported that their self-care needs, such as eating, dressing, and personal hygiene, were disrupted most of the time during periods of sensory overstimulation (see Table 17).

Emotional Wellness

After becoming a mother, there was a decrease in mental well-being. Forty-two percent (n=74) of autistic mothers felt more anxious all of the time, 39% (n=69) felt more depressed some of the time, and 43% (n=76) felt more stressed all of the time. Due to sensory and emotional dysregulation that can occur in social and medical settings, it was important to ask the mothers if they had someone who could advocate for them in those situations. Almost half of the participants, 42% (n=73), agreed that they currently had someone who could advocate for them when they were feeling overstimulated in social or medical situations (see Table 21).

Childcare

When asked about breastfeeding, 52% (n=9) of mothers reported that they breastfed their child all the time. Of the 170 mothers who breastfed, almost half, 39% (n=66), stated that they sometimes had difficulties breastfeeding their child.

When asked whether or not their sensory needs aligned with their child's needs when the children were younger, participants responded that their needs sometimes aligned with their child's, 37% (n= 65). When asked if they had someone to watch their child(ren) when they needed a break, 35% (n= 62) responded sometimes, and 35% (n= 61) responded that they rarely had someone there to take over for them (see Table 18).

Socializing

The majority of participants, 70% (n=123), agreed that they participated in group social activities related to their children. Of the mothers who did participate in social group activities, half, 49% (n=86), strongly agreed that they felt overwhelmed during these social activities. The mothers who did not participate in the activities stated that they agreed and strongly agreed to

feelings of guilt for not doing so (93%, n=77). Lastly, 41% (n=71) of participants agreed that motherhood was isolating (see Table 22).

Leisure

Participants, 50% (n= 88), strongly agreed that their leisure activities changed after having a child, and 48% (n= 84) stated that they rarely had time for participation in leisure activities after having a child (see Table 19).

Work

When participants were asked if they often became dysregulated at work because of coworkers, noises, lights, and/or workload, 68% (n= 101) agreed or strongly agreed with the statement (see Table 20).

Other

Many autistic people, 78% (n= 137), do not disclose their autism diagnosis to their health providers due to stigma and common misconceptions. Additionally, a majority of our participants, 77% (n=135), do not disclose their diagnosis to their child's medical providers.

Although parenting comes with many challenges, a majority of our participants, 84% (n=146), agree and strongly agree that they found motherhood to be rewarding (see Table 25).

Missing Data

When transferring survey questions from our draft document to the survey form, a race was unintentionally omitted as an option from the race/ethnicity question. This category was added to the survey form when the error was noticed, however, data on race and ethnicity was not included in the results due to inaccuracies in the data.

A category for participants to fill in “other” was provided under the co-occurring diagnosis section of the survey. Participant responses that included non-mental health conditions such as stomach issues, apraxia, and eczema, were not included in this study.

Lastly, when the survey was initially created, the consent question was not a required question for participants to respond to. One individual did not consent to the terms of the study and their responses were dismissed.

Discussion

Birthing Process

Labor, delivery, and postpartum are vulnerable times for all mothers, and having an undiagnosed autism spectrum condition can make these situations even more stressful and impact their abilities to carry out their roles as mothers. The birthing process can be an overstimulating time, particularly for autistic mothers who have sensory sensitivities and processing difficulties (Talcer et al., 2021). During the labor and delivery process, participants reported that they were touched too often by their medical staff (during vaginal exams and repetitive pressing on their stomachs), and the environment was too loud (talking, equipment, intercom), leading to the participants experiencing a meltdown or shutdown. This data is supported by results found in articles written by Samuel et al. (2021) and Hampton et al. (2022). Samuel et al. (2021) found that many autistic mothers experienced heightened sensory sensitivities to light, sounds, touch, and smells, contributing to higher levels of discomfort, distress, and anxiety. Hampton et al. (2021) found that autistic mothers were more likely to feel overwhelmed by the sensory input during birth, experiencing a meltdown or shutdown. When a mother does not know they are autistic, they are not able to disclose their diagnosis to their medical providers and, in turn, are unable to ask for accommodations to make situations such as

the birthing process more comfortable for them. These results show the importance of implementing neurodiverse-affirming care in all areas of practice, whether or not providers know patients are autistic, in order to create a comfortable and safe environment.

It is also important to note that after receiving or discovering their autism diagnosis, the majority of the mothers chose not to disclose their diagnosis to their personal medical providers as well as their child's medical providers. In an article written by Hampton et al. (2022), it was discovered that during pregnancy, autistic women experienced a lack of trust and were even fearful of sharing their diagnosis with their maternity doctors. The women who chose to report their diagnosis to doctors were informed that their medical providers did not have sufficient knowledge of autism and how to best accommodate their needs. Dugdale et al. (2021) stated, "Disclosing their diagnosis sometimes created further misinterpretations or negative judgments, such as professionals negatively judging participants' ability to 'cope' or parent and viewing them as 'cold.'" Due to the negative stigma surrounding autism and being an autistic parent, many participants found it uncomfortable speaking with their healthcare providers and their children's healthcare providers.

Self-care and Sleep

Before becoming a mother, participants were able to take care of their basic self-care needs, which included eating, dressing, and personal hygiene. After becoming a mother, participants stated that they were less able to take care of their self-care needs. Their self-care practices were disrupted, and they were unable to perform their self-care activities at the same level as before having a child. When individuals are unable to engage in self-care practices, they find it more challenging to self-regulate when overstimulated, impacting their behavioral and emotional state. They may present as being easily distracted, impulsive, and disorganized (Talcer

et al., 2021). Prolonged states of overstimulation hinder their ability to engage in meaningful occupations alone and with their child.

Sleep is the foundation for all waking occupations, and it is common for autistic people to experience challenges with sleep. The Occupational Therapy Practice Framework: Domain and Process–Fourth Edition (OTPF-IV) states, "The goal of engagement in sleep and health management includes maintaining or improving the performance of work, leisure, social participation, and other occupations" (OTPF-IV, 2020). Participants noted that they had difficulty sleeping before having a child, and this sentiment significantly increased after having a child. They stated that their lack of sleep and sleep disruptions occurred as a result of their child not sleeping through the night. In an article by Dugdale et al. (2021), autistic mothers noted that they, too, were experiencing a lack of sleep and exhaustion due to the impact childcare had on their mental and physical well-being. A common theme found in the results was that in many situations, the child's and the mother's sensory and occupational needs did not align, which can result in either the mother or child experiencing dysregulation.

Emotional Wellness

Many individuals with autism also experience co-occurring mental and physical health conditions. Most of the participants had co-occurring mental health diagnoses that included anxiety, depression, and ADHD. These mental health diagnoses contribute to additional strain for autistic mothers as these diagnoses inhibit their ability to manage stress, which can lead to more difficulty in adapting to the experiences of motherhood (Talcer et al., 2021). Many factors can contribute to these feelings of stress, anxiety, and depression, some of which may include their inability to self-regulate, sensory overstimulation, and lack of knowledge surrounding their autism diagnosis. The coexistence of these factors, along with their autism condition and

co-occurring diagnoses, adds an extra layer of challenge to the parenting experience of autistic mothers. Before becoming a mother, participants stated that they were able to manage their stress most of the time when they were feeling overwhelmed. After becoming a mother, participants reported that they were rarely able to manage their stress and felt more anxious, more depressed, and more stressed than before they had children. Overall, the results showed a decrease in mental well-being.

Childcare

The overall well-being of a mother significantly impacts the well-being of their child. Sensory strategies are different for each person and can be used to stimulate their sensory system (visual, tactile, auditory, etc.) to allow them to self-regulate. Some examples of sensory strategies include deep pressure, soft lighting, noise-canceling headphones, and essential oils. Before having a child, many participants were unaware that they were autistic, yet they were still able to meet their sensory needs effectively. After having a child and later discovering their autism diagnosis, they became more aware of what their sensory needs were but struggled to address them effectively. Mothers noted that their sensory needs aligned with their child sometimes, meaning there is some level of disconnect and misalignment between the parent's and child's needs, potentially leading to a higher likelihood and longer periods of overstimulation. When experiencing sensory overstimulation, many mothers stated that they rarely had someone to watch their children to give them time alone to self-regulate. Dugdale et al. (2021) discovered that participants reported finding it hard to ask for help, but when they did, they found it invaluable. This statement is particularly important because if the mother is not able to take the time to regulate their nervous system, they may be unable to tend to their child's needs effectively. Talcer et al. (2021) found that autistic mothers did not ask for help due to anxiety

regarding the judgment of their parenting capabilities. This was also a theme in the article by Dugdale et al. (2021), where participants reported, “Having another person who understood their specific needs was important for them; some found it difficult to find the right kind of help and were apprehensive through fear of judgment about their ability to parent.” There were some concerns that seeking assistance from a medical professional might increase the chances of being misdiagnosed with a mental illness. The women felt comfortable seeking help from other autistic mothers because they did not feel judged (Talcer et al., 2021).

Socializing

Socialization with other parents as an autistic mother is difficult due to communication differences, feeling different, and other various sensory needs (Talcer et al., 2021). Before becoming a mother, participants avoided social situations and sought out opportunities to spend time alone to manage their sensory overwhelm. However, after having a child, they felt an increased pressure to participate in activities related to their child, for example, attending birthday parties, school parent nights, and children’s playdates. Participating in these activities overwhelmed the mothers, and if they chose not to participate, they experienced guilt for not doing so. These social situations contributed to the increased feelings of being overwhelmed in these mothers, and they felt the struggle between participating and feeling overstimulated, and not participating and feeling isolated and guilty. In the article by Dugdale et al. (2021), she reports, “Participants also reflected on their social and communication differences, such as struggling to ‘socialize with [other] parents’ due to difficulties with ‘conversation that’s not like answering questions or specific,’ feeling different, or sensory needs.”

A majority of the mothers also found motherhood to be an isolating experience. This statement is synonymous with the findings recorded in a study conducted by Pohl et al. in 2020,

where autistic mothers were more likely to find motherhood to be isolating, to feel unable to ask for support when needed, and feel judged about their parenting when compared to non-autistic mothers. Although mothers in this study found motherhood to be isolating, most of them found it rewarding. Moreover, when autistic mothers seek the help of other autistic mothers, they feel understood and not judged (Talcer et al., 2021).

Leisure

One way individuals can experience a sense of freedom, mental and physical relaxation, and exploration is through participation in their leisure activities (Chen & Chippendale, 2018). Before becoming a parent, participants stated that they were able to engage in leisure activities that allowed them to self-regulate, and after becoming a parent, that ability significantly decreased. Their leisure activities changed, and they rarely had time to participate after having a child. Literature has shown that mothers have expressed a desire to have more opportunities and to be supported in their pursuit of leisure activities to promote their well-being and health (Bourke-Taylor et al., 2012). Leisure activities are independently selected, meaningful, and intrinsically motivating to those who participate. Leisurely occupations promote a sense of rejuvenation, allow individuals to build new skills and talents, maintain overall health, and be personally validating and rewarding (Bourke-Taylor et al., 2012). Because our participants lacked the time and opportunity to participate in their meaningful occupations, their self-regulating ability decreased, thus contributing to sustained overstimulation.

Implication for Practice

Because many parents do not discover an autism diagnosis until later in life when their child is diagnosed, occupational therapists can assist parents of their clients or the clients themselves with autism identification and access to services. In addition, this research highlights

the challenges faced by autistic mothers and suggests the need for accommodations tailored to their sensory needs. A neurodiverse-affirming healthcare environment can be beneficial to autistic, undiagnosed autistic, and non-autistic mothers. Access needs are identified as anything a person needs for full participation, such as written communication, help with medical paperwork, scheduling appointments, and environmental lighting and sound. In addition to the above, a practitioner can offer the mother the option of being part of their child's session or having a respite break while their child is in an OT session, giving them an opportunity to regulate their nervous system.

Limitations

There is a lack of ethnic and other types of diversity in the study sample. The survey was posted in two autistic mothers' Facebook groups and reached a limited population of English-speaking mothers who identify as autistic. The vast majority of autistic mothers are undiagnosed or misdiagnosed, limiting the survey's ability to include all eligible participants. Additionally, the survey was only available in English and not translated into other languages. Because a survey was created, it is not a validated assessment tool. The survey lacked specific questions to establish a timeline for how long participants face challenges as mothers, preventing identification of when they felt most supported after becoming mothers. Moreover, this research did not include questions about whether the participants received any assistance in healthcare facilities for their sensory needs, such as being provided with noise-canceling headphones, dimming lights, or having a quiet space.

Future Research

Because there is limited literature about autistic mothers, there are endless opportunities for future research. This study can be divided into several smaller studies to investigate each

occupational category. Each question could be followed by additional questions to gain more details. Another way to further this research is to see if there are differences in responses in different parts of the world. Moreover, future research can improve healthcare providers' knowledge of autistic mothers and identify ways to provide the best care possible. Some research questions that remain unanswered are how greatly each aspect of parenting has affected them. Also, whether each participant's level of autism plays a role in influencing their experiences of motherhood, this information can be utilized to provide care and support to the community of autistic mothers.

Conclusion

In conclusion, this research highlights that autistic mothers face unique challenges that impact their health and well-being. The overarching themes touched on include masking, pressure from society on what motherhood should look like, the stigma attached to being an autistic mother, sensory processing challenges, lack of healthcare provider awareness and acceptance of their autism, delayed diagnosis, isolation, and limited access to accurate screening to get a proper diagnosis. Due to a lack of research regarding autistic mothers' experiences in the transition to motherhood, there is a great misunderstanding. Hence, there are not sufficient resources and services tailored to support the sensory needs of autistic mothers. The goal of this research is to better understand the experiences of mothers' autistic traits and how they impact their daily living and to bring to light how being an autistic mother is a specific challenge that needs more understanding to be able to receive the appropriate support they need.

References

American Occupational Therapy Association. (2020). *Occupational therapy practice framework: Domain and process* (4th edition). American Occupational Therapy Association.

Bargiela, S., Steward, R., & Mandy, W. (2016). The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of Autism and Developmental Disorders, 46*(10), 3281–3294. https://doi.org/10.1007/s10803-016-2872-8

Bourke-Taylor, H., Law, M., Howie, L., & Pallant, J. F. (2012). Initial development of the health promoting activities scale to measure the leisure participation of mothers of children with disabilities. *The American Journal of Occupational Therapy*, *66*(1). https://doi.org/10.5014/ajot.2012.000521

Chen, S.-W., & Chippendale, T. (2018). Leisure as an end, not just a means, in occupational therapy intervention. *The American Journal of Occupational Therapy*, *72*(4). https://doi.org/10.5014/ajot.2018.028316

Dugdale, A.-S., Thompson, A. R., Leedham, A., Beail, N., & Freeth, M. (2021). Intense connection and love: The experiences of autistic mothers. *Autism, 25*(7), 1973–1984. https://doi.org/10.1177/13623613211005987

Hampton, S., Allison, C., Baron-Cohen, S., & Holt, R. J. (2022). Autistic People's Perinatal Experiences II: A Survey of Childbirth and Postnatal Experiences. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-022-05484-4

Milner, V., McIntosh, H., Colvert, E., & Happé, F. (2019). A qualitative exploration of the female experience of autism spectrum disorder (ASD). *Journal of Autism and Developmental Disorders, 49*(6), 2389–2402. https://doi.org/10.1007/s10803-019-03906-4

Occupational Therapy Practice Framework: Domain and Process—Fourth Edition (OTPF-IV). (2020). *American Journal of Occupational Therapy*, *74*(Supplement_2), 7412410010p1-7412410010p87. https://doi.org/10.5014/ajot.2020.74s2001

Pohl, A. L., Crockford, S. K., Blakemore, M., Allison, C., & Baron-Cohen, S. (2020). A comparative study of autistic and non-autistic women's experience of motherhood. *Molecular Autism, 11*(3). https://doi.org/10.1186/s13229-019-0304-2

Price, D. (2022). Unmasking autism: Discovering the new faces of neurodiversity (First edition). *Harmony Books*

Samuel, P., Yew, R. Y., Hooley, M., Hickey, M., & Stokes, M. A. (2021). Sensory challenges experienced by autistic women during pregnancy and childbirth: A systematic review. *Archives of Gynecology and Obstetrics*, *305*(2), 299–311.

Talcer, M. C., Duffy, O., & Pedlow, K. (2021). A qualitative exploration into the sensory experiences of autistic mothers. *Journal of Autism and Developmental Disorders, 53*(2), 834–849. https://doi.org/10.1007/s10803-021-05188-1

Tables

Table 1

Diagnosis Type

Clinical/Self Diagnosis	n	%
Clinical Diagnosis	77	44
Self Diagnosis	98	56

Table 2

Age of participants

Age	n	%
18-24	4	2
25-34	55	31
35-44	85	49
45-54	28	16
55-64	2	1
65+	1	1

Table 3

Timing of Diagnosis

Received/Discovered diagnosis	n	%
Before becoming a parent	13	7
After becoming a parent	162	93

Table 4

Age of Diagnosis

Age	n	%
18-24	7	4
25-34	62	36
35-44	72	41
45-54	20	11
55-64	1	1
65+	0	0

Table 5

Number of Children

Children	n	%
1	56	32
2	69	39
3	34	19
4	11	6
5	5	3
6+	0	0

Table 6

Pathway to Parenthood

Became a parent	n	%
Give birth	169	97
Surrogacy	0	0

Adoption	1	1
Fostercare	0	0
Stepmom	1	1
Adoption, Fostercare	2	1
Gave birth, Adoption, Stepmom	1	1
Gave birth, Adoption	1	1
Gave birth, Fostercare	0	0

Note. A multi-select option was available for this question.

Table 7

Ages of Children

Ages	n	%
Newborn-5 years old	44	25
5-8 years old	16	9
8-11 years old	12	7
11-17 years old	15	9
18 years old	8	5
8-11 years old, 11-17 years old, 18 years old and up	2	1
Newborn-5 years old, 8-11 years old, 11-17 years old	2	1
5-8 years old, 11-17 years old, 18 years old and up	3	2
5-8 years old, 8-11 years old, 11-17 years old	6	3
8-11 years old, 11-17 years old	7	4
Newborn-5 years old, 5-8 years old	18	10

Newborn-5 years old, 5-8 years old, 8-11 years old	6	3
Ages - cont'd	n	%
5-8 years old, 8-11 years old	13	7
11-17 years old, 18 years old and up	10	6
5-8 years old, 11-17 years old	5	3
Newborn-5 years old, 5-8 years old, 11-17 years old	2	1
8-11 years old, 18 years old and up	3	2
Newborn-5 years old, 8-11 years old	1	1
Newborn-5 years old, 11-17 years old	1	1
5-8 years old, 8-11 years old, 11-17 years old, 18 years old and up	1	1

Note. A multi-select option was available for this question.

Table 8

Family Member with a Suspected or Formal Autism Diagnosis

Suspected or formal diagnosis	n	%
Yes	93	53
No	33	19

Table 9

Child with an Autism Diagnosis

Autism Diagnosis	n	%
Yes	93	53

No	82	47

Table 10

Co-Occurring Mental Health Conditions

Mental Health Condition	F(n)	%
Anxiety	6	4
Depression	5	3
OCD	0	0
ADHD	6	4
Anxiety, Depression, ADHD	49	29
Anxiety, ADHD	20	12
Anxiety, Depression, OCD, ADHD, Eating Disorder	2	1
Anxiety, Depression, OCD	8	5
Anxiety, Depression	26	16
Anxiety, ADHD, BPD	1	1
PTSD	0	0
Anxiety, Depression, OCD, PTSD	1	1
Anxiety, OCD	2	1
Anxiety, Depression, ADHD, Eating Disorder	1	1
Anxiety, Depression, ADHD, OCD, PTSD	3	2
Anxiety, Depression, ADHD, OCD, PTSD, Bipolar	0	0
Anxiety, ADHD, PTSD	1	1
Anxiety, depression, Eating Disorder	1	1
Anxiety, depression, ADHD, PTSD	4	2

Anxiety, OCD, ADHD	7	4
Depression, ADHD	2	1
Mental Health Condition - cont'd	F(n)	%
Anxiety, depression, OCD, ADHD	14	8
ADHD, PTSD	1	1
Anxiety, Depression, PTSD	2	1
Anxiety, ADHD, PTSD, OCD	1	1
Anxiety, Depression, OCD, ADHD, PTSD	2	1

Note. Multi-select and fill-in-the-blank options were available for this question.

Table 11

Gender

Gender	n	%
Male	0	0
Female	158	90
Transgender	1	1
Non-Binary	12	7
Other	4	2
Prefer not to say	0	0

Table 12

Marital Status

Marital Status	n	%
Single	12	7
Married	122	70

Divorced	10	6
Widowed	1	1
Marital Status	n	%
Separated	11	6
Long Term Partner	19	11

Table 13

Single Parenthood

Single Parenthood	n	%
Currently a Single Parent	30	17
Single Parent in the Past	24	14
Never Been a Single Parent	118	69

Table 14

Level of Education

Education Level	n	%
Some high school, no diploma	5	3
High school graduate, diploma, or equivalent (GED)	13	7
Some college, no degree	30	17
Trade/Technical/Vocational training	8	5
Associate degree	8	5
Bachelor’s degree	56	32
Master’s degree	38	22
Graduate degree	15	9
Other terminal degree	1	1

Table 15

Status of Employment

Employment Status	n	%
Part-Time	24	14
Full-Time	63	36
Self-Employment	24	13
Stay at home parent	40	23
Out of work	6	3
Student	4	2
Military	1	1
Retired	1	1
Unable to work	11	6
Medical leave	1	1

Table 16

Location of Participants

Country	n	%
United States of America	110	63
United Kingdom: England, Scotland, Wales, Northern Ireland	23	13
Australia/ New Zealand	14	8
Canada	16	9
Luxemburg	1	1
Israel	1	1
Belarus	1	1

Norway	2	1
Hungary	1	1
Country	n	%
Sweden	1	1
Denmark	1	1
South Africa	1	1
Ireland	2	1

Table 17

Self-Care

Variable	Mode	Mean	SD	n	%
Before becoming a parent, I was able to take care of all my basic daily self-care needs (e.g. eating, dressing, personal hygiene, sleeping, using the bathroom when I need to, etc).	4	4.2	0.7	94	54
After becoming a parent, I was able to take care of all my basic daily self-care needs (e.g. eating, dressing, personal hygiene, sleeping, using the bathroom when I need to, etc).	3	3.18	0.94	68	39
When experiencing sensory "overstimulation", my self-care practices are disrupted.	4	4	0.9	77	44
After I had a child, I was able to perform my self-care activities at the same level as before I had a child.	2	2	1	60	34

Note. 1= Not at all, 2=Rarely, 3=Sometimes, 4=Most of the time, 5=All of the time

Table 19

Childcare

Variable	Mode	Mean	SD	n	%
I breastfed my child(ren). (If no, skip the next two questions)	5	4	1.42	90	52
I had difficulties breastfeeding my child.	3	3	1.38	66	39
I had assistance from a medical provider with breastfeeding.	3	2	1.22	63	37
Before having a child, I was aware of my sensory needs.	1	2	1.05	66	38
Before having a child, I was able to take care of my sensory needs.	4	3	1.05	67	38
After having a child, I was aware of my sensory needs.	4	3	1.11	59	34
After having a child, I was able to take care of my sensory needs.	2	2	0.78	75	43
When my child was young, my sensory needs aligned with theirs. (ex: my child and I both prefer a quiet environment and the same temperature settings)	3	3	1.03	65	37
If your sensory needs did NOT align with your child's, were you able to balance your sensory needs along with taking care of your child?	3	3	1.09	78	48

Variable	Mode	Mean	SD	n	%
I had someone to watch my children when I needed a break.	3	2	0.96	62	35

Note. 1= Not at all, 2=Rarely, 3=Sometimes, 4=Most of the time, 5=All of the time, 6= N/A

Table 20

Leisure

Variable	Mode	Mean	SD	n	%
Before becoming a parent, I engaged in activities that helped me self-regulate.	4	4	0.78	92	53
After becoming a parent, I engaged in activities that help me self-regulate.	2	3	0.73	85	49
My leisure activities (what I do for fun/in my free time) changed after having a child	5*	4	1.05	88	50
I still had time for my leisure activities even after having a child.	2	2	0.87	84	48

Note. 1= Not at all, 2=Rarely, 3=Sometimes, 4=Most of the time, 5=All of the time, 6= N/A

**1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

Table 21

Work

Variable	Mode	Mean	SD	n	%
My sensory needs are supported/accommodated at work.	2*	3	1.43	47	32
I often become dysregulated at work because of coworkers, noises, lights, and/or workload.	4*	3	1.69	54	36

*Note. *1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

Table 22

Emotional Wellness

Variable	Mode	Mean	SD	n	%
Before becoming a parent, I was able to manage my stress when I felt overwhelmed.	3	3	0.8	73	42
After becoming a parent, I was able to manage my stress when I felt overwhelmed.	2	2	0.8	82	47
After becoming a mother, I felt more anxious than before I had children.	5	4	1.1	74	42
After becoming a mother, I felt more depressed than before I had children.	3	3	1.16	69	39
After I became a mother, I felt more stressed than before I had children.	5	4	0.93	76	43
I currently have someone, a partner or loved one, who can advocate for me when I am feeling overstimulated in social or medical situations.	4*	3	1.28	73	42

Note. 1= Not at all, 2=Rarely, 3=Sometimes, 4=Most of the time, 5=All of the time, 6= N/A

**1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

Table 23

Socializing

Variable	Mode	Mean	SD	n	%
Before becoming a mother, I would avoid social situations and seek time alone as a way to manage my sensory overwhelm.	4*	4	1.07	72	41
After having my child(ren), I felt an increased need to participate in social activities related to my child(ren) (e.g children's birthday parties, school parent nights, children's playdates, etc.)	4*	4	0.94	88	50
I participated in these group social activities related to my children	4*	4	0.79	123	70
If I did participate in social group activities related to my children, these social group activities felt overwhelming to me.	5*	4	0.74	86	49
If I did not participate in group social activities related to my children, I felt guilty for not doing so.	5*	4	0.97	80	47
I found motherhood to be isolating.	4*	4	1.15	71	41

*Note. *1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

Table 24

Birthing Process

Variable	Mode	Mean	SD	n	%
I attended prenatal classes	Yes	1	0.5	104	60
The birthing process was explained to me, and I felt knowledgeable going into labor or C-section.	4*	4	1.33	70	41
I had a meltdown or shutdown during the labor process.	2*	3	1.39	48	28
I was touched too much by medical staff during the labor process (e.g., vaginal exam, repetitive pressing on belly).	2*	3	1.37	55	32
It was too loud for me during labor (e.g., talking, beeping equipment, talking over the intercom).	2*	3	1.33	57	33

*Note. *1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

Table 25

Sleep

Variable	Mode	Mean	SD	n	%
Before becoming a parent, I had difficulty sleeping.	4*	3	1.31	64	37
After becoming a parent, I had difficulty sleeping.	4**	4	0.96	71	41
I experienced a lack of or disrupted sleep due to my child not sleeping through the night.	4**	4	1	70	40
If my child woke up during the night, I was able to fall back asleep.	3**	3	0.94	79	45

*Note. *1=Strongly disagree, 2= Disagree, 3=Undecided, 4=Agree, 5=Strongly agree*

***1= Not at all, 2= Rarely, 3= Sometimes, 4= Often, 5= Always*

Table 26

Other

Variable	Mode	Mean	SD	n	%
I disclose my autism diagnosis to my medical providers.	3	3	1.26	52	30
I disclose my diagnosis to my child's medical providers.	1	2	1.37	67	38
I find motherhood to be rewarding.	4	4	0.84	102	58
Before becoming a parent, I felt comfortable speaking to my healthcare providers.	3	3	0.99	62	35
After becoming a parent, I felt comfortable speaking to my healthcare providers.	3	3	0.89	72	41

Note. 1= Not at all, 2=Rarely, 3=Sometimes, 4=Most of the time, 5=All of the time, 6= N/A