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Parents' Understanding of Sensory Processing in their Child with Autism Spectrum Disorder

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Parents' Understanding of Sensory Processing in their Child with Autism
Spectrum Disorder

by

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Dedication

For my family and friends, I truly could not have done it without you. Thank you for your support and love.

Acknowledgements

Thank you to the USC Genetic Counseling Program, which continues to foster learning and passion for the field. My classmates, I couldn't have made it through these two years without you beside me. I am proud to call you my colleagues and friends. To the entire faculty upstairs who provide us with support and motivation, your wisdom has helped us develop into a fantastic future cohort of genetic counselors. Thank you to the clinical supervisors for their understanding and dedication to the program.

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Abstract

Purpose: The purpose of this study was to assess the need and desire of parents of children with Autism Spectrum Disorder (ASD) to receive sensory processing disorder (SPD) education. We hoped to identify misconceptions of parents about sensory processing and examined the utility of providing information on SPDs to these parents within the genetic counseling session. **Methods:** Invitations to participate were sent to support groups in the Southeast United States. A survey tool was used to obtain demographic information. A short presentation was given to clarify the definition of sensory processing, give examples of signs and symptoms of SPDs, and provide other information regarding sensory processing. This was followed by a guided discussion with the parents present at the focus group. Participants were asked questions regarding misconceptions, comfort discussing their child's condition, and feelings of parental competency. **Results:** A total of three support groups agreed to participate. Focus groups ranged in size from three participants to four participants and lasted fifty minutes to an hour and fifteen minutes. While many parents had at least vague familiarity with SPDs, having received information from a variety of sources, some expressed misconceptions that needed to be clarified. The information provided allowed for a discussion of the child's behavior in positive terms. A majority of parents expressed a desire for more information regarding sensory processing disorders. **Conclusions:** Based on the information gathered, it is hypothesized that including a discussion about sensory processing may provide an opportunity for parents to discuss their child in a positive

manner. In addition, it may allow for identifying misconceptions and allow for better understanding of their child's behaviors. The findings of this study may assist genetic counselors in addressing parent need for information, therapy, and support as they care for their child with autism.

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Chapter 1. Background

1.1 Autism Defined

Autism spectrum disorder (ASD) refers to a range of neurodevelopmental conditions characterized by deficits in socialization and communication in addition to restricted interests or repetitive behaviors (Miles, 2011). The term spectrum indicates that ASDs occur along a continuum with a wide range of symptoms or characteristics that vary in severity, emphasizing the clinical heterogeneity of the condition. The prevalence of ASDs has increased over the past years (CDC, 2014). While estimated that 1 in 150 children were diagnosed with ASD in 2000, the Centers for Disease Control and Prevention (CDC) has estimated in 2010 that 1 in 68 children is affected by ASD (CDC, 2010). This increase, however, may not be as great as it implies, but rather may reflect an increase in awareness by professionals and the public as well as a continuing development of broader diagnostic criteria (Miles, 2011).

It is widely accepted that the underlying causes for ASDs include both genetic and environmental factors. In addition, ASDs are commonly associated with a number of other comorbidities, such as intellectual disability, language delay, behavior problems, epilepsy, tic disorders, and many others (Chakrabarti & Fombonne, 2005). The nature of deficits associated with ASDs and comorbid conditions has significant implications for children with ASD and their families (Kasari & Sigman, 1997; Lecavalier, Leone, & Wiltz, 2006). Early intervention and increased recognition have had a positive impact on the outcome of patients with ASD, and care for individuals with ASD involves a

multidisciplinary team and individualized treatment in order to achieve the most notable improvements in symptoms (Eldevik, Hastings, Jahr, & Hughes, 2012).

1.2 Causes of Autism

It is widely accepted that ASDs have a genetic component and that gene-environment interactions play a role; they are considered to have multifactorial inheritance.

Recurrence rates in siblings, high concordance rates between monozygotic twins, and higher incidence in males support the notion that genetic factors play a role in the development of ASDs. The heritability is estimated to range between 40–90% (Bailey et al., 1995; Hallmayer et al., 2011; Kelly, Kratz, Bielski, & Rinehart, 2002; Lichtenstein, Carlstrom, Rastam, Gillberg, & Anckarsater, 2010; Ronald et al., 2006; Simonoff, 1998; Taniai, Nishiyama, Miyachi, Imaeda, & Sumi, 2008). The fact that concordance in monozygotic twins is less than 100% emphasizes the role of the environmental factors implicated in ASD (Gardener, Spiegelman, & Buka, 2011). Because there seems to be a number of factors implicated in the etiology of ASD, identifying an exact cause for an individual is difficult.

Epidemiologic research on risk factors for autism has primarily focused on obstetrical and early developmental factors, including the prenatal development of children (Gardener, et al., 2011). Data on environmental factors and autism therefore indicate an association rather than a cause. The genetics of autism has proven even more challenging to uncover. Chromosomal analysis, microarrays, and genome wide association studies have revealed genetic differences that predispose individuals to ASD; however, the penetrance of developing autism is often incomplete (Miles, 2011). Although progress has been made, much regarding the causes of ASD remains elusive.

There is strong evidence for the role of genetics in the development of autism. In fact, ASDs occur more commonly in individuals with certain genetic conditions. Numerous genetic conditions, including Down syndrome, Turner syndrome, and DiGeorge syndrome have higher incidences of ASD than expected by chance alone (Creswell & Skuse, 1999; Kent, Evans, Paul, & Sharp, 1999). Standard genetic testing in individuals diagnosed with ASDs includes microarray, chromosome analysis, Fragile X, and a targeted gene panel if a specific syndromic cause is suspected. With the advances in recent years, a specific cause can be found in approximately 30% of cases (Schaefer & Mendelsohn, 2008)

Many prenatal environmental factors have been associated with ASD. Valproic acid, thalidomide, rubella, and alcohol exposures prenatally have been linked to an increase risk for autism (Deykin & MacMahon, 1979; Rodier, Ingram, Tisdale, Nelson, & Romano, 1996; Strömmland, Nordin, Miller, Akerström, & Gillberg, 1994). In general, a number of late-term complications and labor and delivery complications seem to have an association with ASD. Currently, there is insufficient evidence to suggest any one factor in this area in the etiology of autism. A combination of multiple genetic predispositions and multiple environmental, perinatal and neonatal factors are likely involved in causing ASD. Factors with the strongest evidence associated with autism risk included abnormal fetal presentation, umbilical-cord complications, fetal distress, birth injury or trauma, multiple birth, maternal hemorrhage, summer birth, low birth weight, small for gestational age, congenital malformation, low 5-minute Apgar score, feeding difficulties, meconium aspiration, neonatal anemia, ABO or Rh incompatibility, and

hyperbilirubinemia (Gardener et al., 2011). When looking at causes for ASD, however, no factors studied occur in isolation.

Brain development and function have been studied in individuals with ASD using neuroimaging techniques. Boys with autism are more likely to be born with macrocephaly (Elder, Dawson, Toth, Fein, & Munson, 2008). Additionally, a greater volume of white matter in the cortex and cerebellum has been shown with magnetic resonance imaging (Casanova, 2006). Atypical inflammation and disordered cellular organization have also been identified in individuals with ASD (Casanova, 2006; Vargas, Nascimbene, Krishan, Zimmerman, & Pardo, 2005). The underlying reasons for differences in brain structure and development remain largely unknown.

1.3 Evolution of the DSM

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is used by mental health professionals as a diagnostic reference. It outlines the specific criteria needed to fit a diagnosis of various psychological conditions. The *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (DSM-IV-TR; American Psychiatric Association, 2000), uses the term Pervasive Developmental Disorders (PDDs) to capture five specific diagnoses: Autistic Disorder, Asperger's Disorder, Rett's Disorder, childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS).

Distinctions between the five subcategories of PDDs used within the DSM-IV have been inconsistent in the past. For this reason, the current edition of the DSM, the DSM-V, uses ASD to capture a group of disorders and includes a description of the severity level. Previously defined Autistic Disorder, PDD-NOS, and Asperger's Disorder

now fall under “Autism Spectrum Disorder” while Rett’s Disorder and Childhood Disintegrative Disorder are no longer a part of the ASD classification (American Psychiatric Association, 2013). Notably, language delay is no longer a requirement for the diagnosis of autism.

Sensory processing disorders, which are described in the following section, were under consideration for inclusion in the latest addition of the DSM-V (Champagne, Koomar, & Olson, 2010; Strzelecki, 2008). This may indicate that this particular class of disorders is gaining recognition across multiple medical fields. Because of overlapping symptoms with many disorders, a vague description, and lack of evidence that a diagnosis of sensory processing disorder would be helpful to individuals, it was decided that the new edition of the DSM would not include sensory processing disorders (Koziol, Budding, & Chidekel, 2011). Certain groups are advocating for increased recognition and inclusion of sensory processing disorders in the DSM (Miller, 2012).

1.4 Autism and Sensory Processing

Sensory processing refers to the organization of sensory input. It determines one’s perception of the environment and in turn dictates the response to it (Walbam, 2014; Brock et al., 2012). Sensory processing disorders (SPDs) result from a disturbance in this organization. Differences in sensory responses are divided into two different categories, hyperresponsive and hyporesponsive. There are seven different senses affected by SPDs: vestibular, tactile, proprioception, visual, auditory, taste, and smell. Each child may have a unique combination of hyper-responsivity and hypo-responsively to these seven senses.

SPDs are typically treated by occupational therapists who are knowledgeable about creating plans to suit each individual child's needs. Interventions regarding sensory processing typically focus on self-regulation, helping children integrate sensory input, and increasing their ability to tolerate stimuli (Walbam, 2014).

Sensory processing disorders (SPDs) are common, but not universal, in children with autism. Both caregiver and teacher questionnaires consistently suggest children with ASD have atypical behavioral responses to sensory input (Baranek, David, Poe, Stone, & Watson, 2006; Rodgers, Hepburn, & Wehner, 2003; Tomchek & Dunn, 2007). It is estimated that about 70% of children with autism demonstrate high levels of atypical sensory processing (Baranek, et al., 2006). These differences in sensory processing may hinder daily functioning and negatively influence socialization by affecting the way children behave, play, and learn (Walbam, 2014).

The DSM-V, which was updated in 2013, includes sensory processing in the criteria for the medical and psychiatric diagnosis of autism (American Psychiatric Association, 2013, pp. 299-300). Hyper- or hyporeactivity is recognized as leading to the repetitive behaviors or activities characteristic of people affected by autism spectrum disorders.

Parental explanations of their child's sensory processing disorder focus on the child and the stimulus. However, many have difficulty understanding the sensory experiences of the child (Dickie, Baranek, Schultz, Watson, & McComish, 2009). For example, Dickie et al. (2009) found that parents often struggled to explain why their child reacted to the stimuli differently. In addition, the authors found that those parents who were educated about autism or had a therapist who discussed behaviors in sensory terms

had a better understanding of the concept of sensory experiences. Thus, sensory processing education could help parents better understand their child's sensory experience and the behavioral results, and also provide a means of acknowledging parental stress (Dunn, 2001; Gourley, Wind, Henninger, & Chinitz, 2013).

Parents of children with a sensory processing disorder have reported significantly higher levels of parental stress than parents of children with typical sensory processing (Gourley et al., 2013). Previous studies indicate that parental stress may be reduced and treatment outcome may improve if mental health professionals addressed sensory processing deficits (Gourley et al., 2013). Furthermore, knowledge about sensory processing disorders may help parents identify child's specific sensory patterns and help explain the child's behaviors (Dunn, 2001).

1.5 Care for Children with Autism

A medical home should be provided to children with ASDs. This is an accessible, comprehensive, family-centered, and culturally-effective model of care (American Academy of Pediatrics, 2002). The goals of long-term management for children with ASD are to increase independent functioning, improve community engagement, and provide family and caregiver support. A successful long-term management plan requires coordinating the efforts of many specialists including educators, therapists, physicians, and mental health professionals (Carbone, Farley, & Davis, 2010).

Behavioral therapy, such as applied behavioral therapy and structured teaching, uses several approaches and is the primary management strategy for behavioral deficits (Eikeseth, 2009; Rogers & Vismara, 2008; Ozonoff & Cathcart, 1998). These therapies may be provided by an early intervention program, a school-based special education

program, therapists in private practice, or a combination of the three (American Academy of Pediatrics, 2002). Intensive behavioral therapy initiated at a young age is more likely to lead to improved cognitive, language, and adaptive skill outcomes (Rogers & Vismara, 2008; Eikeseth, 2009; Ozonoff & Cathcart, 1998). Patient and family access to comprehensive treatment programs is currently not available to all who could benefit from the services due to limited number of providers and limited access to providers. However, advocacy by parents and physicians has started to increase public awareness and improve access to a medical home model of care as well as therapy interventions (American Academy of Pediatrics, 2003).

Family-centered care has been linked to improved child and parent outcomes. Behaviors resulting from differences in sensory processing are reported to impact family participation in work, family, and leisure activities (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). For this reason, family-centered care for children with autism must consider unique factors and the impact of these factors in daily life. The US Institute of Medicine emphasized in its 2001 report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the need to improve patients' and families' access to information. In fact, one of the core values established by the American Academy of Pediatrics in 2003 is sharing honest and unbiased information with families on an ongoing basis by using methods that families find useful and affirming.

1.6 Sensory-based Therapies

Sensory processing difficulties are addressed by a variety of sensory-based therapies, which help organize and control the regulation of sensory inputs (Barton, Reichow, Schnitz, Smith, & Sherlock, 2015). Sensory integration therapy is an extension of the

hypothesis that abnormal behaviors observed in autism are a result of deficits of the nervous system, and is based on the theory that the ability to process stimuli can be improved (Lang et al., 2012). Sensory integration therapy typically involves wearing a weighted vest, being brushed, riding a scooter, swinging, sitting on a bouncy ball, being squeezed, or other activities that are based on the child's specific concerns or needs (Lang et al., 2012). Sensory integration should involve child safety; opportunities to obtain sensory stimulation to support self-regulation, awareness, or movement; preferable activities; activities that are of appropriate difficulty level; activities that support the desire to play; and activities that are therapeutic to the child (Parham et al., 2011)

Despite the widespread acceptance and use of sensory-based treatments, empirical evidence to support the utility of these treatments is limited due to insubstantial treatment outcomes, weak experimental designs, or bias of experimental designs (Barton et al., 2015). The evidence-base currently available does not support the use of sensory integration therapy in children with ASD (Lang et al., 2012). Despite the lack of evidence to support the utility of sensory-based treatments, sensory integration therapy is one of the most common interventions delivered to children with ASD (Lang et al., 2012). Previous reviews of sensory integration therapy have arrived at varying conclusions with some providing evidence for utility, and others showing no effect on individuals with ASD (Barton et al., 2015).

Despite evidence against the utility of sensory integration therapy, Thompson's study (2011) provides substantial evidence to support the utility of multi-sensory interventions. This study used an observational instrument to quantify aggressive behavior, self-stimulatory behavior, how relaxed and engaged the child appears, and

several other characteristics relating to focus within the classroom (Thompson, 2011). Observation was performed first in the classroom setting, then in a multi-sensory environment, and finally upon return to the classroom (Thompson, 2011). Most notably, self-injurious behavior decreased by over 98% over the course of the study. In addition, the mean sustained focus and engagement increased following the exposure to a multi-sensory environment (Thompson, 2011). The research of Smith, Press, Koenig, and Kinnealey (2005) and Shapiro, Sgan-Cohen, Parush, and Melmed (2009) further supported the notion that a sensory integration approach is an effective intervention to reduce self-stimulating and self-injurious behaviors that interfere with daily functional activities.

1.7 Genetic Counseling and Autism

Copy number variations, single-gene disorders, chromosomal abnormalities, and epigenetic factors have been implicated as causes of ASDs. The 2013 American College of Medical Genetics and Genomics (ACMG) Practice Guidelines indicated that every individual with an ASD should be offered a genetic evaluation (Schaefer & Mendelsohn, 2013). This genetic evaluation should include defining an etiology if possible, providing genetic counseling, and contributing to the case management of the individual. It is estimated that a genetic etiology can be identified in up to 30% of children with ASD, although this percentage may increase using a tiered testing approach with involvement of a genetics team (Schaefer & Lutz, 2006; Schaefer & Mendelsohn, 2008).

In 1975, the American Society of Human Genetics (ASHG) proposed a definition of genetic counseling which has served for many years as the basis for development of

the field (ASHG, 1975). More recently, Resta et al. (2006) developed the following definition which was accepted by the National Society of Genetic Counselors:

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. This process integrates the following:

- 1) interpretation of family and medical histories to assess the chance of disease occurrence or recurrence;
- 2) education about inheritance, testing, management, prevention, resources and research; and
- 3) counseling to promote informed choices and adaptation to the risk or condition (Resta, et al., 2006).

This first definition of genetic counseling has continued to evolve over the years. Since the coining of this fundamental definition of genetic counseling, researchers have delved into the specifics of patient needs. One of the three broad goals of genetic counseling established by Wang, Gonzalez, and Merajver (2004) is educating and informing clients of the genetic condition. Pediatric genetic counselors are expected to review the natural history of diagnoses within the session. For patients with an ASD, this includes the potential for discussion and education about sensory processing deficits. Education may be a venue to relieve parental distress and to motivate parents to find a solution or utilize resources (Kessler, 1997). Parents of children newly diagnosed with ASD expect genetic counselors working with them to describe the variability within the spectrum, acknowledge the emotional challenges their family will face, and to be current on research and treatment options (Selkirk et al., 2009). This suggests that information

regarding sensory processing may be beneficial to parents of children with autism.

Making parents aware of sensory processing principles may increase a parent's sense of competence and reduce self-attribution of behaviors to "poor" parenting (Gourley et al., 2013).

1.8 Purpose

Parents of children with autism feel the need to understand their child's disabilities as a part of their coping mechanism. In addition, they desire information regarding the natural history and prognosis of the condition, means for discussing the condition with others, and appropriate parenting in regards to the condition (Mercer, Creighton, Holden, & Lewis, 2006). The genetic counseling session provides an empathetic and supportive environment in which to receive information about sensory processing disorders.

Furthermore, providing this information can encourage parents to take an active role in utilizing resources and advocating for their child. A discussion of sensory processing within autism genetic counseling sessions may fill an existing gap and allow for providing optimal care. The purpose of the present study is to explore the utility of providing sensory processing information within the genetic counseling session.

Chapter 2. Parents' Understanding of Sensory Processing in their Child with Autism Spectrum Disorder¹

2.1 Abstract

Purpose: The purpose of this study was to assess the need and desire of parents of children with Autism Spectrum Disorder (ASD) to receive sensory processing disorder (SPD) education. We hoped to identify misconceptions of parents about sensory processing and examined the utility of providing information on SPDs to these parents within the genetic counseling session. **Methods:** Invitations to participate were sent to support groups in the Southeast United States. A survey tool was used to obtain demographic information. A short presentation was given to clarify the definition of sensory processing, give examples of signs and symptoms of SPDs, and provide other information regarding sensory processing. This was followed by a guided discussion with the parents present at the focus group. Participants were asked questions regarding misconceptions, comfort discussing their child's condition, and feelings of parental competency. **Results:** A total of three support groups agreed to participate. Focus groups ranged in size from three participants to four participants and lasted fifty minutes to an hour and fifteen minutes. While many parents had at least vague familiarity with SPDs, having received information from a variety of sources, some expressed misconceptions that needed to be clarified. The information provided allowed for a

¹ Anderson, K., Ravan, S., Hill-Chapman, C., & Lebowitz, M. To be submitted to *American Journal of Occupational Therapy*.

discussion of the child's behavior in positive terms. A majority of parents expressed a desire for more information regarding sensory processing disorders. **Conclusions:** Based on the information gathered, it is hypothesized that including a discussion about sensory processing may provide an opportunity for parents to discuss their child in a positive manner. In addition, it may allow for identifying misconceptions and allow for better understanding of their child's behaviors. The findings of this study may assist genetic counselors in addressing parent need for information, therapy, and support as they care for their child with autism.

2.2 Introduction

Autism spectrum disorder (ASD) refers to a range of neurodevelopmental conditions characterized by deficits in socialization and communication as well as restricted interests or repetitive behaviors (Miles, 2011). ASDs encompass a wide range of symptoms or characteristics that vary in severity. The Centers for Disease Control and Prevention (CDC) estimated in 2010 that 1 in 68 children is affected by ASD (CDC, 2010). The increasing prevalence of ASD over the past years may reflect an increase in awareness by professionals and the public, in addition to a continuing development of broader diagnostic criteria (Miles, 2011). Both genetic and environmental factors play a role in the development of ASDs (Chakrabarti & Fombonne, 2005).

Sensory processing disorders (SPDs) are common in children with autism, as approximately 70% of children with autism demonstrate atypical sensory processing (Baranek, David, Poe, Stone, & Watson, 2006). The term sensory processing refers to the organization of sensory input (Walbam, 2014). SPDs result from a disturbance in this organization. Three different categories describe the differences in sensory responses,

including hyperresponsive and hyporesponsive. There are seven different senses affected by SPDs: vestibular, tactile, proprioception, visual, auditory, taste, and smell.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-V), which was updated in 2013, includes sensory processing in the criteria for the medical and psychiatric diagnosis of autism (American Psychiatric Association, 2013, pp. 299-300). Hyper- or hyporeactivity is recognized as leading to the repetitive behaviors or activities characteristic of people affected by autism spectrum disorders.

One of the three broad goals of genetic counseling established by Wang et al. (2004) is educating and informing clients of the genetic condition. Pediatric genetic counselors are expected to review the natural history of diagnoses within the session. For patients with ASD, this includes the potential for discussing sensory processing deficits. Education may be a venue to relieve parent distress and to motivate parents to find a solution or utilize resources (Kessler, 1997). Parents of children newly diagnosed with ASD expect genetic counselors working with them to describe the variability within the spectrum, to acknowledge the emotional challenges their family will face, and to be current on research (Selkirk et al., 2009). This suggests that information regarding sensory processing may be beneficial to parents of children with autism. Therefore, the purpose of this study is to explore the utility of providing information about sensory processing issues to families who are bringing their children with ASD to a genetic counseling session.

2.3 Materials and Methods

2.3.1 Participants. The target population was parents with children who have been diagnosed with ASD. Six emails were sent to support groups in the Southeast United

States for parents of children with ASD. From these requests, three groups agreed to participate in the study. Participants were informed of the study before the meeting. Inclusion criteria included individuals over the age of 18 with one or more children with ASD. Exclusion criteria included individuals who did not speak English. This study was approved by the Institutional Review Board, Office of Research Compliance, University of South Carolina at Columbia, SC, in June, 2015.

2.3.2 Survey tool and Focus Group Information. A questionnaire with 13 items was designed to collect demographic information as well as to collect background familiarity with SPDs. A discussion guide was developed to elicit information regarding participants' perceptions of SPD and guide discussion regarding SPD in their children with ASD. A copy of the participant invitation letter, the survey tool, and the focus group outline can be found in Appendix A, B, and C, respectively. Focus groups were conducted between August, 2015, and January, 2016. To protect the identity of participants, no identifying information was collected.

2.3.3 Qualitative Analysis. The focus groups were recorded and transcribed verbatim to produce qualitative data. Emerging themes were coded using the transcripts from three focus groups.

When focus group discussions were analyzed, themes emerged regarding parents' beliefs and perceptions about various aspects of sensory processing and autism. Themes were identified if multiple individuals across two or more groups stated similar responses or expressed similar opinions. Supporting quotes were identified and documented.

2.4 Results

2.4.1 Participant Demographics.

Ten individuals participated in this study. Demographic data regarding the participants' age, sex, greatest level of education obtained, marriage status, and race - were collected using the questionnaire found in Appendix B. Information about the children with ASDs was also collected. These demographic results can be seen in Table 2.1 and Table 2.2.

Table 2.1 Participant Demographics

Characteristics of Participants		Total Sample (<i>N</i> = 10)	
		<i>n</i>	%
Age	<30	1	10
	30-39	3	30
	40-49	3	30
	>50	3	30
Sex	Male	2	20
	Female	8	80
Education	High School	1	10
	Some college	2	20
	Bachelor's	6	60
	Master's or higher	1	10
Marriage Status	Single	2	20
	Married	6	60
	Divorced	2	20
Race	White	5	50
	Black/African American	2	20
	Asian	1	10
	Hispanic	2	20
Do you have a child with Autism?	Yes	10	100
	No	0	0

Table 2.2 Participants' Children Information

Characteristics of Participants' Children	Total Sample (N = 12)	
	n	%
Child's Age		
<5	1	8
5-10	2	17
10-15	3	25
15-20	4	33
>20	0	0
No response	2	17
Does your child have a sensory processing disorder?		
Yes	6	60
No	1	10
No response	3	30
Has your child seen a genetic counselor?		
Yes	4	40
No	6	60

2.4.2 Questionnaire for Qualitative Analysis. The following questions were included as a part of the written questionnaire. Questions as well as resulting themes are listed below along with supporting evidence.

Question: Are you familiar with the term sensory processing disorder? Two opposing themes were identified based on participant responses to this question.

Theme: Familiarity with the term. Few participants reported familiarity with the term sensory processing disorder. These participants typically described their child's negative responses to stimuli to define the term.

Theme: Lack of familiarity with the term or uncertainty. Some parents expressed some familiarity with the term but struggled to put its meaning into words, while others

had not heard the term or did not know the meaning of the term. The majority of participants reported being unfamiliar with the term. The following quotes illustrate and support this finding:

- One participant was “not real[sic] familiar.”
- Others described being “a little” or “somewhat” familiar.

Question: Does your child with autism have a sensory processing disorder? If so, how do you describe your child’s sensory processing disorder to others? Two themes were identified based on participant responses to this question

Theme: Describing sensory processing in terms of behavior. Participants who responded to this question described their child’s sensory processing disorder in terms of behavior. The following quotes illustrate and support this finding:

- “She bites objects and stomps her feet.”
- “She eats only five food[sic]. She is afraid of loud noises.”
- One participant stated his child was “resistant to touch.”

Theme: Describing sensory processing in terms of stimuli. Fewer participants who responded to this question described their child’s sensory processing disorder in terms of stimuli. The following quotes illustrate and support this finding:

- One participant stated that her child has “difficulty with loud noises, crowds, bright lights, and excessive stimulation of any kind.”
- Another stated that his child has “high pain tolerance.”

Question: Would you like to receive information on sensory processing in a medical setting? Why or why not? One theme was identified based on participant responses to this question.

Theme: Desire of more information in order to understand the child better. A majority of parents expressed desire for more information. Some of these individuals elaborated that it is beneficial because it increases understanding of their child. The following quotes illustrate and support this finding:

- “This is an integral part of the autism diagnosis, and it would be helpful to parents of newly diagnosed children to understand it better.”
- “Yes, because any information that can help me understand my child and how things may affect him are of interest to me.”

Question: Have you received information on sensory processing? If so, in what setting? Participants responded that they had received some sensory processing information from developmental pediatrics, occupational therapists, and other therapists.

2.4.3 Focus Group Qualitative Analysis. After the initial discussion, the focus group leader provided a brief presentation on sensory processing disorders in children with autism. The following questions were asked as a part of the focus group.

Question: Please describe misconceptions, if any, that have been clarified with this information. One theme was identified based on participant responses to this question.

Theme: Clarification of misconceptions. The following quotes illustrate and support this finding:

- “A lot of people think that sensory processing disorder is just when they feel everything. They don’t know that it can be the opposite.”
- “Hyper vs the hypo. I thought that it was just hyper, over-sensitive.”

Question: What challenges do you face when discussing your child's behaviors with friends, families, and teachers? One theme was identified based on participant responses to this question:

Theme: Lack of understanding. A majority of parents reported frustration that others could not understand their child.

- “Most people haven’t been around it. You know, teachers, they haven’t experienced this.”
- “The thing with autism is she looks like any other regular child. A lot of people think she’s just spoiled, just a picky eater.”

Question: Could receiving information about SPDs help? If so, how? One theme was identified based on participant responses to this question

Theme: Uncertainty of child's experiences. Several participants reported uncertainty in understanding their child's experiences. The following quotes illustrate and support this finding:

- “Unfortunately, I think in my case I don’t know what his sensory processing issues are – he’s not able to tell me.”
- “But other than that I mean other than that I think there’s[sic] probably other things. He doesn’t verbalize so it’d be hard to tell teachers or someone else you’re working with because I don’t know that we know everything.”

Question: How would a genetic counselor acknowledging these challenges affect this? One theme was identified based on participant responses to this question.

Theme: Desire for acknowledging unique challenges faced. The following quotes illustrate and support this finding:

- “I think if it helped me understand more about how things would affect him I might be more motivated to make changes in our life, you know?”
- “and being defiant vs. truly having a problem”

Question: Would you like to receive information about sensory processing in a medical setting? Why or why not? One theme was identified based on participant responses to this question

Theme: Desire to receive more information. A majority of participants reported that they would like more information regarding sensory processing. The following quotes illustrate and support this finding:

- “When your child’s diagnosed with autism, you’re handed a packet of information. It would be nice to have someone sit down and walk you through that information.”

2.5 Discussion

2.5.1 Sensory Processing Information. While some respondents were familiar with the term sensory processing, the majority of the respondents had trouble articulating the definition or were unfamiliar with the term. The majority of the parents reported that they would desire to receive and discuss this information within the genetic counseling. Multiple individuals expressed that misconceptions had been clarified based on the information provided. Furthermore, participants expressed that the amount of information available was overwhelming and difficult to navigate.

2.5.2 Description of the Child's Behavior. Broaching the subject of sensory processing allowed for the parents to discuss their child's behavior in a positive light by describing behaviors in terms of what the child enjoys doing. By framing the question in regards to sensory processing, the moderator was able to obtain information regarding the child's behavior without directly asking, "What are your concerns with your child's behavior?" This allows for the parent to discuss behavior without specifically asking about behavioral concerns. In addition, parents were able to express their frustrations and concerns about not being able to understand their child. This offers an opportunity for the counselor to support the family's psychosocial needs. Furthermore, providing a label to the child's reactions to stimuli can help parents, teachers, and health care providers implement plans to address the underlying issue. Discussions regarding sensory processing enable counselors to address roles such as providing information regarding the natural history of conditions and information on the latest research and treatments.

2.5.3 Implications for Genetic Counseling. This study suggests that providing additional information regarding the overlap of SPDs and ASD may be beneficial to patients and their families. The genetic counseling session provides a supportive environment in which parents can review the natural history and new updates regarding ASD. Counselors can connect with patients and acknowledge parental stresses by discussing SPDs within the genetic counseling discussion about the natural history of the condition.

2.5.4 Limitations. This was an exploratory study examining parental perceptions on sensory processing and their needs regarding information provided within the genetic counseling session. Overall, the group included diverse participants with various ethnic

and age groups represented. Furthermore, participants had a variety of educational backgrounds providing diverse perspectives. However, the small sample size limits the ability to generalize the findings of this study to the larger population of families who have a child diagnosed with autism. Additionally, because questions were asked in a group setting, some individuals may have felt uncomfortable expressing a differing opinion. Furthermore, because the focus groups were conducted in person, participants did not have the opportunity to express completely anonymous statements. Finally, some opinions may have not been expressed due to the method of data collection. The current study sample was chosen using a non-random sampling method which may have introduced bias in the data. Moderators were not formally trained and this could have influenced the outcome of the results.

2.5.5 Future Research. Additional research needs to be performed on the role of genetic counselors in providing information about SPDs to parents of children with ASD within the genetic counseling session. Research could examine the goals of genetic counselors working with referrals for ASD as well as awareness of updates to the diagnostic criteria of ASD. By examining these areas, we can identify ways to improve care for families with children with ASD.

2.6 Conclusions

This study provides new and valuable insights to parents' perception of sensory processing in their child with ASD and the role of genetic counselors in providing support in this regards. The participants were a diverse group and their children were a wide range of ages. Participants demonstrated gaps in knowledge regarding sensory processing and expressed that misconceptions had been clarified after being provided

with information. Participants also acknowledged challenges that they face resulting from SPD in their child. The participants had difficulty describing both SPD and identifying their child's sensory experience. This study suggests providing information regarding SPD within the genetic counseling session may benefit parents by constructing a safe environment to talk about their child's behavior as well as challenges they face every day. Better understanding of the information regarding SPD may help parents explain their child's unique condition to others as well as help them to be proactive about addressing their child's sensory differences.

Genetic counselors can be a source for updating families about the latest research and information about ASD. ASD is a complex and variable condition and this study provides genetic counselors with insight to parents' needs and wants from a genetic counseling session. Navigating a diagnosis of ASD can be complex, and this study alerts genetic counselors to the potential benefit of presenting information on SPDs as genetic counseling is provided to parents of children with ASD.

Chapter 3: Conclusions

This study provides new and valuable insights to parents' perception of sensory processing in their child with ASD and the role of genetic counselors in providing support in this regards. The participants were a diverse group and their children were a wide range of ages. Participants demonstrated gaps in knowledge regarding sensory processing and expressed that misconceptions had been clarified after being provided with information. Participants also acknowledged challenges that they face resulting from SPD in their child. The participants had difficulty describing both SPD and identifying their child's sensory experience. This study suggests providing information regarding SPD within the genetic counseling session may benefit parents by constructing a safe environment to talk about their child's behavior as well as challenges they face every day. Better understanding of the information regarding SPD may help parents explain their child's unique condition to others as well as help them to be proactive about addressing their child's sensory differences.

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Appendix A: Letter to Participant

Dear Potential Participant:

You are invited to participate in a graduate research study focusing on parents of children with autism. I am a graduate student in the genetic counseling program at the University of South Carolina School of Medicine. My research investigates parental perceptions of sensory processing and families' desire to receive information about it in a medical setting. The research involves a short presentation followed by a group discussion.

The survey portion asks a number of demographic questions, while the focus group will contain opinion based questions. If you do not wish to answer a certain question, please skip that question and continue with the rest of the survey.

All responses gathered from the surveys will be kept anonymous and confidential. The results of this study might be published or presented at academic meetings; however, participants will not be identified.

Your participation in this research is voluntary. By completing the survey and participating in the focus group, you are consenting that you have read and understand this information. At any time, you may withdraw from the study by not completing the survey and/or not participating in the group discussion.

Thank you for your time and consideration to participate in this study. Your responses may help genetic counselors create more helpful education materials for parents of children with autism and their families. If you have any questions regarding this research, you may contact me using the contact information below. If you have any questions about your rights as a research participant, you may contact the Office of Research Compliance at the University of South Carolina at (803)777-7095.

Sincerely,

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Appendix B: Questionnaire

Age

- <30 years
- 30-39 years
- 40-49 years
- ≥50 years

Sex

- Male
- Female

Education

- High School
- Some college
- Bachelor's degree
- Master's or higher

Marriage Status

- Single
- Married
- Divorced
- Widowed

Race

- White
- Black or African American
- Hispanic
- Pacific Islander
- Asian
- Other: _____

Do you have a child with autism?

- Yes
- No

How old is your child with autism?

- <5 years
- 5-10 years
- 10-15 years
- 15-20 years
- >20 years

Does your child have a sensory processing disorder?

- Yes
- No

Has your child seen a genetic counselor?

- Yes
- No

1. Are you familiar with the term sensory processing disorder?
2. Does your child with autism have a sensory processing disorder? If so, how do you describe your child's sensory processing disorder to others?
3. Would you like to receive information on sensory processing in a medical setting?
Why or why not?
4. Have you received information on sensory processing? If so, in what setting?

Appendix C. Focus Group Questions

1. Question: Please describe misconceptions, if any, that have been clarified with this information.
2. Question: What challenges do you face when discussing your child's behaviors with friends, families, and teachers?
3. Question: Could receiving information about SPDs help? If so, how?
4. Question: How would a genetic counselor acknowledging these challenges affect this?
5. Question: Would you like to receive information about sensory processing in a medical setting? Why or why not?