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Walden University

College of Social and Behavioral Sciences

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Melissa Scotch

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Walden University

2017

Abstract

The Experience of Children Living with Sensory Processing Disorder

by

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MS, Walden University, 2011

BA, University of South Florida

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

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Abstract

Sensory processing disorder (SPD) is a neurological condition that alters the way an individual perceives sensory information. Although the condition has been studied for more than 40 years, SPD remains a difficult condition to diagnose, treat, and live with because it affects individuals uniquely, and the symptoms can change from childhood to adulthood. For children diagnosed with SPD, the misinterpretation of sensory cues can cause difficulties in family, social, and academic settings. While there is some research on the assessment and treatment of SPD, what is missing is a deeper understanding of the family, social and academic challenges these children and their families face. The purpose of this case study was to examine the experiences of children diagnosed with SPD, as told by 4 parents and their occupational therapist in semi-structured interviews. Four themes emerged from the analysis: family dynamics (challenges within the family structure), support impact (seeking and having support), emotion and balance (overcoming the struggles related to the emotional demand), and an SPD child (the search for balance for the child and the family). The results may serve as a catalyst to encourage positive social change for the children with SPD and their families by expanding the available knowledge on the challenges of SPD.

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Dedication

This dissertation is dedicated to my children Lucas Allan Scotch and Logan Ayana Scotch, as I have watched you both grow and flourish during the years that I have also dedicated to my PhD program. I hope that all of the time and struggles that coincided with this journey provides you with not only a sense of pride for everything we all have sacrificed, but with the knowledge that hard work and passion are necessary for your continued and future success. You both amaze me every day and I am better because of you both. You are my heart and soul, and I love you both always and forever, no matter what. Thank you for your endless patience through the entire process.

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Chapter 1: Introduction to the Study

Sensory processing disorder (SPD) is a neurological condition that alters the way an individual perceives sensory information (Miller, 2012, 2013; Miller, Coll, & Schoen, 2007). SPD is a chronic condition and causes mild to severe disruptions in the daily lives of those who struggle with the disorder (Kraus, 2001; Miller et al., 2007). Although the condition has been reconized, researched, and reviewed for more than 40 years, the condition remains a difficult diagnosis due to the complexity of its multiple facets (Ayers, 2005; Collier, 2008; Dunn, 2007; Johnson-Ecker & Parham, 2000; Kraus, 2001; Miller, 2012, 2013; Miller et al., 2007; Tomchek & Dunn, 2007). Individuals with SPD misinterpret sensory cues, creating on-going struggles in family and social settings inclusive of school-aged children in an academic setting (Byrne, 2008; Miller et al., 2007). SPD was denied entrance as a stand-alone diagnosis in the *DSM-V*; SPD is a comorbid diagnosis among many other diagnoses, such as autism spectrum disorder, attention deficit-hyper disorder, Down's syndrome, neurocognitive learning disabilities; in addition, the complexity of diagnosing and receiving treatment remains a challenge (Byrne, 2008; Collier, 2008; Kraus, 2001; Miller, 2012). The rates of SPD are one in 20 children; therefore, more research is needed to provide support to individuals and families with children struggling with SPD (Byrne, 2008; Collier, 2008).

Background

Families with children diagnosed with SPD experience multiple challenges within the family structure, academic settings, and social relationships. Support for families from multiple avenues is vital. Families may experience difficulties coping because SPD is not included in the *DSM-V* creates added difficulties for families. Byrne (2008) defined

SPD and claimed that there is a need for an increase in diagnoses and for research and resources to be allocated to SPD. Miller et al. (2007) highlighted that SPD is a neurological disorder that impacts many areas of a child's development. Collier (2008) noted that one in 20 children without comorbid diagnoses are struggling with SPD and suggested that SPD should be its own diagnosis in the *DSM-V*. Orloff (2007) also provided examples of the struggles that coincide with SPD. As the prevalence of SPD continues to increase, so does the need to understand and aid children with SPD and their families.

Problem Statement

SPD has been researched, recognized, and reviewed for more than 40 years (Ayers, 2005; Collier, 2008; Dunn, 2007; Johnson-Ecker & Parham, 2000; Kraus, 2001; Miller, 2012, 2013; Miller et al., 2007; Tomchek & Dunn, 2007). SPD is a neurological condition that affects an individual's ability to perceive sensory cues (Miller, 2012, 2013; Miller et al., 2007). It is a chronic condition and can be a daily disruption for those struggling with SPD (Kraus, 2001; Miller et al., 2007). For individuals with SPD, sensory information can be misinterpreted from any or all of their senses. Due to a neurological "traffic jam," the misinterpretation can lead to heightened responses and/ or reduced responses and even sensory-motor difficulties (Byrne, 2008; Miller et al., 2007). Children with SPD experience many challenges that include gross and fine motor development delays, behavioral struggles, and visual complications (Byrne, 2008; Collier, 2008; Kraus, 2001; Miller, 2012).

SPD remains a difficult diagnosis for multiple reasons (Miller, 2012). Although SPD is linked to other diagnoses, such as autism spectrum disorders, ADHD/ ADD,

Down's Syndrome, and neurocognitive learning disabilities, the *DSM IV- TR 2000* has not recognized a separate diagnosis for SPD. Therefore, families and children without linked diagnoses struggle to understand the tools that can help lead to their success (Byrne, 2008). At least one in six children struggle with sensory issues, if combined with rates of children with coinciding diagnoses (M. Roth-Fisch, personal communication, December 4, 2012).

SPD is typically diagnosed by an occupational therapist. Beyond the occupational therapist, health care providers, such as doctors and nurse practitioners, may also diagnose children with SBD (Byrne, 2008; Miller, 2012). As the number of children diagnosed with SPD continues to increase, so does families' demand for understanding their children who struggling with SPD (Byrne, 2008; Miller et al., 2007). Understanding how children with SPD can impact families may aid in providing the needed environment, tools, and resources to help families support diagnosed children.

Purpose of the Study

Using a basic qualitative methodology, the purpose of the case study was to explore the experiences of families and children with SPD. This approach allotted for a rich exploration of the lived experiences of the families and children in multiple settings, including family, academic, and social settings. To address the gap in the literature, semi-structured interviews were conducted with an occupational therapist and parents of children with SPD to capture the experience of families and children and to advance the knowledge on the challenges of SPD.

Research Questions

Research Question 1: What is the experience of children diagnosed

with SPD in the areas of social relationships and school performance?

Research Question 2: What is the experience of families living with children diagnosed with SPD?

Theoretical Framework

Multiple challenges exist for families with children diagnosed with SPD (Dunn, 2007; Kraus, 2001; Orloff, 2007). An SPD diagnosis typically comes from occupational therapists, and the individual may have a cooccurrence with other diagnoses. Although SPD has not yet been added to the *DSM IV* as a stand-alone diagnosis, one in 20 children (with some researchers showing prevalence rates as high as one in six) struggle with these neurological traffic jams absent of any links to additional diagnoses (Byrne, 2008; Collier, 2008; Miller, 2012). An occupational therapist who specialized and worked with children diagnosed with SPD and families already receiving services from the same occupational therapists agreed to respond in written format to open-ended questions in this study. General impressions of social development, home experience, and school environments regarding children diagnosed with SPD were explored to provide information, perspective, and future thoughts regarding children diagnosed with SPD.

Nature of the Study

The nature of this study was a qualitative case study. Qualitative research has been used to develop answers to questions surrounding social phenomena (Smith, 2008). Qualitative studies need to have a range of flexibility so that the topic is able to be explored with depth (Sandelowski, 1993). In this qualitative case study, an occupational therapist and parents of children with SPD participated in semi-structured interviews so

that I could develop themes related to the experience of families and children living with SPD.

Definitions

Comorbid diagnosis: A comorbidity is defined by the cooccurrence of two or more diagnoses occurring in one person at the same time, and is reviewed in relation to the combination of multiple diagnoses that impact the person's prognosis and treatment (Kranowitz, 1998; Leitner, 2014).

Sensory integration disorder: Sensory integration disorder was the original name for the SPD diagnosis that created sensory struggles. Sensory integration (SI) was recognized, identified, and labeled first by Ayres (Ayres, 2005; Collier, 2008; Miller, 2012; Miller, 2013; Miller et al., 2007; Tomchek & Dunn, 2007). It is defined by the neurobiological activity where there is a breakdown in the nervous system processes that feeds the information from a person's senses and organizes stimuli (Ayres, 2005; Miller, 2012). It is these processes that develop a person's perceptions, learning abilities, and behaviors, and when there is a breakdown, or jam in this system and information is not delivered to the correct place in the brain, or not delivered at all, challenges develop due to these struggles (Ayres, 2005; Miller, 2012).

Sensory processing disorder (SPD): SPD is defined as a neurological traffic jam, and it impacts sensory cues. It is considered an umbrella term to represent the uniqueness of experienced challenges that individuals struggling with SPD experience (Miller, 2012, 2013; Miller et al., 2007). Persons with SPD cannot function or adapt to normal social circumstance, they do not fit easily into other known physical or psychological diagnoses, and laboratory studies suggest that both the sympathetic and parasympathetic

nervous systems are not functioning in a typical manner (Ayers, 1979, 2005; Kraus, 2001; & Miller, Nielsen, Schoen, & Brett-Green, 2009).

Assumptions

Qualitative researchers assume that understanding from the lived experiences of participants can be acquired (Guest, Bunce, & Johnson, 2006). Another assumption of this study was that the children of the parents who had received services from the occupational therapist had an SPD diagnosis. It was also assumed that the occupational therapist and the parents of the children diagnosed with SPD were able to articulate the experiences of the children within their family structure, social settings, and the academic arena. In addition, it was assumed that the participants shared honest information regarding their experiences (Patton, 2002). I continued to foster a relationship based on mutual respect so the participants felt at ease and comfortable when sharing details of their experiences. The study provided anonymity for all participants, and semi-structured interview questions were developed to seek out the experiences associated with SPD. I assumed that the information shared was honest and provided a brevity of shared experiences to the point of saturation. The study relied on such assumptions to ensure the rigor and validity.

Scope and Delimitations

In this study, I investigated the experiences of children living with SPD from the perspective of an occupational therapist and their parents. The experiences were collected from semi-structured interviews that were developed for this study to ensure a thorough analysis of a child's experiences diagnosed with SPD.

In this qualitative case study, the transferability of the study was achieved from the evolution and content of the themes that developed from the interviews with the occupational therapist and the parents. Although there was a limited sample, the participants were focused on providing a comprehensive view of the experiences of a child with SPD in the context of family, social, and academic settings.

Limitations

The study had minimal limitations. The first possible limitation was approach. Qualitative research is multifaceted; yet, the rigor for such remains questionable among some researchers (Houghton, Casey, Shaw, & Murphy, 2013; Sandelowski, 1993). The second limitation stemmed from a single occupational therapist and four parents who were used to gather feedback on open-ended questions for data collection. The third limitation was the data collected were gathered from a rural area of Northeast Pennsylvania with mainly a White population. Lastly, possible researcher bias must be mentioned for a limitation, as she has two diagnosed children.

Significance

There is a significant body of literature on the diagnosis of SPD as a stand-alone diagnosis. Both qualitative and quantitative study have been conducted on SPD from the past 4 decades. A recognition by Carol Kranowicz nearly forty years ago who has led a global outreach, continued study, and research centers that are devoted to sensory processing disorder, the research associated with the diagnosis, its treatment, and support for families.

SPD prevalence rates are continuing to increase. At least one in 20 children struggle with SPD issues, while rates of children with autism spectrum disorders,

pervasive developmental disorders, Down's syndrome, and neurocognitive learning disabilities were 85% or higher (M. Roth-Fisch, personal communication, December 4, 2012). With increased prevalence rates and limited awareness of SPD, research needs to be developed that can increase awareness and provide resources and tools for families that have children diagnosed with SPD. The families can use these resources to provide higher success rates for children who may struggle with motor, social, behavioral, and academic skills.

Although there are various comorbid diagnoses that exist with SPD, needing a stand-alone diagnosis for both support and treatment of children and their families has left many parents searching for answers with little support. Medical community and insurance companies do not currently provide the needed aid for families with children with SPD as a stand-alone diagnosis remains difficult. The significance of the study really is 2-fold. First, there is the hope to shed additional light on sensory processing disorder as a stand-alone diagnosis. Secondly, there are hopes that adding continued research to this area will highlight the urgency and need to be added to future DSM publications. In this study, I highlighted that it is important that families have the ability to reach out and receive services, and that parents of the children with SPD know that there is a host of support venues for them.

Summary

The purpose of this study was both to gain insight regarding the social, emotional, and family experiences that SPD can have if living with a SPD child. SPD needs to be recognized as a stand-alone diagnosis in future *DSM* manuals to help those seeking and requiring services via occupational therapy.

Chapter 2 was a review of the literature that both reflected and supported the direction of the study. The literature review provided the foundation needed to further explore sensory processing disorder and the experiences on the diagnosed children and their families.

Chapter 2: Literature Review

SI, now termed SPD, is an area that has been identified and researched for more than 40 years (Ayers, 2005; Collier, 2008; Dunn, 2007; Johnson-Ecker & Parham, 2000; Kraus, 2001; Miller, 2012, 2013; Miller, Coll, & Schoen, 2007; Tomchek & Dunn, 2007). The original theory of SI was recognized, identified, and labeled first by Ayers (Ayers, 2005; Collier, 2008; Miller, 2012, 2013; Miller et al., 2007; Tomchek & Dunn, 2007). SPD is an umbrella term that aids in labeling and identifying sensory issues that are both multilayered and multifaceted (Miller, 2012, 2013). It is a complex diagnosis that presents definitive physiological differences between children with SPD and those who are considered to be developing according to traditional milestones (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009). Researchers have claimed that there is a genetic link between environmental factors and SPD (Miller, 2012).

Literature Search Strategy

A literature search was conducted using libraries, as well as multiple web pages and search engines. Research was obtained from multiple resources including Educational Resources Information Center (ERIC), PsycINFO, PsycARTICLES, Psychology: A SAGE Full-Text Collection, CINAHL & MEDLLINE Simultaneous, *Diagnostic Statistical Manual of Mental Disorders (DSM-5)*, Mental Measurements Yearbook, Academic Search Complete, Dissertations, and the Sensory Processing Disorder National Conference. Integral searches completed included the following key words: *sensory integration dysfunction*, *SPD*, *SPD comorbidities*, *Sensory modulation disorder (SMD)*, *sensory-based motor disorder (SBMD)*, *sensory discrimination disorder (SDD)*, *red flags for SPD*, *multisensory integration*, *occupational therapist and sensory*

treatment, assessment of SI, assessment of sensory processing, Sensory Profile, Sensory Short Profile, SI and Praxis Test, neurology of SPD, Sensory Processing Measure, Dr. Jane Ayers, Carol Kranowitz, Dr. Lucy Miller, grounded theory, and qualitative rigor.

Origination of Sensory Integration

SI is defined as the neurological process that organizes multiple sensations (Ayers, 2005). Also called multisensory development, it allows the body to effectively identify, process, and use information from a person's environment (Ayers, 2005; Collier, 2008; Dunn, 2007; Johnson-Ecker & Parham, 2000; Miller, 2013; Miller et al., 2007; Tomchek & Dunn, 2007). The theory of SI (now termed SPD) stated that sensations received during activities provides the bases of neuronal intake and the precept of an individual's body in space and time (Ayers, 1979, 2005; Miller, Anzalone, Lane, Cermak, & Osten, 2007). Necessary for every aspect in life, SI provides the ability for a person to relate to his or her body in space while deciphering the possible needed adaptation and meaningful body precept. Praxis is the underlying skill that provides a person the ability to develop properly and milestone-appropriate adaptive skills of conceptualization, motor planning, and execution (Ayers, 1979, 2005; Miller, 2013). Both perception and praxis are the results of a person's sensory integration abilities; somatosensory, vestibular, and visual input for development of a person's sensory integration and praxis abilities are essential to the person's environmental interactions (Ayers, 1979, 2005).

Theoretical Foundation

The purpose of theory within science, regardless of approach, is to provide possible typologies, logical explanations, predictions, potential for control, and a sense of

understanding (Sandelowski, 1993; Smith, 2008). Like any theory, the original work of Dr. Jean Ayers has seen many developments, expansion, changes, and examination via continued research throughout many decades. Stating that it is a neurological ‘traffic jam,’ the fact remains that sensory integration (now termed sensory processing disorder) is a chronic, neurological condition that disrupts a person’s ability to interpret readings on a person’s senses or how he or she perceives sensory cues (Ayers, 1979, 2005; Byrne, 2009; Miller, 2012, 2013).

The label Sensory integration dysfunction raised concerns in the medical realm because its signature abbreviation of SID (sometimes SI) was causing confusion with another diagnosis, sudden infant death syndrome (also SIDs; Miller, 2012). Sensory integration dysfunction was changed to SPD, which will be used for the remaining text when referring to the diagnosis (Miller, 2012). Recognizing SI as the initial theory prior to being adapted to SPD is necessary to be able to infuse and integrate past and current research (Miller, 2012).

SPD was a diagnosis for behavior in ‘otherwise healthy children (Ayers, 1979, 2005; Kraus, 2001). Researchers found that children with SPD could not function or adapt to normal social circumstance, they did not fit easily into other known physical or psychological diagnoses, and laboratory studies suggest that both the sympathetic and parasympathetic nervous systems are not functioning in a typical manner (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009). The daily disruptions for persons with SPD may involve many, if not all, aspects of their lives. At least one in 20 children struggle with sensory issues (Ayers, 2005; Collier, 2008; Dunn, 2007; Johnson-Ecker & Parham, 2000; Kraus, 2001; Miller, 2012, 2013; Miller et al., 2007; Tomchek & Dunn, 2007), but may

be as many as one in six children (Collier, 2008; M. Roth-Fisch, personal communication, December 4, 2012; Miller, 2012). Due to the theory's relative newness, researchers are also finding that many adults have remained undiagnosed until more recent times (Miller, 2012).

Although pediatricians, physician assistants, nurses, and other clinicians may provide an SPD diagnosis, most diagnoses to date have been, and continue to be from, occupational therapists (Byrne, 2009; Collier, 2008; Kraus, 2001). Due to the unique set of sensory symptoms that are not able to be explained by other disorders, current routes to identify children with SPD include clinical assessment and observation, parent surveys, and laboratory protocol (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009; Parham, 1998). Tools of assessment for diagnosing SPD may include, but are not limited to, the Sensory Integration and Praxis Test (SIPT), The Sensory Profile, The Short Sensory Profile, and the Sensory Processing Measure. These scales are filled out by parents, teachers, and additional caretakers and are used as a means of screening children for indicators of SPD (Ayers, 1989, 2005; Brown & Dunn, 2002; Dunn, McIntosh, Miller, & Shyu, 2002; Miller, 2012; Parham, Ecker, Kuhanek, Henry, & Glennon, 2007).

In addition to assessments, observations for an evaluation are conducted in a clinical setting with an occupational therapist using age-appropriate life situations, as well as interviews that may be conducted with children and/ or parents, teachers, and other concerned caregivers (Ayers, 1989, 2005; Brown & Dunn, 2002; Byrne, 2009; Dunn et al., 2002; Miller, 2012; Parham et al., 2007). Parents/caregivers, teachers, and other caretakers can usually identify red flags for varying age groups (Byrne, 2009; Miller, 2012). Red flags of SPD are divided into the following subgroups: infants and

toddlers, preschoolers, grade-schoolers, adolescents and adults (Miller, 2012). All of the methods are used as tools to help identify and diagnose children with SPD, as early intervention can lead to better adaptive behaviors, less disruption, and positive social interactions (Collier, 2008; Kraus, 2001; Miller, 2012).

As a global umbrella term, SPD is both multilayered and multifaceted (Kraus, 2001; Miller et al., 2007; Orloff, 2007). The latest nosology proposed for diagnostic categories has SPD divided into the following subgroups: SMD, SBMD, and SDD. Each of the subgroups also has additional layered divisions of the sensory modulation disorder, sensory-based motor disorder, and sensory discrimination disorder (Miller, 2012; Miller et al., 2007; Reeves & Cermak, 2002).

Sensory Modulation Disorder

Sensory modulation disorder (SMD) is one of 3 main sub-groups under the main umbrella term, sensory processing disorder (Mangeot et al., 2001; Miller et al., 2007). Sensory modulation disorder is a label that explains the modulating difficulties that occurs upon sensory intake. Divisions within the SMD label include sensory overresponsiveness (SOR), sensory under-responsiveness (SUR), and sensory craving (Miller et al., 2007). Sensory over-responsiveness, or sensory defensiveness, refers to the hypersensitivity that is felt from an overload of sensory input. Children who experience over-responsiveness may exude multiple behaviors including: frequent meltdowns, aggressiveness, irritability, frustrations in social circumstances, difficulty transitioning, and adapt slowly to new environments (Miller et al., 2007). Children who exhibit behaviors from this sub-group may be sensitive to loud noise, be bothered by bright lights, have multiple texture issues, and get upset by light or soft touch (Miller, 2012;

Miller et al., 2007). A child with sensory under-responsiveness will appear calm and quiet, and may not even realize differences in temperatures (if an object is too hot or too cold), or even acknowledge a scrape or injury if hurt (Miller, 2012).

Sensory-Based Motor Disorder

Sensory-based motor disorder occurs when sensory intake becomes disorganized and leads to improper processing of information (Miller, 2012). The result is postural disorders or dyspraxia (Miller, 2010; Miller, 2013). Postural disorder consequences are poor muscle tone and balance challenges. The combination leads to a child being uncoordinated and uncomfortable in their own body (Miller, 2007).

Postural challenges lead to dysfunction and limited oral motor, ocular motor, vestibular motor, and proprioceptive motor skills (Miller, 2007). Occupational therapist's observations and parent reports reveal multiple struggles and challenges. Frequent drooling, poor eating habits, visual issues regarding tracking, convergence, double vision, and poor depth perception, and a tendency to lean or slump is reported (Densmore, 2009; Miller, 2007). Additional challenges shown are uncoordinated physical activities, poor gross and fine motor development, consistent fidgeting, and irregular respiration and heartbeat (Densmore, 2009; Miller, 2007).

Dyspraxia presents additional unique challenges to those diagnosed with sensory processing disorder. Dyspraxia, meaning 'dys,' or badly and 'praxis,' or to do, reveals multiple challenges regarding motor planning, organizing, sequencing, and timing (Miller, 2007; Reeves & Cermak, 2002). Research shows that children struggling with dyspraxia have difficulties in areas of performing fine motor activities, eating with utensils, working with scissors, zipping or buttoning skills, handwriting, completing

multi-step or complex tasks, and a display of poor hand-eye and foot-eye coordination skills (Miller, 2007).

Sensory Discrimination Disorder

There is support showing children diagnosed with sensory discrimination disorder have an altered view of the world in which they live. The information received from their senses becomes disorganized and miscommunicated to the body and results in a confusing world (Miller, 2012). Sensory discrimination disorder results in challenges regarding tactile, gustatory, auditory, visual, vestibular, proprioceptive, and interoceptive discrimination abilities (Cermak & Henderson, 1990; & Miller, 2012).

Specific challenges have been found regarding sensory discrimination disorder (Miller et al., 2007; & Miller, 2012). Children diagnosed in this specific area have difficulties inclusive of being touched, connecting an object in space, describing an object by touch alone, distinguishing temperatures and flavors, struggle with dysgraphia, consistent displays of inappropriate pressures during activities, and distinguishing individual objects in a group (Miller et al., 2007).

Assessment

SPD is a neurological traffic jam for persons of all ages and is a global umbrella term for sensory challenges. Sensory issues can present themselves in multiple ways via various senses allotting for a multitude of recognizable red flags for all ages. Usually grouped as the following; infants and toddlers, preschoolers, grade-schoolers, adolescents and adults, sensory issues present serious challenges because of the numerous ways it can exhibit its red flags (see Table 1).

Prominent infant and toddler red flags include recognizable eating and sleeping

problems, a resistance when being held, motor delays, over-all uncomfortableness when dressed, and inability to soothe oneself (Miller, 2012). Often preschoolers will display an over-sensitivity to smells, touches, and noises, delayed motor skills, struggles with eating, sleeping, and toilet training, and can exhibit extended ‘meltdowns’ (Miller, 2012). Grade-schoolers display similar challenges as their preschool counterparts, but become Sensory processing disorder is a neurological traffic jam for persons of all ages and is a global umbrella term for sensory challenges. Sensory issues can present themselves in multiple ways via various senses allotting for a multitude of recognizable red flags for all ages. Usually grouped as the following; infants and toddlers, preschoolers, grade-schoolers, adolescents and adults, sensory issues present serious challenges because of the numerous ways it can exhibit its red flags (see Table 1).

Table 1

Red Flags for Diagnosing Sensory Processing Disorders in Children

Infants and Toddlers	Pre-schoolers
Sleeping and eating problems	Over-sensitive to touch, noise, smells
Irritable when being dressed	Difficulty making friends
Uncomfortable in clothing	Difficulty dressing, eating, sleeping
Resists cuddling	Clumsy or weak motor skills
Unable to self-soothe	Frequent and extended ‘melt downs’
Motor delays	In constant motion
Grade schoolers	Adolescents and adults
Over-sensitive to touch, noise and smells	Over-sensitive to touch, noise, smells
Constantly fidgets	Fear of failing at new tasks
Easily distracted	Slow and lethargic
Difficulty with motor skills	Impulsive and distractible
Difficulty making friends	Poor motor skills
Lack of awareness of surroundings	Lack of focus

*Adapted from Miller, Anzalone, Lane, Cermak, & Osten, E.T. (2007).

Prominent infant and toddler red flags include recognizable eating and sleeping problems, a resistance when being held, motor delays, over-all uncomfortableness when dressed, and inability to soothe oneself (Miller, 2012). Often preschoolers will display an over-sensitivity to smells, touches, and noises, delayed motor skills, struggles with eating, sleeping, and toilet training, and can exhibit extended ‘meltdowns’ (Miller, 2012). Grade-schoolers display similar challenges as their preschool counterparts, but become more involved with age. Red flags recognizable for this particular age-group include all of the preschool red flags, but also incorporate possible issues in areas of handwriting and other fine motor skills, have increased difficulty interacting in a social circumstance, exhibit extreme fidgetiness, and often live in an overwhelmed state (Miller, 2012). Building upon prior red flags, adolescents and adults render that of their prior counterparts as well as an overall lethargy to life. They can be extremely impulsive and distract easily in various settings. Adolescents and adults exhibiting red flags for sensory processing disorder may also leave projects incomplete, suffer from poor self-esteem, and have anxiety regarding new tasks (Miller, 2012).

Tools for Assessment

Tools for assessment are utilized for screening indicators for sensory red flags. Developed by Dr. Jean Ayers and still part of an evaluation for children 4 to 8 years of age, the Sensory Integration and Praxis Test (SIPT) helps to identify developmental and learning delays such as; praxis difficulties, tactile issues, and struggles with visual discrimination (Ayers, 1989).

The Sensory Profile is a 125 item questionnaire answered by parents/ caregivers. The profile is utilized to aid in determination of a child’s daily functioning (Dunn,

McIntosh, Miller, & Shyu, 2002). The profile exists for children ages 5 – 10 years of age, but can be easily adapted to 3 to 4 year-olds. The 125 items are divided into 3 main sections including sensory processing, modulation abilities, and behavioral and emotional responses (Dunn et al., 2002). Measures from this profile reflect parents/ caregivers opinions regarding their child's sensory processing systems including: auditory, oral, multisensory, touch, vestibular, and visual sensory systems. The profile takes approximately 30 minutes and is based on a 5-point scale (Dunn et al., 2002).

The Short Sensory Profile (SSP) is a quick screening tool that provides a 38 item questionnaire (Dunn et al., 2002). It takes approximately 10 – 15 minutes is also answered by parents/ caregivers. In addition to The Sensory Profile and the Short Sensory Profile, there are extended designs of the profile that includes the Infant/ Toddler Sensory Profile, the Infant/ Toddler Sensory Profile – Clinical Edition, the Sensory Profile School Companion, and the Adolescent/ Adult Sensory Profile (Dunn et al., 2002).

The Sensory Processing Measure (SPM) is a measure for ages 5 – 12 years of age and is a 75-item rating scale (Parham et al., 2007). The measure is given to parents/ caregivers and teachers and is based on the 4-point Likert scale (Parham et al., 2007). It is an independent measure that provides interpretive measures of dysfunction inclusive of: typical range, some problems range, and the definite dysfunction range (Parham et al., 2007).

In addition to the profiles that are utilized as indicators of sensory processing disorder, the profiles often coincide with a comprehensive evaluation from an occupational therapist (Miller, Schoen, James, & Schaaf, 2007). As part of the evaluation, behaviors and reactions to environmental stimuli is observed (Miller et al., 2007). An

occupational therapist may also conduct interviews with parents/ caregivers, teachers, and other relevant persons in the child's life (Miller et al., 2007).

Laboratory settings are also providing support in a clinical setting. With the use of Positron Emission Tomography (PET) scans and Electroencephalogram (EEG), clinicians have been able to show definitive differences between a child with sensory issues and child that does not have sensory issues (Davies & Gavin, 2011; Miller, 2012). Changes in the nervous system have been reported by monitoring the neurophysiological processes or the neural organization abilities of the child (Davies & Gavin, 2011; Miller, 2012). Both the PET scan and the EEG examine the central nervous system (CNS integration abilities (Davies & Gavin, 2011; Miller, 2012). The PET scan is an imaging test that utilizes nuclear medicine, or radiation, to produce 3-dimensional, color images of the functional processes in the human body (Wampole, Kairys, Mitchell, Ankeny, Thakur, & Wickstrom, 2013). The EEG allows the medical community to measure the activity of the child's brain cells communication abilities via electrical signals, or impulses (Davies & Gavin, 2007). In addition to the PET scan and the EEG, clinicians are measuring muscle response to induced sensory input via Electromyography (EMG) (Fuentes, Mostofsky, & Bastian, 2011; Miller, 2012) It is motor neurons that transmit electrical signals that cause a person's muscles to contract (Fuentes et al., 2011). The EMG is a diagnostic procedure that assesses the health of muscles and nerve cells that control them (Fuentes et al., 2011; Stein, 2013). It is then translated into various graphs, sounds, and numerical values to obtain results (Fuentes et al., 2011).

More recent study utilizing diffusion tensor imaging (DTI) investigated what, if any, role white matter in the brain may be implicated in differences between children

with and without sensory processing disorder (Owen et al., 2013). Significant decreases in posterior white matter were measured in the posterior corpus callosum, the posterior thalamic radiation, and the posterior corona radiata (Mukherjee et al., 2008; Owen et al., 2013).

Being defined by microstructural characteristics such as myelination, fiber density, and axonal diameter, white matter tracts are vital to the human brain in establishing bandwidth, or the amount of information the brain can store, and speed of communication of the information (Owen et al., 2013). With the recent development of DTI measures for SPD, researchers now have substantial, non-invasive ways to measure brain differences between children with and without SPD. This also establishes further support to the argument that sensory processing disorder is indeed a stand-alone diagnosis and should be reconsidered for admission to the DSM (Mukherjee et al., 2008; Owen et al., 2013).

Sensory Processing Disorder and Comorbidities

Although research supports sensory processing disorder as a stand-alone diagnosis, there is an estimated forty to sixty percent of children with other comorbid diagnoses such as autism, attention-deficit hyperactivity disorder, downs syndrome, learning disabilities and other pervasive developmental disorders (Miller, 2012; Owen et al., 2013). The most common comorbid diagnoses with sensory processing disorder are autism and attention-deficit hyperactivity disorder (Miller, 2012; Owen et al., 2013).

Sensory Processing Disorder and Autism

Autism spectrum disorders (ASD) are recognized markedly by their qualitative impairments that are observed in a person's communication and social interaction skills

(Dawson & Watling, 2000; Dovydaitienė, Vaitiekutė, & Nasvytienė, 2013; Owen et al., 2013). It is a neurodevelopmental disorder that has restricted-type repetitive behaviors (American Psychiatric Association [APA], 2000; & Dawson & Watling, 2000). In addition to typical ASD behaviors, persons with autism exhibit more sensory processing issues than their counterparts without disabilities (Miller, 2012; Pfeiffer, Koenig, Kinnealay, Sheppard, & Henderson, 2011; Tomchek & Dunn, 2007). The sensory processing disorders that coincide with ASD have been well documented through-out multidisciplinary scientific research (Ornitz, 1989; Ornitz, Lane, Sugiyama, & de Traversay, 1993; Yeung-Courchesne & Courchesne, 1997). Children with autism tend to exhibit increased sensory, behavioral, and emotional struggles over their typically developing counterparts (Dovydaitienė, Vaitiekutė, & Nasvytienė, 2013; Ermer & Dunn, 1998; Kientz & Dunn, 1997; Watling, Deitz, & White, 2001). For most cases, it is usually a recognition of sensory issues that are a prelude for further investigation and lead to ASD diagnosis (Adrien et al., 1993; Baranek, 1999; Dahlgren & Gillberg, 1989; Lord, 1995). Thus far, sensory issues in ASD diagnosed children and adolescents continue to come from parent/ caregiver reports, observations in clinical settings, self-reports which are showing both groups; under-responsiveness and over-responsiveness (Miller et al., 2005; Pfeiffer et al., 2011). Providing a better understanding that sensory processing difficulties create for children with autism will provide greater insights and understanding to daily struggles and future treatment (Dovydaitienė, Vaitiekutė, & Nasvytienė, 2013).

Sensory Processing Disorder and Attention Deficit-Hyper Disorder (ADHD)

Although research has answered many questions regarding SPD and ADHD, many more questions remain (Byrne, 2009; Mangeot, Miller, McIntosh, McGrath-Clarke,

Simon, Hagerman, Goldson, 2001). It is known that an estimated forty to sixty percent of the children that have one disorder also show symptoms of the other disorder (Byrne, 2009; Mangeot et al., 2001; Miller, 2012). Sensory processing disorder and ADHD are both neurological deficits, but are separate diagnoses with a unique set of symptoms (Mangeot et al., 2001; Miller, 2012; Muro, 2011). Inattentiveness, instances of hyperactivity, and uncontrollable impulsivity all help define characteristics of ADHD (Muro, 2011). Like sensory processing disorder though, ADHD also provides varying levels of difficulty in daily functioning (Mangeot et al., 2001; Miller, 2012; Muro, 2011). Distinguishing between the 2 disorders, but knowing the possibility of comorbid diagnosis may exist can provide better treatment and outcomes for the diagnosed child (Miller, 2012).

Diagnostic Statistic Manual 5 (DSM-V)

The rally for the inclusion of sensory processing disorder into the DSM began in the year 2000 (Miller, 2012; Miller, 2013). Not only would the DSM acceptance provide a foundational push for additional research and funding, but would also help provide needed scientific support for services in a treatment capacity (Miller, 2012; Miller, 2013). In December 2012, a decision by the American Psychiatric Association was reached (American Psychiatric Association, 2013). The decision to exclude as a standalone diagnosis in the DSM-5 was announced. Although the decision caused disappointment to the sensory processing disorder community, research and advancements in the study of SPD continue with the hopes for further consideration (Miller, 2012; Miller, 2013).

Summary and Conclusions

Chapter 2 affords an overview of various literature linked to SPD and its multiple facets regarding diagnosis. The overview of the literature highlights the important role that exists for occupational therapists regarding children diagnosed with SPD. In addition, the literature explains the multifaceted and multi-layered dimensions to sensory processing disorder, as well as the current status of the diagnosis among the clinical world.

In addition to treatment setting, families of children with SPD face many challenges in various settings. Research is showing that at least one in twenty children struggle with sensory issues and that the possible more realistic number attached to such may be as much as one in six children. With increasing prevalence, exclusion in the DSM-V, and the abundant variations labeled under the umbrella term of SPD, review of the literature and support for future study is warranted. Also, not always being a stand-alone diagnosis, as many and multiple co-morbid diagnoses can exist with sensory processing disorder, the impact on a daily basis for many, is felt in multiple circumstances and in various communities. Occupational therapists remain the leading practitioner to assess and provide treatment for children struggling with sensory processing disorder.

The following, Chapter 3 expresses the research design, the approach and methodology of the study, and a comprehensive synopsis of procedures. Chapter 3 also provides data collection methods, explanation of setting and sample, and materials utilized in the study.

Chapter 3: Research Method

The purpose of the study was to research, collect data, and provide a qualitative perspective as to the family experiences of children diagnosed with SPD. Chapter 3 provides a synopsis of the research design; the role of the researcher; and the procedures for selecting participants and collecting data, the interview guide, data analysis plan, and ethical and quality considerations. My personal experience as a parent of children with SPD is considered, along with possible researcher biases and the strategies for minimizing them. In addition, the role of advocacy integration as the conceptual framework is presented.

Research Design and Rationale

A qualitative, exploratory study from an advocacy perspective was used to examine commonalities of children diagnosed with SPD and provided perspectives from the children's occupational therapist and their parents/ caregivers. Qualitative methodology provides a range of flexibility that allows a subject to be viewed in depth via a description of the social phenomena (Casey, Shaw, & Murphy, 2013; Cope, 2014; Strauss & Corbin, 1990). A basic design was appropriate for this exploratory study, as this phenomenon had not yet been explored. Integration of advocacy issues also were infused throughout the chapter to include a discussion regarding information and support for SPD. I established direction on the development of theory related to social phenomena of SPD. The results of this study can contribute to research and advocacy for SPD to be added to the *DSM* as a stand-alone diagnosis to aid children and families to receive needed services for treatment (Miller, 2012, Miller, 2013). The study was designed to answer the following research questions:

Research Question 1: What is the experience of children diagnosed with SPD in the areas of social relationships and school performance?

Research Question 2: What is the experience of families living with children diagnosed with SPD?

Role of the Researcher

In qualitative research, the researcher is the principal instrument when collecting data for a study (Hoepfl, 1997). For this study, I was both the researcher and parent of two children diagnosed with SPD. In cases where the researcher has multiple roles, ethical concerns must be handled, and the multiple positions of the researcher must be reported honestly to maintain integrity in the study (Connelly, 2014). Furthermore, the occupational therapist interviewed for this study was the occupational therapist for both of my children who were diagnosed SPD. She was their occupational therapist for over 4 years. The occupational therapist and I had a professional relationship that extended beyond her role as my children's occupational therapist. Although differing roles, we were both therapists and we were placed on the same cases for several children in my prior position as an expanded mobile therapist.

As a parent, I have dealt with this diagnosis for more than a decade; researching, reaching out to others with similar stories, and living with SPD has been integral into daily life. Two of the most difficult questions have remained: what does SPD look like? Is that behavior due to SPD or is it the age and acting out? To separate a diagnosis that is infused into every aspect of a child's life seems problematic at best; yet, more than a decade after diagnosis of my children, understanding and acceptance of SPD as a stand-alone diagnosis remains unrecognized, according to the *DSM-V*. Due to a lack of

acceptance, receiving services for SPD children remains a daily challenge. SPD aspects are blanketed under a massive umbrella. Children and their environments continue to grow and change, making the ability to adapt to environments for long periods of time impossible. The examination expressed the multi-faceted challenges and the demand for continued support to the evolving child. As both the researcher and parent, I see the urgency to contribute to greater acceptance and understanding in social settings, such as school and home, and to advocate for on-going resources for children who have SPD challenges.

As the researcher for this qualitative examination on SPD, I had to remain focused throughout, to ensure that personal interjection, preconceptions and notions, and personal experience did not influence the data collection or analyses of data for this study. The following strategies were employed in order to reduce the risk of bias. Member checking, or sending each interviewee a summary of his or her responses to the open-ended questions and asking them to ensure accuracy of interpretation, was employed. In addition to member checking, an audit trail as a secondary approach was also used to aid in the reduction of researcher bias. An audit trail provided a concise trail of documentation regarding the data collection and analyses processes (Shenton, 2004).

Methodology

Participant Selection

SPD research remains limited in regards to the length of time it has been studied and received recognition within the medical community. However, understanding the experience of SPD requires perspectives from multiple experienced, information-rich viewpoints (Miller, 2013). Therefore, an intensity sampling strategy was used to collect

data from the exemplar (but not extreme) individuals involved in the social and family experience (Patton, 2012).

The occupational therapist selected to participate had been working the field for more than 25 years and had specialized knowledge and training in the area of SPD. She had attended national seminars sponsored by the SPD Foundation and was associated with other experts in the field. I used the occupational therapist as a conduit to gain access to parental information. Parents who received services from the occupational therapist provided multiple parents the informed consent form (see appendix A) and the parent contact information form (see appendix B). If parents were interested in volunteering as a participant in the study, they then contacted me via email. The occupational therapist was not aware of who decided to participate, and no traditional recruiting was conducted.

Instrumentation

Demographic/ Parent Form

The demographic form was a set of five questions regarding a personal information sheet that remained confidential, but provided best points of contact for future communication. The form also contained demographic information on their location and data on their child diagnosed with SPD. The information that was collected and relevant for this study included (a) name, (b) address, (c) phone, (d) email, and (e) child's age and gender.

The open-ended questions were developed based on the information from the literature. Being able to ask questions that are timely and relevant to continue the advancement of knowledge and understanding for SPD was needed (Miller, 2013).

Questions developed for the occupational therapist and for the parents were varied, as they represented multiple perspectives on the topic. The occupational therapist (Appendix C) and the parental (Appendix D) open-ended questions were focused to gain a rich understanding of the experience of both the children diagnosed with SPD and their families.

Recruitment, Participation, and Data Collection

Recruitment

The occupational therapist was initially contacted by phone regarding her willingness to participate in the study. The parents received an informational sheet, and I explained to each parent that if they participated in the study, it was voluntary. To avoid conflict with the professional relationship with the therapist, they contacted me directly via email if they so chose to participate.

The occupational therapist, after verbal agreement to participate, received an informed consent and explanation of minimal risk via email that was returned immediately. The occupational therapist then received the invitation for parents to participate. Only parents with children diagnosed with SPD were provided the invitation. Parents who contacted me were then emailed an informed consent and the minimal risk that was to be signed, emailed, and returned to me.

Participation and Data Collection

After participants agreed to participate in the study and signed the informed consent, they received an email containing an introduction and an attachment with a series of open-ended questions that were designed for this study and will be responded to in written or typed format, or via a semi-structure phone conversation. Providing multiple

ways such as mail, email communication, and phone responses for collection regarding the parents/ caregivers open-ended questions was necessary. The occupational therapist suggested that for various reasons, parents/ caregivers may need to be offered multiple routes as listed prior when responding to open-ended questions due to hectic schedules of parents with special needs child and the possibility of being unwilling to meet someone new regarding further questions involving additional explanation of their special needs child. Due to various options, all participants were provided multiple contact venues including phone numbers, email contact information and mailing address in case any additional questions or concerns that develop. The contact information for dissertation chair and Walden University's contact information was additionally provided in case of emergency related to the study.

Data Analysis Plan

To assess the experiences of the children diagnosed with sensory processing disorder and their families, semi-structured phone interviews and email responses were accepted. The initial data analysis developed initial codes that were furthered expressed by themes of the experiences. Within those themes, categories for each developed and were expressed by the occupational therapist and the parents. There was no analytic software utilized for data expression, and all experiences were turned into transcripts within a word document.

Issues of Trustworthiness

There were several limitations to the proposed research that may challenge the credibility and transferability of the results. First, there was limited number of participants who met the inclusion criteria in the rural area of northeast Pennsylvania.

This limitation could have impeded the availability of data to be collected. Also, the researcher relocated to a new state during the dissertation process and as such the researcher's location and access could have also impacted the results to other locales and family experiences with an alteration in the collected data approach. The researcher used member checking and audit trails to demonstrate the dependability of the findings. In addition, consideration of researcher bias based on having 2 children diagnosed with SPD needs to be considered.

Ethical Procedures

Institutional review board (IRB) reviews aid in the protection of study participants (Connelly, 2014). It is the IRB that oversees the protection of all subject participants, both human or animal, and specific attention is given to possible vulnerable populations such as; children, elderly and those part of special populations (Connelly, 2014). This study does not include any participants from vulnerable populations. The study will abide by all affirmed institutional review board and federal guidelines. Providing an informed consent is critical to the research process (Connelly, 2014). The participants in the study will be given research study information in writing or via email communication. By the occupational therapist and the parents/ caregivers signing the informed consent, all participants in the study are confirming their understanding of all procedures, possible risks, and benefits regarding their participation. Within the informed consent, there will be a statement of participants' rights that will allow them to withdraw contribution and involvement in the study at any time. To aid in maintaining the integrity of the study, participants will be allotted the opportunity for a debriefing of the study. The researcher, via phone, will provide an overview that is applicable to both

the occupational therapist and the parents/ caregivers. The discussion will provide an overview of the study including; nature of the study, required informed consent, and any concerns related to the study. Personal contact information, as well as directions for contact with the dissertation chair and Walden University are included in the Informed Consent form (Appendix A). Data will remain on a password protected file for 5 years after the completion of the study. After the 5 years, the data will be destroyed at its location of storage.

Summary

In chapter 3, the research questions that provided the foundation of this study are expressed, in addition to explanation of research design, description of approach and methodology, and participant information was explained. The expectation regarding the proposed research was an addition to current works of literature. It provided an exploratory study from an advocacy perspective using a basic qualitative design. It focused on the social phenomena that brought needed awareness for children who require services due to their sensory processing disorder and the challenges faced from the perspective of an occupational therapist and their parents/ caregivers.

Chapter 4: Results

The purpose of this qualitative study was to investigate experiences of an occupational therapist and parents regarding children with SPD. Data were collected and analyzed in order to answer the research questions:

Research Question 1: What is the experience of children diagnosed with sensory processing disorder in the areas of social relationships and school performance?

Research Question 2: What is the experience of families living with children diagnosed with sensory processing disorder?

Chapter 4 includes a description of the data collection and analysis procedures for both the occupational therapist and the parents ($n=5$) living with children diagnosed with SPD. A description of the thematic analysis is presented, followed by a description of the results and summary of how the data addresses the research questions. Chapter 4 is segmented into three additional sections. The following section are inclusive of general descriptions of the participants in the study. Next, I include a brief look at the qualitative methodology and the use of thematic analysis, including the data presentation. The final segment includes a summary of the chapter.

Settings

The original study was designed so I would conduct face-to-face interviews with the participants. Due to relocation during the process, I altered the data collection method from face-to-face interviews to phone conversations and e-mail communications. What was missed was being able to see the nonverbal communication that can enhance the data collection experiences; however, the e-mail and phone conversations afforded more

prolonged contact that was essential for collecting rich, thick descriptions (Creswell, 2007).

Data Collection and Demographics

The occupational therapist worked in a rural area in northeast Pennsylvania. She had been working with and specializing in the area of SPD for over 25 years. Collection of the experiences was completed via e-mail communication.

The four parents who participated are referred to by code number Parent 1 (P1), Parent 2 (P2), Parent 3 (P3), and Parent 4 (P4). The parents who volunteered to share their experiences for the study were all from similar circumstance. They all lived in Northeast Pennsylvania, had children diagnosed with SPD, and three of the four parents' children were school-aged; the other was younger than 5 years of age. In addition, three of the four children had siblings, and one was an only child.

Parent 1 was the parent of a non-school-aged boy who was diagnosed with SPD as a stand-alone diagnosis. Other diagnoses had been discussed with their pediatrician; but, no formal diagnoses had evolved from the conversation or evaluations. P1 had been receiving services for her child for 8 months at one time per week. The diagnosed child had siblings who do not share this diagnosis and were not experiencing other psychological or physical issues. The parent was a physical therapist and "works with pediatric occupational therapists." Being able to seek support, she felt, was easier for her than others, due to her education and professional background.

Parent 2 was the parent of a school-aged female who was diagnosed with SPD, and a comorbid of autism spectrum disorder (ASD). P2 had been receiving services for her child for 7 years, 3 months, for once-a-week sessions with the private occupational

therapist. Her child also received additional school services. This child had additional siblings at home. The parent did not discuss employment, but did relay that having her daughter and all therapies needed had required her to be more than a full-time mother.

Parent 3 was the parent of a school-aged child. Her son was diagnosed with SPD, with multiple comorbid diagnoses including attention-deficit hyperactivity disorder, and hyperacusis. Her son had been receiving occupational therapy for “approximately 2 years,” and once a week during that time. She also stated that she had other children. Although employment was not discussed, she considered being her son’s advocate for school and being the main parent to take to therapies was a full-time job.

Parent 4 had a school-aged child. Her son’s diagnosis was SPD, and it coincided with other comorbid diagnoses; but, the parent preferred not to share the additional information. Her child had been receiving therapeutic services for 2 years and 3 months. He was an only child, and the parent had opted to homeschool due to “on-going challenges and poor circumstances” within his school setting. With his “meltdowns” described as multiple times daily and consistent, being a full-time parent was her “first job.”

Data Analyses

The interview data were analyzed using the thematic process as described by Braun and Clarke (2006). The analysis process was conducted and originally written by hand’ then, the information was then transferred MSWord™, version 10. The analytic review began with the initial read-through of the written notes taken from the phone conversations and returned written data regarding the occupational therapist and parental

experiences. After a minimum of three rereads of data, initial codes were developed, as well as basic impressions that were associated with the data codes.

The next step was to officially develop recognizable data codes. Various prospective codes were initially highlighted, as the initial codes seem to emphasize multiple interesting factors of the topic explored for the study. After reading and listening to the interviews multiple times, approximately 40 codes— words, phrases, and sentences were identified as meaningful moments, experiences, descriptions, or memories. Examples of codes included stress, struggles, support, schedules, frustrations, and exhaustion. A complete list of codes is provided in Appendix A. As each interview was coded, the process of audit was completed. The audit of the data analysis process was completed in a separate journal and included insights or ideas as to how these codes could be combined, and how they might relate to the research questions.

Because there were so many codes, an interim synthesis of moving from codes to categories was completed. Categories reduce the number of different pieces in order to reveal possibilities for commonalities and further reduction (Silverstein, Auerbach, & Levant, 2006). As shown in Table 2, 14 categories were eventually grouped into four themes: family dynamics, support impact, emotion and balance, an SPD child.

Table 2

Organization of Categories and Themes

Family Dynamics	Support Impact	Emotion and Balance	A Child with SPD
Revolving 'real' life around needed schedule	Occupational Therapy	Guilt	Interruptions and struggles
On-going conflicts between parents	Academic Support	Living with increased stress	Social relationships
Loving 'through' the diagnosis	Additional Services	The struggle for balance among all family members	A day in the life...
Missed or clouded memories		Today's society lives a fast-paced life	

After creating the categories, I began to search for common themes. Excluding potential sub-themes and themes that did not warrant substance, I discovered statements that were organized into significant components that related to the exploratory nature of the study. Examples of these were categories including occupational therapy, academic support, and additional services, which were repeated and led to the development of the support impact theme.

Thematic Analysis

Family Dynamics

Family dynamics was the first theme and expresses the experiences described by both the occupational therapist and the parents as they reiterated the massive impact felt within the family environment. The categories for this theme included challenges of the pressures of 'real life' while trying to maintain sometimes a very needed, rigid schedule,

and on-going conflicts between parents: loving through the diagnosis to look beyond the behaviors; and a grave emptiness that exists because (a) the family has to miss so many events or (b) event memories are clouded by the child's particular behavior at the event.

Revolving 'Real' Life Around Needed Schedule. Parents consistently reported the struggle to manage the day-to-day activities around the SPD child's need for scheduling. Parent 1 stated, "I feel most challenged to plan out each day just to try to prevent issues." Parent 2 said, "As a family, we miss out on family gatherings because of our child's behavior." Parent 3 stated, "transitioning from one activity to another is a major stressor for all family members," and Parent 4 discussed the difficulty of having to micromanage every aspect of family life in an attempt to help her child cope with the severe texture issues (e.g. removing various tastes from the menu and smells from the house). This parent reported that if this was not completed successfully, the "stress levels of our family all shoot through the roof and I feel like I walk on eggshells every day."

The occupational therapist verified the parents' experiences in describing that "for these families, life is an emotional roller coaster." This is supported by the conversations with the parents as well. The occupational therapist and parents all expressed the increased levels of exhaustion that coincided with caring for a child with SPD. In sum, the analysis revealed the dynamic and turbulent family life that juggled the need and desire to 'live' in the real world (maintain jobs, meet other family expectations) with the micromanaging life on a minute-to-minute basis to create a positive environment for the child with SPD.

On-Going Conflicts Between Parents. The stress that this puts on parental relationships was summarized by the occupational therapist:

All too often I see families that were torn apart, and literally this usually occurred on multiple levels. It can occur between the 2 parents, a parent and child, or even between siblings of the diagnosed child that are struggling to understand and cope with their siblings' challenges. In my practice, you typically would see one parent over another that is *the* one that consistently brought the child to therapy, and was usually not due to work/scheduling conflicts. One parent always seemed to struggle more than another. I also have had multiple children receiving services that parents were divorced, and in passing, the final word was always blamed on the stress created by their special needs child.

Parent 1 shared detailed experiences of on-going conflict and challenges within her home. She says, "It was challenging for my husband to understand . . . [and] he was not patient with our son." She continued to explain that it was more complicated because the diagnosed child's sibling is younger (3 years old) and in an attempt to make things work, "she often had to go with the flow and she was now acting out and mimicking her older brother."

Parent 2 and parent 4 were more general in their responses referring to the stress that occurred between parents if not in agreement on approaches to settings and events when dealing with behavioral struggles, and continually trying to develop new and creative strategies to handle their child. Being able to agree on these continually, "Proved to be very difficult." P3 preferred not to respond to the question.

Loving 'Through' The Diagnosis. The occupational therapist conveyed repeated parental concerns that included the struggle of not only caring for their child with sensory struggles, but being able to see their child instead of seeing just a diagnosis. She shared

that when parents were living in it, meeting needs of the child and their family, and integrating all other responsibilities; “it could be difficult to not just see, hear, and breathe a diagnosis.” There were also a host of emotions, usually negative, associated with this action. Parents may have “felt guilty and self-blamed to their own detriment.”

All parents conceded that some days more than not, they were so worried about getting through their days, and planning and managing circumstances to help their child, that the exhaustion and guilt of not being able to split time appropriately with all family members was overwhelming. It WAS the diagnosis that “guided our daily lives,” state P2.

Missed or Clouded Memories. This category revealed 2 dimensions, described by both the occupational therapist and the parents. The first dimension referred to the *feelings of loss* encountered by parents who “could not go out publicly, partake in family gatherings, and could lose touch with what was once thought to be close family and friends.” (OT). Many participants reported that the stress of preparation to attend various events could exhaust a parent prior to the event itself.

This situation could take its toll on the strongest of families. In the event they made it to the birthday party, family reunion, or otherwise, these families almost always dealt with a meltdown, or even multiple meltdowns, while attending an event (OT).

In many instances, parents reported that repeated scenarios of avoidance, last minute cancellations, and not enough preparation time (“... to actually get the child out the door” as stated by P1) interfered with attendance and reduced opportunities to participate over the years.

Second, the occupational therapist explained that many families were still facing the traditional stigma associated with bringing a special needs child to an event. She stated that the parent or parents self-blamed for “it happening to their child”, and were continually asked questions such as, “When was he/she going to get better? Will they always act like this?” (P1) or heard comments like “it was not real, it was just your parenting style that caused this!” (P4) In some cases, the experience of stigma would come from the immediate or greater family, where blame is placed upon the non-biological related parent.” In fact, the experience or fear of stigma was present throughout the content analysis process in association with times where the family or parent and child had to interact with the world external to the family system.

In sum, participants shared an overwhelming and complex set of thoughts, feelings and experiences that expressed the theme of family dynamics that were affected when caring for a child with SPD. The requirements of adherence to a schedule and need for constancy interacted with daily life normal adjustments and changes and contributed to a chaotic family system. The occupational therapist compared it to “A Tale of 2 Cities,”; and all parents seemed to agree that caring for a child with SPD was a ‘bittersweet’ life.

Support Impact

Support for special needs children, inclusive of those diagnosed with SPD, came from various avenues and in multiple arenas. This typically includes the following types of support: occupational therapy, speech therapy, therapeutic staff support, and an educational team associated with an individual education plan (IEP) or a 504 plan of action. The occupational therapist and all parents concurred regarding the importance of

therapeutic support being integral for moving a child with SPD forward. The greatest aid for a child with SPD was occupational therapy, as this was reiterated over and over by all parents during the phone conversations.

Occupational Therapy. As an occupational therapist diagnosing and treating sensory processing disorder, the first and most critical detail was to provide sensory inventories to the parent (and to the child if old enough to provide their own responses). Tools utilized to evaluate the child included the Sensory Integration and Praxis Test (SIPT) (Ayers, 1989; Ayers, 2005; Brown & Dunn, 2002; Dunn, McIntosh, Miller, & Shyu, 2002; Miller, 2012; & Parham, Ecker, Kuhanek, Henry, & Glennon, 2007), a parent screening on the Sensory Profile (Ayers, 1989; Ayers, 2005; Brown & Dunn, 2002; Dunn, McIntosh, Miller, & Shyu, 2002; Miller, 2012; & Parham, Ecker, Kuhanek, Henry, & Glennon, 2007), the Short Sensory Profile (Dunn et al., 2002), the Sensory Processing Measure (Ayers, 2005; Brown & Dunn, 2002; Dunn, McIntosh, Miller, & Shyu, 2002; Miller, 2012; & Parham, Ecker, Kuhanek, Henry, & Glennon, 2007), and clinical observations.

SPD is “recognized by a unique set of sensory symptoms, yet can often remain undiagnosed or misdiagnosed”, according to the occupational therapist. “It was ADHD first, then ASD that were the most often of misdiagnoses. From my view this occurred approximately 50% of the time.” Families usually

found me, and other occupational therapists, when the child consistently had repeated meltdowns at a very young age. These ‘meltdowns’ far surpassed a typical tantrum, could appear to be for no reason, were consistent, and lasted

hours or even carried over day-to-day. They were extreme and most often unexplainable till a parent sought support and began to get educated.

The occupational therapist conducted sessions with the child, although often times also became the main support of the parent as well, providing explanation, tools, education, and more on a weekly basis. Early intervention usually consisted of a more encompassing approach, multiple therapists and a minimum of 3 days a week for sessions and were usually conducted in the home.

I know longer did early intervention, so parents typically brought their child to me and more times than not, therapy consisted of one day a week. This was in part due to the difficulties with insurance, as sensory processing disorder as a standalone diagnosis had not been added to the latest edition of the Diagnostic Statistic Manual (DSM-V), so unless children had a co-morbid diagnosis it could be difficult to get covered by insurance companies. Individual deficiencies such as gross and/ or fine motor delay could be coded separately, but may not have been the root of the struggle and challenges that existed for the child, and inevitably their families.

All parent conversations conveyed the vital importance of occupational therapy for their child, and for them as the parent.

P2: Therapy was indispensable!

P1: [the occupational therapist that provided the most] substantial education and necessary tools to support their child with SPD... while also providing family guidance and parental support.

Parent 1 continued to explain that she did not know where she, or her child, would be as

she [the occupational therapist] was the only true local support system I had. I wish there was more knowledge for pediatricians, teachers, and other parents, and that I had a local support system . . . or even just one other mom to talk to and share struggles, situations, and stories.

P2 and P4 expressed that it is the occupational therapist that had provided them and taught them to utilize “creative ways to support and help their child” (P4). P2 explained that she “feels therapy is a place to push a child with these struggles outside their typical boundaries so they can have ‘controlled, repeated exposure’ to necessary situations that could only happen in therapy.” The occupational therapist and all parents expressed that therapy could help and support a child with SPD and their families. The occupational therapist also noted that progress was “also dependent on how much support they got from a school environment as to how well they can truly do.”

Academic Support. The most consistent comment made by parents was the lack of understanding in the school system regarding how to work with SPD children in the classroom. P? indicated that many schools were not are not familiar with SPDP noted “a lack of friends and schools did not understand my child.” Often times a child was labeled according to their behavior, while not addressing the source of their struggles. The OT therapist noted:

For example, if a child consistently fidgeted in a classroom, the proper way to address the situation was not to teach a child ‘not to fidget’, it has neurological advantages for the child to fidget, but instead provide them a tool belt that

allowed them to fidget appropriately and quietly within the classroom setting. This helped the child's neurons fire, stay focused, and not be disruptive. It was truly unfortunate that most teachers [and their schools] did not have a true comprehension of this or other pieces to this umbrella term

She went on to explain that, "good school districts had an occupational therapist in the classroom assisting the teacher to make it sensory friendly and to maximize the functioning of all children".

Parent 2 clearly expressed the same feelings as Parent 3 and Parent 4, and stated that the diagnosis "always seemed to be seen as behavioral rather than neurological." Parent 2 and Parent 3 both conveyed that teachers 'simply did NOT understand [my] child or the diagnosis.'" Parent 4 was unforgiving in her response to the question 'How has your over-all experience within the academic setting been pertaining to meeting the needs of your child with SPD?' She simply stated, "POOR! THAT IS WHY WE NOW CYBERSCHOOL!" [*Capitalization hers*]. Choosing to cyber-school seemed like the only alternative:

... as teachers, administration, and staff repeatedly showed that they did not understand my child, his needs, and his diagnosis. Cyber-schooling could still prove difficult some days, but so many of the additional challenges that was keeping him from absorbing the content had been removed. Now he was learning and was far more successful academically speaking

Parent 2 still had her child enrolled in a traditional school setting, but stated that: they were NOT helpful because they COULD NOT and WOULD NOT make necessary, and even sometimes recommended or federally mandated, exceptions

and accommodations that were necessary to help the child find success in the classroom. If teachers were educated, they would be able to effectively address the issues of my child, allowing him to absorb what they were learning.

With similar experiences, Parent 3 expressed that a joint effort would be beneficial to both the child and the classroom setting. However, “the implementation of his plan did not get followed as most teachers did not have an understanding of my child or his diagnosis. They did not seem to care to inform or educate themselves either.”

Various teachers could provide different experiences and with diagnoses of associated learning struggles increasing in prevalence rates, a person was far more likely to have an experience with a teacher whose own child struggled with a diagnosis. Parent 3 continued:

My best teacher experience was a woman whose son was diagnosed ADHD and both recognized and reported problems or areas of concern that otherwise would have gone perhaps unnoticed. Unfortunately, this was the only positive experience to discuss within the academic setting for my child; the rest had been a struggle. I did, however, continue to consistently advocate for him as much as I felt needed.

Parent 1 had a child that was not school-age and did not partake in this part of the study. She did comment however, “I am looking forward to reviewing your study when complete, in particular, to see what challenges could be headed my way in regards to the academic setting.” The occupational therapist and parents 2, 3, and 4 all conveyed similar disappointment and frustrations within the academic setting. It was expressed that working jointly would be the best route for benefits to the diagnosed child, but the occupational therapist stated that, “it was very difficult to even talk to an educator

regarding a student, and with the current HIPPA laws; it could be very complicated to work in a holistic approach on behalf of the child.” The parents that currently have school-aged children diagnosed with SPD supported a lack of support and a lack of understanding within the academic experience for their child.

Additional Services. Additional services were often utilized to compliment occupational therapists to aid in the child’s abilities and over-all current and future success. All participants utilized a range of services. All participants felt that additional services a critical piece to the child’s success, and these could be incorporated into the child’s routine. The education, understanding, and support for parents to help their children in the best possible realm must be was described as coming from various avenues and fields, comprising a “pie” of multiple services and supports.

The occupational therapist humbly expressed that she is simply “one piece of the pie. There were usually multiple people involved in the support and education of child that was diagnosed with SPD.” Common additional support often came in the form of, “speech therapy, psychological support, therapeutic staff support, and even additional home support such as respite care and more, especially when dealing with a child with multiple diagnoses that encompassed SPD.” It was also explained that if the parent chose the additional support through the same provider where the occupational therapist provided services, they could exchange and communicate regarding the child far easier and jointly develop therapeutic plans. If a different provider was chosen, “which happened often due to insurance requirements, it could be far more difficult to develop a cohesive plan to help the child.”

Parent 1 explained that her son was younger and recently diagnosed, so no other interventions had been “explored at this time, but assuming there would be in the near future.” Parent 2 and Parent 3 conveyed that although other interventions and support had been explored, “scheduling and time can make multiple therapeutic approaches difficult,” and they both concurred that the occupational therapy approach has been indispensable. Seeking additional support from the school district was important, but due to experiences in the academic setting, support from this area was not expected. Parent 4 stated she was, “disgusted as to how the traditional academic setting handled my son,” and since homeschooling we had also, “sought out additional support from mobile therapists, a psychiatrist, and medicinal routes.”

The occupational therapist expressed that, “it could be difficult, as parents of special needs children were typically already overwhelmed, and even though multiple forms of intervention are beneficial; the actual process, the wait times, and coordinating a schedule could be extremely difficult.” The parents all concurred. The group thought expressed that the more support “the merrier.” All parents stated that they felt the more scheduling though, especially those with other children, “proved to be very difficult,” and that was prior to mentioning incorporating work schedules, children’s activity schedules, and family responsibilities.

Emotion and Balance

The third theme that developed from the semi-structured phone conversations, or email responses, was the importance of the range of emotion experienced by a parent goes through caring for a child with SPD, and the constant search for balance in all areas of life while caring for their child with a diagnosis that often goes misunderstood,

undiagnosed, or misdiagnosed. The occupational therapist and the parents discussed difficult feelings of guilt that continued even with services sought, elevated stress levels that were infused in daily lives, the enduring search for balance that met the rigid needs of the child while accommodating other family members, and the need to continually find inspiration for all that is creative to exist in a family with a special needs child.

Feelings of Guilt. Parents of special needs children often suffered through the ongoing feelings of guilt and guilt is a prominent experience of parents of special needs children (Miller, 2013). Thoughts of wondering if they could have done anything differently to prevent or help are common, while the mothers struggle even more especially with sensory processing disorder, as no one scientific-based cause has been distinguished, and the thought that something was caused in utero is a heavy burden to be carried forward (Miller, 2013).

The idea that parents of children with sensory processing disorder carried large amounts of guilt around with them was “probably a mild understatement.” The occupational therapist continued to explain that:

... it really did not seem to matter how old the child, how long they had received services, or even where they were located in the sensory umbrella (meaning more or less severe), every parent seemed to blame themselves for their child’s struggles. It was something they do upon an initial diagnosis and it did not go away; they continued to blame themselves. Parents had many questions upon diagnosis, but the one question that was always asked was, ‘what was the cause?’ And when I could not respond with a definitive answer, you could see a change in them. It was immediate, and I could always see it from there forward. I saw it in

their eyes as they asked for updates or had questions about the disorder. Every time I spoke to a parent, you could see it.

Similar feelings were expressed by the parents. Parent 1 stated, I did not feel like I had a true understanding of the diagnosis. I felt like it was hard to grasp, understand, and explain because there were so many variables to the diagnosis. As a physical therapist, I kind of worked in the field, or at least with colleagues and I was familiar, and I still struggled.

Beyond the fact that sensory processing disorder was multifaceted and multileveled, parents often blamed themselves for what their child experienced. “By not feeling like I truly understood and seeing my child struggle, the feelings of guilt were a constant. I carried those feelings with me all day every day.” Parent 4 expressed similar thought to Parent 1, and explained that

...there was so much to the diagnosis, it was difficult to be able to deal with all aspects that my child may be going through. Feeling like a bad parent or feeling guilty, and sometimes not even knowing what for exactly, was very hard.

Parent 2, although similar in thought and in complete agreement that the diagnosis had many facets, unlike Parent 1 and Parent 4 though, she stated,

I did not think I needed any more information regarding the diagnosis at that time. I tried to approach current challenges with my current level of understanding. I felt that more information at this point would have been overwhelming and unnecessary and would have weighed me down more than the guilt that I struggled with daily. Perhaps as we met new challenges, I could incorporate small

pieces of information, but having an overwhelmed parent as the caretaker of a child who is constantly overwhelmed just seemed like a bad mix.

Parent 3 expressed that as her child's caretaker, advocate, and main connection with intervention programming, she felt she had a pretty good understanding to help and support [her] child, but this did not stop the heavy burden of guilt she beared for her child's struggles. Filling all of these roles and more was the least I could do, as every parent wanted their child to experience success.

The occupational therapist and all parents expressed similar thoughts when they discussed the impact of guilt on parents of children with sensory processing disorder. The question of "why me" came up, then the parents explained they felt even guiltier even thinking such. While Parent 3 was clear that she would never be able to do enough for her child, no matter what role that required her to take due to the weight felt from learning of her child's diagnosis.

Living With Increased Stress. The expressions of all participants communicate a shared experience of long-lasting negative effects to people that suffer with constant, long-term stress. The occupational therapist explained that unless you are the caretaker of a special needs child, "you could not possibly understand the amount of stress and worry these parents go through minute-to-minute, daily, and for a lifetime." It was conveyed by the parents that took part in the phone conversations, or responded via email, that their lives truly 'revolved around their special needs child' and putting their health concerns or stress at the top of a list 'just never seemed to happen.'

The Struggle For Balance Among Family Members. All families struggled to find balance in daily routines, schedules, work-family life, and balance among various

members remained a constant struggle for all to endure. So often, living with a child diagnosed with SPD affected every member of the family, sometimes on “levels they could not even recognize.” So many families worked on just getting “through another day, and that a focus on the future, setting long-term goals, and dreams that traditional parents have blurred till unrecognizable images.” The parents also conveyed similar thought, in that the goal was always to ‘make it through another day with as few meltdowns as possible, and to hopefully get to see their child ‘be a kid’ even if just a little while.

The occupational therapist worked directly with the child, but also provided tools, resources, education, and supported for the families, “especially upon initial diagnosis.”

The minimal balance that

... parents thought existed dissipated upon diagnosis. There were multiple challenges for families with a child diagnosed with SPD. The occupational therapist said that “receiving a diagnosis was enough for families, but start integrating therapies, doctor appointments, protocol for insurance companies, wait lists, filling out required forms in duplication over and over, dealing with school administration, teachers, and if a parent has other children, even sometimes multiple diagnosed children; finding any sort of balance seemed like the impossible task. I tried to, at minimum, reduce the amount of information that may bombard them all at once. If they could take items more individually, glimpses of the balance they desire started to appear.

She continued explaining that it, “really could be a snowball effect, and when one thing went right and helped bring a little sense of balance, repeating and expanding on it was key.”

P1, P3, and P4 did not have other children, therefore sibling concerns were not an issue when trying to find balance within the family structure. Parent 2 expressed concerns and frustrations regarding with such, that not only was her younger child mimicking her diagnosed child, but trying to “teach a young sibling to love their sister unconditionally was extremely difficult. The meltdowns could scare her younger sibling and learning to love through the diagnosis and the behaviors was extremely difficult to teach and balance.” In addition to siblings, finding a balance for spouses to even carve out time for themselves individually and as a couple would seem impossible. The fact that they could be overwhelmed and disagree on intervention and discipline approaches, have been dealing with school administrators and faculty, and have job interruptions due to therapeutic responsibilities could lead to on-going stressors, arguments, and more. Being able to hold down a full-time job, ensure that a diagnosed child makes it to therapies, while getting up hours early to “prep the day before you take the time to prep your child’s day could have you exhausted before they even wake up.” Parent 1 explained that

[I] feel challenged to plan out each day, anticipating certain meltdowns and challenges, then planning accordingly to prevent issues from arising. Also, my husband and I planned our lives around our child and his needs. Not only did this not lead to balance, but often led to disagreements.

Today Society Lives a Fast-Paced Life. Technological advances, shifts in expectations within family structures (households with 2 working parents), and financial

stressors have had many living in what appears to be a chaotic world. Adding a child diagnosed with sensory processing disorder to the situation could alter what balance families were able to find in current society. The “demands, expectations, and weight felt by these families leave very little time to organize and find balance,” the occupational therapist explained.

Theme 4 provided details and data related directly to the children as to the ongoing interruptions and struggles, existing social relationships, and the view of what a day in the life looked like in regards to a child with SPD; as reported in the semi-structured phone conversations, or responses to email, by the occupational therapist and the parents. The categories developed from common themes as presented by all those that participated.

The occupational therapist commented that interruptions and struggles were ongoing and would be a permanent way of life. She stated that

...as children continued to grow and their environments and settings were continually altered due to time and age, so do their struggles. As environments change, so do the struggles and it required an entirely new group of tools in their tool belts to cope as effectively as possible, and just as this changes for the children . . . it continued to change for their parents also. It brought a whole new meaning to the phrase ‘the only thing that was constant was change’ for these parents.

All parent participants seemed to reiterate the same theme, as one parent commented, “Just as I think I have something figured out, and our daily schedule was

intact . . . a schedule would get changed, a new setting developed, or all of the above, and I was simply back at square one trying to figure everything out.”

A Child With SPD

Interruptions and Struggles. The parents and occupational therapists consistently reported that children diagnosed with sensory processing disorder suffered and struggled in various ways and on multiple levels. “The diagnosis was so multi-faceted, and no 2 children truly look-alike, or at least the symptomology and struggles vary from child to child,” stated the occupational therapist. “Although as a therapist there were some ‘overall’ themes to the diagnosis, how one child reacted to a setting, situation, or treatment could look completely different for another child.”

Considering sensory processing disorder was also a multi-leveled diagnosis, but children tend to be as smart, or smarter than their peers, children struggled in traditional settings.

My clients usually ended up with me, not because parents think they have SPD. Most do not even know what it is. They ended up here [at occupational therapy] because children tested very high in intelligence, there were behavioral issues that were typically not defined by other diagnoses, and parents were at their wits end with a school district. After you have experienced an 8 hour meltdown, or one that ends by a child eventually falling asleep only to wake the next morning and continued with the meltdown (that literally can last days), only then could you begin to understand the magnitude of struggle and interruption a child suffers with a diagnosis of SPD. The struggles and interruptions were also dependent on age, and gender to a degree.

Daily interruptions and struggles were discussed by the parent participants. Although the interruptions were consistent and considered daily by all 4 parents, the degree and the specific types of interruptions varied. Parent one clearly listed the most common interruptions and struggles as poor sleep, getting dressed, brushing teeth, anxiety from routine alterations, and increased negative behaviors in the late afternoon and early evening hours. Parent 2 stated that the most common interruptions and struggles for her child were when there is a change in routine, on-going 'fights' over food choices, getting dressed, and leaving the house. Repeating similar and same types of interruptions and struggles, parent 3 expressed that most common for her child was when a change in routine occurs, increasing anxiety in multiple settings, and dealing with the morning chaos of getting ready and out the door. Parent 4 explained the biggest interruptions and struggles to her child's day stems from anxiety in social settings and multiple environmental triggers including certain smells in the kitchen, textures and tastes of foods, and a severely limited diet that has led to health concerns. All parents also stated that the interruptions and struggles not only occurred on a daily basis, but also happened multiple times daily.

Social relationships. The parents reported consistently that a strain on various social relationships typically coincided with a child diagnosed with sensory processing disorder. The occupational therapist stated that the

...strain on social relationships may come between parent-child, child-sibling, teacher-child, teacher-parent, peers-child, and more. Additional strained relationships could develop between parents, or even between the parents of the other child and other caretakers, or adults. We did not, nor did our children, live

in a bubble, so their behavior that coincided with the diagnosis of SPD impacted many, in particular when there is a lack of understanding. The lack of understanding was usually seen from the academic setting, so not only did the children not thrive, but parents become frustrated and overwhelmed just like their children.

Parents 1, 2, 3, and 4, all agreed that in a social setting, their child diagnosed with sensory processing disorder stood out, and usually not in a 'positive light.' The child of parent one was the youngest among the parents and she did comment that he "probably did not have as much experience as other children in social settings due to his young age, but I was concerned for his ability to develop deep and substantial relationships in the future." Parent 2 explained that her child was "unable to do all the other activities, and go all the other places her peers go. It was simply too overwhelming." Parent 3 reiterated parent 2 concerns. Parent 3 was concerned over on-going 'isolation and loneliness due to a lack of ability to fit into traditional social settings, and it was so overwhelming for her child." In addition, social settings of every sort became difficult for all, as the common response was that, "he looks normal," but then the misunderstanding as to why the child did not integrate into group settings like other children remained misunderstood. Parent 4 continued and stated, "My son was so misunderstood!" Parent 4 also stated that the on-going concern in public settings was so stressful for all, and avoidance was now being used as a coping mechanism. All the words or statements varied in exact verbiage, the overall theme and categories showed an extremely similar overlap.

A Day In The Life. A day in the life of child diagnosed with sensory processing disorder could and often was exhausting, frustrating, and overwhelming. For most

children diagnosed with SPD, waking up began the process of being overwhelmed. Prior to getting out of bed, a child with sensory processing disorder was already thinking about all the items they typically struggled with, various settings that could come their way, and although if younger cannot always verbalize . . . struggled with knowing that ‘their filter is broken.’

All parents reported that the experience of over-stimulation presented obvious difficulties for parent and child alike. The struggles could appear to be what looked like a mild temper tantrum to an ‘all-in’ meltdown that could last for hours. They could be fidgety, appear nervous, or even ‘tuned-out’ from the setting (Davies et al., 2009).

The occupational therapist explained that children diagnosed with SPD “typically struggle with and had lower self-esteem and lower self-confidence.” A day in the life of a child diagnosed with sensory processing disorder also impacted those around them. This could lead to multiple situations that provided a sense of stress and anxiety for both the child and parents, and even the siblings if applicable. Sensory processing disorder remained a large umbrella term, and encompassed multiple struggles and interruptions. For most this began in the morning. Reported by most of the parents, the occupational therapist explained,

...most children began with struggles right out of the gate, like as soon as they wake. The battles of getting a child to brush their teeth or hair, dressing, eat specific breakfast foods, and get out the door on a schedule was really beyond for most. It was to the point where some parents I know have quit jobs because it just became too overwhelming for all involved.

A day in the life of a child with sensory processing disorder

may also vary and partially be dependent on their support system. The better a parent understood the diagnosis and the specifics related to their child, mixed with a lot of patience, the easier the days would fair for the child. This was not to discount that there still could be ‘those days’ and also, some children were just more difficult to soothe, treat, and had a more difficult time regardless. Sensory processing disorder looked a little different for everyone, and there was no such thing as an ‘all or none’ fix for children diagnosed. What I can say was that the struggles are very real, they were consistent, they could be similar, and they were forever. As a child’s environment, expectations, and settings change, so did their needs, ability to adjust, and possibly more therapy to help.

All parents were in agreement that a day in the life from their child’s perspective was not easy. Children with sensory processing disorder could wake up overwhelmed and exhausted and it could be for the day, a month, or even years. Parent 4 explained that when your child’s “filter is broken, and they hear and smell everything, and taste and feel things so differently . . . they were going to be exhausted.” Terms and settings repeatedly highlighted by all parents included increased anxiety in social settings, feelings of being overwhelmed, being isolated, and frustrations of daily tasks that led to lower self-esteem. Parent 1 expressed concerns of her child “possibly never fitting in, and just being able to go with the flow like other children.” Parent 2 reiterated the same feelings as parent one and stated that her biggest fear was that her child “would never get to enjoy what we call a normal life. There were so many struggles associated with [the child’s] SPD, that [the child] lived in a state of being overwhelmed. Parent 3 also supported the above thoughts, and expressed her “concern for her child now and for [the child’s] future.” Parent 3

stated, “That my child lives in a constant state of stress with high levels of anxiety. A day in the life of a child diagnosed with SPD, although may vary from an outside view, remained difficult for the children struggling with diagnosis.

In summary, the 4 themes capture the challenging and chaotic daily experience of life with a child with SPD. These represent the child’s individual experience, family, school, and larger social systems where struggle, stress, and stigma are daily challenges.

Evidence of Trustworthiness

Considering the researcher was the primary instrument in a qualitative study, researcher bias was inevitable (Shenton, 2004). In addition, the qualitative design was utilized to collect in-depth data to enhance understanding, yet barriers to the study’s transferability remained limited. This was primarily due to the limited geographic reach of the researcher, and the difficulty in potential participants finding the time to spend talking or emailing their experiences.

To verify my interpretations, member checking of participants data was completed. Being able to reiterate the summarization of details and data collected to ensure its accuracy to the participants was an additional step to aid in this process. The member checking process consisted of the openness to return at any point for clarification if needed, and allowing the parents who were contacted after data review, and provided the opportunity to make adjustments if needed to understanding of the data analysis. Member checking was defined as seeking the perspectives of members regarding the accuracy of any and all data, descriptions, and interpretations (Richards, 2003). When complete and a feeling of saturation of data and its accuracy was obtained, it was determined to move forward with the data.

The dependability and confirmability of the data were maximized during the data collection and analysis process. Interviews were taped, and copious notes were taken to insure the accuracy of the data gathering process.

In addition, Shenton (2004) discussed the importance of researcher credibility for qualitative research, as the researcher is the primary instrument for data collection. The researcher had 15 years working with children with sensory processing disorder, of which more than 4 years was in a therapeutic circumstance. The researcher also was the facilitator of a parent support group for more than a year, for parents with children with sensory processing disorder, and has provided educational presentations regarding sensory processing disorder in an academic setting to K12 faculty.

This study explored and examined the experiences of an occupational therapist and parents of children with sensory processing disorder. The one occupational therapist and the 4 parents who participated in a semi-structured phone conversation, or email responses, and conveyed their experiences, thoughts, and opinions regarding the impact of SPD on their child's social relationships and school performance, as well as the impact on families living with children diagnosed with SPD. Significant statements were expressed by all participants regarding the experiences associated with a child diagnosed with sensory processing disorder.

Themes explored within this study were inclusive included: family dynamics, support impact, emotion and balance, and simply the child with SPD. They shared experiences from all participants' and uncovered important and detailed data. In answer to the first research question, the results of the thematic analysis revealed that despite the diagnoses unique and changing manifestations, there was a common experience of the

children's general lack of ability to connect across and within different settings; i.e., the family, school, and other social settings. A child may struggle with many sensory inputs – loud noises, temperature of the setting (too warm or too cold), the number of people in the setting, light (not enough or too much light) – but the results showed a consensus among parents and the occupational therapist that the “overwhelm” from their environment interrupts, inhibits, and breaks down the child's ability to communicate, meet behavioral expectations, and act age appropriately across multiple settings.

According to the results, the parents were in agreement that the challenges within the family structure with, for, and because of their child included the family as a unit, sibling-to-sibling relationships, and parent-child relationships. This was made more complicated depending on the family structure, and if other siblings perhaps also had a diagnosis. The parents revealed that it is multi-layered, “and just when you feel you have something figured out, whether a setting or situation, the environment changes again and [they] are back are square one.” With the consistent changes in an environment, age of the child, or settings they are exposed, the challenges create a chaotic and confusing world. When the child's attention is focused on what is new, how to handle, or even how to remove themselves from a particular setting, social cues may often be missed, overlooked, or misunderstood completely.

The results also revealed that a school setting provides some of the most difficult challenges. The parents conveyed that the school district, and specifically teachers, are not educated about SPD and revealed that they felt that teachers ‘had no idea how to appropriately provide needed accommodations for [their] child.’ Challenges also existed directly for the child to handle environments that are typically overwhelming. Because

they can be socially awkward, ‘they tend to suffer at the hands of the class bully.’ Homeschooling has become a popular choice, as it helps to control for some of the additional challenges that exist in a traditional classroom, and provides the child diagnosed with SPD an opportunity to concentrate on actual learning.

In answer to the second research question regarding the experience of families living with children that are diagnosed with sensory processing disorder, the results of this study indicated the common themes, such as transitions, missed events, and family conflicts. A major struggle within this community were transitions, and when trying to move the family to needed activities and responsibilities, and the child diagnosed with SPD is unable to transition, the struggle is very real, meetings and appointments are often missed, and being left out in future invitations is a constant within this community. Missed events, although common, is not even the most difficult struggles, but clouded memories of events dampened by an SPD meltdown pervaded all of the recollections; e.g., family accusations and judgements from lack of understanding, and a consistent removal of the SPD child, or the family leaving an event early due to social or behavioral inappropriate actions.

In addition, the occupational therapist and the parents discussed conflicts that developed between parents because of their SPD child. The OT stated that it is consistently the ‘same parent that partakes in therapy’ for the child, and data showed that the parents reported having ‘very different viewpoints and strategies’ based on who was the primary caretaker, who was more involved in the therapeutic process, and who was the more removed parent. The differences not only wreaked havoc on the family paradigm, but led to a divorce also.

In sum, the results of this study present a rich and poignant representation of the life of families with a child diagnosed with SPD. Chapter 5 presents the results in relation to prior literature so that meaningful conclusions are identified and presented. In addition, possible challenges to current data and the importance of adding to current literature are explored. Lastly, the direction for future research and the possibility of advocacy and intervention are examined.

Chapter 5: Discussion, Conclusions, and Recommendations

This exploratory case study was conducted to help identify and explain the experiences of an occupational therapist and parents of children with SPD. The rationale for such a design is supported in the scientific community and now is a leading methodological approach (McBride & Schostak, 2008). Maxwell (2005) noted that it is this approach that allows a researcher to focus on a sole target group when needed. Chapter 5 provides a summary of the results that developed from the occupational therapist and the four parental, semi-structured phone conversations, as well as how the findings of the study can be applicable to the questions of the research.

In this chapter, I will also revisit the literature review completed in Chapter 2 to provide an update on current research that only became available during this study. This chapter will also provide elements of the basic qualitative design and the thematic analytic process, express possible limitations related to the study, and interject potential thoughts for associated future study. Chapter 5 is designed to guide the readers through the interpretation of the data, provide conclusions specific to the study, and serve as a reference for future scholarship.

Interpretation of the Findings

The study was a basic qualitative design based on an exploratory study from an advocacy perspective. The design of the study was developed to examine commonalities of children diagnosed with SPD and to provide detailed thought from the children's occupational therapist and their parents/ caregivers. Using qualitative methodology allows a subject to be viewed in depth. This was completed via a thorough description of the social phenomena, and aided in theory development (Casey et al., 2013; Cope, 2014;

Strauss & Corbin, 1990). A basic design was appropriate for this exploratory study, as this phenomena had not yet been explored. I established direction and understanding to the development of theory related to social phenomena of SPD.

The first theme developed out of the data led to discussions that surrounded family dynamics with at least one child diagnosed with SPD within the family unit. The occupational therapist and the parents in this study were all impacted by the struggles associated with caring for a child diagnosed with SPD. A child with SPD demands a structured schedule to aid with success in various areas of life, and being able to revolve life around this schedule posed considerable challenges to the families involved. An SPD child is faced with massive challenges when transitioning which leads to ongoing interference when trying to meet demands of timed events. A parent getting to work on time and getting the child to brush his or her hair or teeth creates meltdowns and makes the child late for school more times than not. Helping siblings meet appointment times and expectations are usually and abruptly interrupted by the SPD sibling. As the stress increases from repeated struggles, parents reported having conflicts between their spouse that may or may not have even been related to the source of the struggle. When the challenges are ongoing, and numerous, the occupational therapist stated, "losing sight of the real struggle is easy." In addition, the occupational therapist and parents stated that it can be a struggle to continue loving the child through the diagnosis when the parent knows that the challenges are always going to be there, and they are exhausted from meeting the demands of life with a special needs child. This aligns with prior studies wherein authors discussed the unique set of sensory symptoms displayed by the children

diagnosed with SPD and the dynamics that result (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009; Parham, 1998).

Having a child diagnosed with SPD presented significant challenges and commanded the need for support. The second theme encompassing both the need for, and sometimes the lack of awareness for support, was reported as critical to positively impacting the child with SPD and his or her success in various settings. Parents stated that occupational therapy “was priceless,” where support in an academic setting remained a challenge due to a lack of knowledge, training, and tools. Additional services were remanded by the child’s needs and included areas such as speech therapy, psychological support, therapeutic staff support, and various forms of home support. The occupational therapist referred to herself as “one piece to the puzzle” to aid in the child’s success. Miller (2013) explained that SPD is both multilayered and multifaceted; there are definitive physiological differences between children who are and are not diagnosed with SPD, rendering challenges to meeting of milestones for SPD children (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009). This supports the demand for social support from various avenues.

The third theme that evolved from the data was related directly to the areas of emotion and balance. The occupational therapist and the parents stated that their daily lives were negatively impacted by feelings of guilt and added stress associated with their SPD child and that the struggle to obtain, then maintain, a sense of balance within the family structure seemed an impossibility. The parents agreed that the challenges of SPD are on-going because a child continues to age, creating different challenges. Settings continue to alter day-to-day and year-to-year, creating a constant cycle of starting “at

square one.” These finding aligned with multiple authors as they described a child diagnosed with SPD as a child who ‘does not fit in easily’ (Ayers, 1979, 2005; Kraus, 2001; Miller et al., 2009). With traditional living entirely removed from the family equation, emotion and balance were considered a consistent struggle.

In Theme 4, the occupational therapist and the parents reported that their child diagnosed with SPD is negatively impacted with daily struggles and interruptions and poor social relationships. Although there are overall themes for children diagnosed with SPD, under a metaphorical microscope, SPD remains an umbrella term, and no two children and their challenges look identical. Transitioning, environmental settings, lack of routine, textures, tastes, sounds, and more can all set the backdrop for an SPD child that creates pandemonium. Miller et al. (2007) identified common red flags. A brief review of the common struggles and interruptions for an SPD child does not encompass the entirety and brevity of many additional challenges, as explained by the multiple subgroups, SMD, SBMD, SDD (Collier, 2008; Kraus, 2001; Miller, 2012).

Limitations of the Study

There were multiple limitations to this study that future studies could improve upon. First, the sample turned out to be homogenous, as it was all Caucasi mothers with children diagnosed with SPD who responded to the initial invitation to participate; the occupational therapist was also female. No input from fathers or other male figures were included. No minority families were included. All were receiving services from the occupational therapist, and all were from a rural area of Northeast Pennsylvania. Another limiting factor to the study included my relocation during the middle of the study and the

original design that included face-to-face interviews to collect the data. Without the face-to-face contact, only limited emotion supporting the data was available.

Recommendations

Future research studies are encouraged to increase the size and diversity of the sample if possible, to explore if demographics and ethnic variations revealed variations in the day-to-day experiences and struggles of families with and SPD child. It is also recommended that fathers or male guardian figures be included. In addition, perspective of experiences from multiple occupational therapists would be recommended. Also, future studies should encompass a broader area in which to obtain participants in order to aid with transferability of the study.

Implications for Social Change

This study was intended to serve as a catalyst to encourage social change regarding the lived experiences of children with sensory processing disorder and their families. Regarding sensory processing disorder, it may prove most beneficial for those with diagnosed children to be able to receive needed support, both personally and professionally. This remains a current obstacle due to lack of awareness and understanding from family and friends, and lack of recognition on a diagnostic level for treatment. Without further action, parents are likely to remain feeling frustrated, overwhelmed, and alone, while professionals are likely to continue to feel parents pangs when trying to provide needed services for the benefit of the diagnosed child and their families.

By expanding the knowledge base that reflects the experiences of children with sensory processing disorder, parents will have the opportunity to understand that they are

not alone on so many of the commonalities (struggles, frustrations, rigidity) experienced, be provided perspective and direction from the occupational therapist, and support the current movement that encompasses local community and beyond, and inevitably help with the addition of sensory processing disorder to the next DSM.

Common themes that developed from the data showed that the commonalities were experienced by children with sensory processing disorder and their families. Four vivid themes developed from the data. The first, and clearly stated theme from both the occupational therapist and the parents was that the family dynamics and structure were massively impacted, and interruptions were a way life. The second theme regarded the ability to successfully seek out and obtain support proved difficult, and was not typically through what would be considered mainstream routes. Next, the families strived, although not often achieved, for life balance. They hoped that the balance would come in multiple forms including some peaceful moments that would allow their diagnosed child to 'simply be a child,' and balance for their demanding schedules, and an ability to meet the expectations of maintaining husband/ wife relationships, career expectations, and inevitably 'having a life.' Lastly, a true overview as to what a day-in-the-life looks like for the child diagnosed with SPD. Explanations of the consistent interruptions and struggles were expressed.

Conclusion

This basic qualitative designed study highlighted the lived experiences of children with sensory processing disorder and their families. As an exploratory study, the design allotted for a range of flexibility that provided an in depth view of the social phenomena from an advocacy perspective. The developed themes, and then categories

that developed left the researcher with a deep sense of connectedness. What profoundly emerged from the analysis of the data was that the children diagnosed with sensory processing disorder, struggle similarly, and the parents of the diagnosed children are doing the same, encompassing feeling alone, frustrated, and overwhelmed. A mutual respect for all involved in the day-to-day processes that help provide children diagnosed with sensory processing disorder the structure, patience, and understanding required to not just survive, but thrive through their days.

The findings of this study revealed that the family dynamics were substantially impacted. Children struggled with day-to-day tasks that other children do not, parents struggled with the rigidity and patience required with their children and each other, and if a sibling was involved, getting ‘shafted’ due to the time, focus, and energy required for the diagnosed sibling was a common experience. The occupational therapist felt that trying to maintain a positive family dynamic with a diagnosed child was exhausting to the entire family unit. Finding, having and continuing support in multiple settings for the child and their family was declared critical to provide help for the child, and needed education and aid for the families of the diagnosed child. Common, as stated by the parents, was a lack of understanding of the diagnosis in an academic setting, which intern drove the consistent need for support in other realms of life. Sensory processing disorder is an umbrella term, complicating the ability to understand and educate yourself as a parent.

The multifaceted and multileveled diagnosis provided ongoing frustrations for the parents because just as they felt they had ‘mastered’ a struggle, the child’s age, environment, and/or needs changed, and starting from square one over and over in life is

beyond any typical term associated with being an ‘exhausted parent.’ With unmeasurable stress levels within the family unit, finding balance daily, or even weekly proved to be yet just another daunting task to add to the ‘list of goals that will never be.’ Celebrating small victories, accomplishments, and sometimes the fact that we are not having to accomplish something, which according to occupational therapist is a whole other level of achievement for the parents. So often over-looked, but critical to everyone is the ability to ‘not do something, be somewhere, or keep to a schedule’ is the true accomplishment in this setting.

Generally the participants of the study accepted the challenges, educated themselves, and sought out support for their children diagnosed with SPD and the families. They did not complain, although there was a comment in regards to the fact that there ‘simply was not time to complain.’ The participants were honest, and spoke with their soul when conveying the struggles that exist with children diagnosed with SPD. Each family was doing their best to provide needed tools for their diagnosed child, while trying to balance the needs of their family unit. Their devotion to the family, their children, and their demands is to be commended.

Finally, this study was a basic qualitative design. It was designed as an exploratory study from an advocacy perspective. Due to the flexibility allotted with the design, the participants (n=5) were able to provide a rich, detailed perspective of the experiences of children diagnosed with sensory processing disorder and their families. The study offered a copious vignette of daily lives, daily tasks, and the struggles and expectations of the experiences of a sensory processing diagnosed child and their family. Lastly, the parents that shared their experiences are providing other parents what they felt

most important . . . that without support from the APA and academic settings, you are not alone, and other support is available.

References

- American Psychiatric Association. (year). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC: Author.
- Anzalone, M. E., Lane, S. J., Cermak, S. A., & Osten, E. T. (2007). Concept evolution in sensory integration: A proposed nosology for diagnosis. *The American Journal of Occupational Therapy, 61*(2), 135–140.
- Ayres, A. (1979). *Sensory integration and the child*. Los Angeles, CA: Western Psychological Services.
- Ayres, A. (1989). *Sensory Integration and Praxis Tests*.
- Ayres, A. (2005). *Sensory integration and the child*. (25th anniversary ed). Los Angeles, CA: Western Psychological Services.
- Brown, C. E., & Dunn, W. (2002). *Adolescent/Adult Sensory Profile*.
- Burke-Harris, N. (2014). *Nadine Burke-Harris: How childhood trauma affects health across a lifetime* [Video file]. Retrieved from https://www.ted.com/talks/nadine_burke_harris_how_childhood_trauma_affects_health_across_a_lifetime
- Byrne, M. (2009). Sensory processing disorder: Any of a nurse practitioner's business? *Journal of the Academy of Nurse Practitioners, 21*, 314-321.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 77*-101. doi: 10.1191/1478088706qp063oa

- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. Thousand Oaks, CA: Sage
- Caelli, K., Ray, L., & Mill, J. (2003). 'Clear as mud': Toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods*, 2(2). Article 1. Retrieved from http://www.ualberta.ca/~iiqm/backissues/2_2/html/caellietal.htm
- Cantu, C. O. (2002). Self-regulation and stress management. *The Exceptional Parent* 32 (II) , 4-47.
- Cermak, S., & Henderson, A. (1990). The efficacy of sensory integration procedures. *Sensory. Integration Quarterly*, 1-23.
- Collier, N. "Sensory Processing Disorder (SPD) Fundamentals for Professional Counselors." Texas Counseling Association Professional Growth Conference [Conference]. Houston. November 2008.
- Connelly, L. M. (2014). Ethical considerations in research studies. *MEDSURG Nursing*, 23(1), 54-55.
- Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher*, 18(4), 17-22.
- Cooper, S., & Endacott, R. (2007). Generic qualitative research: A design for qualitative research in emergency care? *Emergency Medicine Journal*, 24, 816-819. doi:10.1136/emj.2007.050641
- Cope, D. G. (2014). Methods and Meanings: Credibility and Trustworthiness of Qualitative Research. *Oncology Nursing Forum*, 41(1), 89-91. doi:10.1188/14.ONF.89-91
- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among the 5 traditions*. Thousand Oaks, CA: Sage.

- Davies, P., & Gavin, W. (2007). Validating the diagnosis of sensory processing disorders using EEG technology. *The American Journal of Occupational Therapy*, 61(2), 176 -189.
- Dawson, G., & Watling, R. (2000). Interventions to facilitate auditory, visual, and motor integration in autism: A review of the evidence. *Journal of Autism and Developmental Disorders*, 30(5), 415 - 421.
- Densmore, R. (2009). Understanding regulation disorders of sensory processing in children: Management strategies for parents and professionals. *Canadian Journal of Psychiatry*, 54(9), 645 - 646.
- Dovydaityienė, M., Vaitiekutė, G., & Nasvytienė, D. (2013). Sensory processing and emotional and behavioral difficulties in children with autism. *Special Education*, (1), 20-31.
- Dunn, W., McIntosh, D. N., Miller, L., & Shyu, V. (2002). Sensory Profile.
- Dunn, W. (2007). Supporting children to participate successfully in everyday life by using sensory processing knowledge. *Infants & Young Children*, 20(2), 84-101.
- Engward, H. (2013). Understanding grounded theory. *Nursing Standard*, 28(7), 37-41.
- Erik, B. (2016). A reflexive exploration of 2 qualitative data coding techniques. *Journal of Methods and Measurement in the Social Sciences*, Vol 6, Iss 1, Pp 14 – 29 (2016), (1), 14. Doi:10.2458/jmm.v6i1.18772
- Fuentes, C., Mostofsky, S., & Bastian, A. (2011). No proprioceptive deficits in autism despite movement-related sensory and execution impairments. *Journal of Autism & Developmental Disorders*, 41(10), 1352-1361.

- Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory*. Aldine de Gruyter, Hawthorne, NY.
- Goldson, E. (2001). Sensory modulation dysfunction in children with attention-deficit-hyperactivity disorder. *Developmental Medicine & Child Neurology*, *43*, 399 - 406.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82.
DOI: 10.1177/1525822X05279903
- Hoepfl, MC (1997). Choosing qualitative research: A primer for technology education researchers. *Journal of Technology Education*, *9*(1). Retrieved from <http://scholar.lib.vt.edu/ejournals/JTE/v9n1/hoepfl.html>
- Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative casestudy research. *Nurse Researcher*, *20*(4), 12-17.
- Hoyt, W., & Bhati, K. (2007). Principles and practices: An empirical examination of qualitative research in the Journal of Counseling Psychology. *Journal of Counseling Psychology*, *54*, 201-210. doi:10.1037/0022-0167.54.2.201.
- Kranowitz, C. S. (1998) *The Out of Sync Child: Recognizing and Coping with Sensory Integration Dysfunction*. New York: The Berkley Publishing Group.
- Kraus, E. (2001). The out-of-sync child: Recognizing and coping with sensory integration dysfunction. *Australian Occupational Therapy Journal*, *48*(2), 99.
- Leitner, Y. (2014) "The Co-occurrence of Autism and Attention Deficit Hyperactivity Disorder in Children-What Do We Know?" *Frontiers in Human Neuroscience* *8*: 1-7.

- Mangeot, S.D., Miller, L.J., McIntosh, D.N., McGrath-Clarke, J., Simon, J., Hagerman, R., & Maxwell, J. A. (2005). *Qualitative Research Design: An Interactive Approach* (2nd Ed.). Thousand Oaks, CA: Sage.
- McBride, R. & Schostak, J. (2008). *An introduction to qualitative research*. Retrieved from <http://www.enquirylearning.net/ELU/Issues/Research/Res1Cont.html>
- Miller, L.J. (2013). Sensory Processing Disorder. Presented at the Sensory Processing Disorder National Conference. Retrieved October 21, 2013. Charlotte, NC.
- Miller, L. J. (2012). Star Foundation. What is SPD? Retrieved from: <http://spdstar.org/what-is-spd/>
- Miller, L.J., Anzalone, M.E., Lane, S.J., Cermak, S.A., & Osten, E.T. (2007). Concept evolution in sensory integration: A proposed nosology for diagnosis. *The American Journal of Occupational Therapy*, 61(2), 135 - 140.
- Miller, L. J., Coll, J. R., & Schoen, S. A. (2007). A randomized controlled pilot study of the effectiveness of occupational therapy for children with sensory modulation disorder. *The American Journal of Occupational Therapy*, 61(2), 228-238.
- Miller, L.J., Nielsen, D.M., Schoen, S.A., Brett-Green, B.A. (2009). Perspectives on sensory processing disorder: a call for translational research. *Frontiers in Integrative Neuroscience*, 3(22), 1 - 12.
- Miller, L.J., Schoen, S.A., James, K., & Schaaf, R.C. (2007). Lessons learned: A pilot study on occupational therapy effectiveness for children with sensory modulation disorder. *American Journal of Occupational Therapy*, 61, 161 - 169.

- Morrow, S. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*, 250-260. doi:10.1037/0022-0167.52.2.250.
- Mukherjee P., Berman J., Chung S., Hess C., Henry R. (2008). Diffusion tensor MR imaging and fiber tractography: theoretic underpinnings. *American Journal of Neuroradiology, 29*, 632–641.
- Muro, C.A. (2011). Sensory Processing Disorders and ADHD Subtypes (Master Thesis). Retrieved from ERIC and Dissertations. (1494467).
- Orloff, S. (2007). Sensory processing disorders: Fact or fiction?. *Exceptional Parent, 37*(9), 45.
- Owen, J. P., Marco, E. J., Desai, S., 4ie, E., Harris, J., Hill, S.,... Mukherjee, P. (2013). Abnormal white matter microstructure in children with sensory processing disorders. *NeuroImage : Clinical, 2*, 844–853.
- Parham, L. (1998). The relationship of sensory integrative development to achievement in elementary students: 4-year longitudinal patterns. *Occupational therapy journal of research, 18*(3), 105-127.
- Parham, L., Ecker, C., Kuhanek, H., Henry, D. A., & Glennon, T. (2007). Sensory Processing Measure.
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, Ca: Sage.
- Pfeiffer, B.A., Koenig, K., Kinnealay, M., Sheppard, M., Henderson, L. (2011). Effectiveness of

sensory integration interventions in children with autism spectrum disorders: A pilot study. *American Journal of Occupational Therapy*, 65(1), 76 - 85.

Prestia, K. (2004). Incorporate Sensory Activities and Choices Into the Classroom. *Intervention in School & Clinic*, 39(3), 172-175.

Reeves, G. and Cermak, S. (2002). Disorders of praxis. In Bundy, Lane, and Murray (Eds.),

Sensory integration: Theory and practice. Philadelphia: F.A. Davis Company.

Richards, K. (2003). Qualitative inquiry in TESOL. Basingstoke, UK: Palgrave Macmillan.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8.

Shenton, A. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22, 63 – 75.

Silverstein, L., Auerbach, C., & Levant, R. (2006). Using qualitative research to strengthen clinical practice. *Professional Psychology: Research and Practice*, 37, 351-358. doi:10.1037/0735-7028.37.4.35.

Smith, P. (2008). Qualitative and Quantitative Research. *Research Starters Education (Online Edition)*.

Smith, T. (2015). Qualitative and quantitative research. *Research Starters: Education (Online Edition)*.

Stein, B. (2013). Multisensory integration. Presented at the Sensory Processing Disorder National Conference. Retrieved October 21, 2013. Charlotte, NC.

- Strauss, A., & Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Second edition. Sage Publications, Newbury Park, CA.
- Tomchek, S., & Dunn, W. (2007). Sensory processing in children with and without autism: A comparative study using the short sensory profile. *American Journal of Occupational Therapy*, *61*, 190 - 200.
- Wampole, M.E., Kairys, J.C., Mitchell, E.P., Ankeny, M.L., Thakur, M.L., & Wickstrom, E. (2013). Consistent surgeon evaluations of 3-dimensional rendering of PET/CT scans of the abdomen of a patient with ductal pancreatic mass. *Plos ONE*, *8*(9), 1 - 9.

Appendix A: Informed Consent

Informed Consent

Melissa Scotch

Dissertation

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Project Description: *Dissertation*

CONSENT FORM

You are invited to take part in a research study regarding the experience of children with sensory processing disorder. The researcher is inviting an occupational therapist and parents/ caregivers of children with sensory processing disorder receiving services from the same occupational therapist. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Melissa Scotch, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to provide further understanding in the area of sensory processing disorder.

Procedures:

If you agree to be in this study, you will be asked to:

- Answer open-ended questions regarding the experiences of children diagnosed with sensory processing disorder.
- Questions will be answered from both an occupational therapist’s perspective and from the parents of children diagnosed with sensory processing disorder.

Participants will not be rushed and provided as much time as necessary to answer the open-ended questions whole-heartedly and truthfully.

Once the questions are distributed, the answers will be collected once, but followup for clarity will be executed.

Here are some sample questions:

1. Can you share your experiences as to how you feel the school districts are accommodating children with SPD?
2. From your professional experience, what do you feel is the impact of children's social relationships and school performance that are diagnosed with SPD?
3. In your professional experience, what is the impact on families living with children diagnosed with SPD?
4. Can you please describe two experiences that stand out more than any other experiences with your child? Explain the experiences and what tools as a parent you utilized to help you child.
5. Was your child ever diagnosed with a different diagnosis that eventually you found was incorrect, prior to receiving a sensory processing disorder diagnosis?
6. Once receiving a diagnosis of sensory processing disorder, was it difficult to find/ receive services specific to this diagnosis.

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one at Wayne Memorial Rehabilitation Services will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as stress or becoming upset. Being in this study would not pose risk to your safety or wellbeing.

Benefits of the study will include but are not limited to highlighting the importance of sensory processing disorder being recognized as a stand-alone diagnosis, bringing awareness to those that work with these children in social settings, and to develop understanding of the disorder on a much broader spectrum.

Payment:

There will be no payment or gifts provided in this study, however a follow-up thank you via email communication will be sent to all participants.

Privacy:

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by providing anonymity to participants. In addition, storage of all data will be placed on an external drive and will be password protected. Any hard copies of material will be destroyed after scanning and moving to the external drive. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via phone at ***.916.0681 or by email at

melissa.*****@waldenu.edu. If you want to speak privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is ***-312-1210. Walden University's approval number for this study is #05-31-16-0172240 and it expires on May 30th, 2017.

Please print or save this consent form for your records.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Only include the signature section below if using paper consent forms.

Printed Name of Participant _____

Date of consent _____

Participant's Signature _____

Researcher's Signature _____

Appendix B: Demographic/ Parent Contact Information

Parent Contact Information

*This information is to be utilized if and only further contact, questions, or clarification is needed on any questions pertaining the Parent/ Caregiver open-ended questions. Thank you in advance for any and all time, helping us advance research and knowledge regarding Sensory Processing Disorder.

Name_____

Address_____

Phone_____

Email_____

Child's age and gender_____

*if you have any further questions or concerns, please feel free to contact me directly at mscotch_****@hotmail.com

Appendix C: Occupational Therapist Open-Ended Questions

7. How many years have you been working with children diagnosed with SPD?
8. Have you seen an increase in the number of children diagnosed with SPD?
9. Who diagnoses SPD?
10. What tools do you utilize to identify SPD?
11. What would be your estimation of children with co-morbid diagnoses with SPD and what percentage of children have a stand-alone diagnosis of SPD?
12. What would be your estimation of children with co-morbid diagnoses with SPD?
13. SPD is an umbrella term for many groups and sub-groups of children with SPD; what do you see most often? What group or possible sub-group do you treat most?
14. Can you identify what you feel are the most common red flags to help identify SPD in: Infants? Preschoolers? Grade-schoolers? Adolescents and Adults?
15. Current research is showing 1 in 20 children struggle with sensory issues that impact them daily with even some research showing higher statistics as much as 1 and 6 children struggling; do you agree? Will you elaborate regarding thoughts as to current statistics?
16. What do the families of the children you work with state are the most difficult daily challenges?
17. How does SPD impact of the families most?
18. Do you provide families with tools and resources to utilize at home? Which seem to provide a positive impact (families prefer)?
19. How long do families of children with SPD usually seek treatment?

20. Do you offer family therapy that includes family members directly in treatment plan of children with SPD? Please explain.
21. What seems to be the biggest complaints for parents regarding their child's school system?
22. Can you share your experiences as to how you feel the school districts are accommodating children with SPD?
23. From your professional experience, what do you feel is the impact of children's social relationships and school performance that are diagnosed with SPD?
24. In your professional experience, what is the impact on families living with children diagnosed with SPD?
25. Can you please discuss your thoughts regarding SPD not being added to the DSM-V? And do you feel this impacts needed services for children with SPD?
26. Please discuss, highlight, or provide any additional thoughts or data you feel relevant or important to future study regarding SPD.

Appendix D: Parental Open-Ended Questions

Diagnosis of children with SPD. Think about recent experiences with your child that is diagnosed with sensory processing disorder, or perhaps some times that have stood out in the past.

1. Can you please describe two experiences that stand out more than any other experiences with your child? Explain the experiences and what tools as a parent you utilized to help you child.
2. Was your child ever diagnosed with a different diagnosis that eventually you found was incorrect, prior to receiving a sensory processing disorder diagnosis?
3. Once receiving a diagnosis of sensory processing disorder, was it difficult to find/ receive services specific to this diagnosis.

In looking back at your experiences with your child with sensory processing disorder...

1. How often do you feel SPD issues interrupt your daily lives (daily, weekly, monthly), and how many times within the choice you circled (i.e. if you circled daily, you may say 4X)?
2. If your child has multiple diagnoses, how important do you feel that it is to deal with the sensory issues/ struggles first?
3. What are some of your positive experiences your child has due to their SPD? Please explain.

Children with SPD and Social Relationships

1. What do you feel is the biggest struggle for a child with SPD regarding social relationships?

2. If you could name the most effective tool to help a child with SPD in a social setting, what would it be and why?
3. What is the negative impact on the child with SPD if they struggle with social relationships?

Children with SPD and the Academic Experience

1. How has your overall experience within an academic setting been pertaining to meeting the needs of your child with SPD?
2. Are behavioral struggles or learning a bigger concern in an academic setting?
3. Do you feel that administration, teachers, and staff have a true understanding of sensory processing disorder in order to effectively aid children with SPD in an academic setting? How does this impact your child's academic experience? Please explain.

Children with SPD and their Families. Based on your experience of living with your child with SPD:

1. What is the most difficult issue you face? Please describe in detail for full understanding.
2. Is there another difficult issue you face as a family? Please explain in detail for full understanding.
3. What are the most common interruptions in a typical day for you (and sibling if applicable) regarding your child with SPD?
4. What is THE biggest challenge for you as a parent of a child with SPD?
5. What is the biggest challenge for their siblings? (if applicable)
6. What is the role of occupational therapy regarding support for your child with SPD?

7. What other interventions (therapy, training, programs) are helpful to you as parents of a child with SPD?
8. Do you feel you have a true understanding of the diagnosis? And what could be approached differently, or better to provide you with needed SPD educational information?

Please take an additional space to express additional important direction or information you would like to share regarding your child with SPD.