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Caregiver Perspective on Sensory Diet and Therapeutic Listening for Children with Autism Spectrum Disorder and/or Sensory Processing Disorder

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#### Abstract

Due to the high prevalence of Autism Spectrum Disorder (ASD) and Sensory Processing Disorder (SPD), there is a high demand for more research on effective interventions in order to improve quality of life and engagement in meaningful occupations for individuals with ASD and/or SPD. Sensory Diet (SD) and Therapeutic Listening © (TL) are interventions commonly utilized with individuals with ASD and/or SPD, however, there is limited research on their combined use. The purpose of this study is to determine the effectiveness of the combined occupational therapy (OT) interventions of SD and TL on the occupational performance of children with ASD and SPD. Four participant responses were obtained and analyzed to provide a caregiver perspective on how the combined interventions improved their child's occupational performance. Findings indicated that a TL and SD combined intervention resulted in improvement in three occupational areas: dressing, social participation, and participation in formal education. A positive correlation was identified between length and intensity of treatment and occupational improvement. These findings are consistent with previous research findings on the SD and TL as a combined intervention. This research provides insights and implications for future research on occupational therapy interventions for children with ASD and/or SPD.

# Keywords

Autism Spectrum Disorder (ASD), Asperger Syndrome (AS), Sensory Processing Disorder (SPD), Therapeutic Listening © (TL), Sensory Diet(s) (SD), Occupational Therapy (OT)

# Sensory Processing Disorder

Dr. A Jean Ayres (1972) first described sensory processing theory in the early 1970s to describe children who appeared to have problems processing and integrating sensory input (Critz, Blake, & Nogueira, 2015). Ayres created the theory of sensory integration (SI), which later led researchers to find that sensory processing disorder (SPD) is involved with neurological functioning and affects the brain's ability "to integrate the sensory input it receives from the sensory systems and turn the input into effective responses" (Critz et al. 2015, p. 710). Although a large amount of research has been dedicated to SPD since Ayers created the SI theory, this neurological disorder is still very difficult to diagnose, as it is still not an official mental condition according to the *Diagnostic and Statistical Manual-5* (Critz et al. 2015).

According to Engel-Yeger, Hardel-Nasser, and Gal (2011), "SPD encompass difficulties in registering and modulating sensory information and organizing sensory input to execute successful adaptive responses to situational demands. They lead to maladaptive behaviors and to difficulties in meaningful engagement in daily occupations" (p. 1771). SPD affects the way a person's brain organizes sensory input, which can influence their ability to appropriately adapt and regulate mood, maintain attention span, and function appropriately in social situations (Critz et al. 2015). Difficulties with sensory processing can also affect a person's behavioral regulation, motor performance, and participation in daily occupations (Ryckmana, Hilton, Rogers, & Pineda 2017).

#### Autism Spectrum Disorder

According to the Centers for Disease Control and Prevention [CDC] (2016), Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder which affects behavior, communication, and socialization. Children diagnosed with ASD can present a variety of symptoms, ranging both in severity and pervasiveness. Symptoms can include, but are not limited to deficits in social communication and interaction and restricted, repetitive behaviors or interests ("DSM-5 Criteria," 2018). The "DSM-5 Criteria" (2018) requires that in order to meet diagnostic criteria for ASD, these symptoms must present themselves in a child's early developmental period across multiple contexts and cause significant impairment in multiple areas of functioning. These areas of impairment can often lead to difficulties in social interactions, relationships, occupations, intelligence, language, and various forms of communication, including social, verbal, and nonverbal ("DSM-5 Criteria," 2018).

# Therapeutic Listening

Therapeutic Listening © (TL) is a sound-based intervention (SBI) that utilizes adapted music programs to treat SPD and other sensory-based disorders. The theory of sound-based intervention, created by Alfred Tomatis, is based on the idea that when an individual listens to certain frequencies of sound, the brain can retrain itself and create new pathways at the neural level (Gee, Devine, Werth, & Phan 2013). This can compensate for the existing dysfunction in the structure or pathways of the brain that are leading to the presenting impairments (Gee et al., 2013). Frick and Hacker (2001) stated that Sheila Frick created TL to combine SBI with traditional SI strategies by incorporating individually selected music that has been altered to maintain attention and promote listening skills (Bazyk, Cimino, Hayes, Goodman & Farrell, 2010). Clients who are prescribed TL by an occupational therapist will be given a home program that involves a variety of compact discs (CDs) with headphones. Commonly the client will listen to the CDs for up to 30 minutes, two times per day while engaging in a low stimulating task (Frick, 2006). Typical programs last between three and six months (Hall & Case-Smith, 2007). TL interventions used by occupational therapists aim to improve self-regulation in order to promote increased occupational engagement.

#### Sensory Diets

A sensory diet (SD) is an intervention comprised of activities and accommodations that are designed and implemented based on a child's unique sensory needs (Kelly, n.d.). Examples of activities that may be included in a SD could include: use of a weighted lap pad for proprioceptive input, oral stimulation from eating crunchy foods to promote alertness, or use of a swing to promote vestibular input (Hatch-Rasmussen, 1995). SDs are used to help a child with sensory needs achieve an optimal state and improve their occupational engagement (Kelly, n.d.). Rood (1962) suggested that the timing of which a sensory activity is applied is important, as the nervous system may only be impacted by that activity for a distinct period of time (as cited in Wilbarger & Wilbarger, 2002). Therefore, the important events of a child's day serve as a reference for when specific sensory activities should be implemented (Stackhouse, 2008). The ultimate goal of a SD is to improve the client's occupational performance using the context of their daily routine (Wilbarger & Wilbarger, 2002).

#### Background

One of the most common challenges for individuals with ASD is difficulty interpreting and processing sensory stimulation within the natural environment (Davis et al., 2017). Between 60 and 70 percent of children diagnosed with ASD will experience a variation of comorbid SPD (Davis et al., 2017). According to Jones et al. (2003), "the description of sensory modulation symptoms in persons with ASD is somewhat baffling as it is described both as a source of distress and anxiety as well as a source of fascination and interest" (as cited in Ben-Sasson et al. 2009, p. 1). Children with ASD often show symptoms of SPD, including sensory seeking, distractibility, and over or under-responsivity (Tomcheck, Huebner, & Dunn, 2014). "Together, these sensory processing deficits limit a child's ability to sustain attention, regulate arousal, and ultimately achieve and maintain an optimal range of performance for adaptation and learning" (Tomcheck et al. 2014, p. 1221).

According to SI theory, providing input to various sensory systems can help to decrease or eliminate sensory-based barriers to occupational participation. SD and TL are two interventions based upon SI theory that strive to reduce sensory-based barriers to occupational engagement. Previous studies show the positive outcomes and impacts of a combined TL and a SD intervention, however, little evidence exists that studies the effects of the two interventions combined. The only study at this point that utilizes both TL and SD to treat ASD and SPD was done by Hall & Case-Smith in 2007. This study involved ten children ranging in age from five to eleven years old. Results showed major behavioral improvement in addition to an average increase of 71 points on the Sensory Profile (Hall & Case-Smith 2007). Significant improvements were noted on the Visual Motor Integration assessment and Evaluation Tool of Children's Handwriting when comparing pre and post test scores. Caregiver observation logs showed reports of increased school performance and eye contact, as well as decreased tantrums, anxiety, and auditory hypersensitivity. This study supports the use of TL with SD as a combined occupational therapy (OT) intervention in elementary-age children and that the best outcomes can be achieved by combining TL with OT to promote the highest level of occupation participation (Hall & Case-Smith 2007).

Although these results support the efficacy of combining SD and TL strategies to improve the functional performance, there is very little additional research on this topic overall. Due to the large number of children that are affected by ASD and SPD and the lack of research in this treatment area, there is a significant need for further research to support this combined intervention approach. The current study was created to increase knowledge and evidence-based support of interventions for children with ASD and SPD. This study investigated caregiver perspectives on occupational performance outcomes for their children with the use of TL and SD treatment approach. The goal was to demonstrate further implications for use in the field of OT.

#### Methods

This study aimed to evaluated the perspective of caregivers of children with ASD and/or SPD who received combined treatments of TL and SD in the United States (US). The research question guiding this study is "What do caregivers of children with ASD and/or SPD perceive are the occupational performance and engagement outcomes related to their child having received combined SD and TL intervention?" In order to address this question, a uniform encrypted online survey was utilized to gather responses from caregivers across the United States. The survey was designed with feedback from three occupational therapists specializing in pediatrics in order to ensure content validity. The survey questions collected quantitative and qualitative data on goals, occupational performance, frequency and duration of each intervention, and caregiver perspectives. The 10 survey questions assessed the duration of treatment as well as a list of the occupational areas of difficulty for the respondent's child before and after receiving SD and TL as a combined treatment. The survey was open and accepted responses for 17 weeks. After 17 weeks of data collection, the survey was closed, and the data was analyzed. Transferability was ensured through the phenomenological design of this qualitative study, aiming to gather a human perspective on the phenomenon of combined TL and SD treatment. This uniform survey can be reused to repeat the study as needed, ensuring that this study meets dependability standards. The researchers used public emails to reach out to outpatient OT clinics, state-led occupational therapy associations, and caregiver support groups through social media in order to gain participants. To attract participants, social media posts and a flyer were utilized. A total of 50 responses were collected and of those responses 14 met inclusion criteria, but only four completed the entire survey. Only the completed surveys were analyzed and all other surveys were discarded. The inclusion criteria was comprised of the following:

- The survey participant must be a caregiver of a child between the ages of four and ten years old.
- The child must have received a medical diagnosis of Autism, ASD, Asperger's Syndrome, or Pervasive Developmental Disorder OR the participants must have been advised by a professional that their child has sensory processing issues.
- The child must have received the combined TL and SD treatment under the supervision of an OT from within an outpatient or community setting.
- The child must have received the combined treatment of TL and SD in the United States as well as currently live in the United States.

This inclusion criteria ensured that the study contained validity. Survey participants who did not meet the inclusion criteria were exited from the online survey and thanked for their participation.

#### Population and Sampling

This study is a line of inquiry from a previous research study who only focused on clinics within the state of Michigan. To broaden the subject pool, responses from across the United States were accepted in order to increase external validity. Purposive sampling was implemented to pursue participants who are caregivers for children with ASD and/or SPD. This was accomplished by targeting ASD and/or SPD social media groups and pediatric outpatient clinics. Since a combined treatment of TL and SD for children with ASD and/or SPD is relatively

uncommon for the general population, purposive sampling was also employed to maximize reaching participants who met the inclusion criteria by posting the flyer on social media groups and organizations who employ these treatment options. In addition, the sampling method included convenience sampling, as the survey was sent to clinics and posted in various Facebook groups that were open access.

# Data Gathering Methods and Analysis

A flyer (Appendix A) along with uniform scripts were distributed in various formats. The flyer consists of a brief description of the survey and a digital link to access the survey electronically. Personal identifiable information was not collected and the survey was encrypted in order to protect the location and identity of those taking the survey. This prevented the survey from being testable for test-retest and intraobserver reliability.

Data analysis was performed on all completed survey responses. Questions one and seven of the survey include a checklist of occupations the child had difficulty with before and after use of the combined intervention. Data from these responses were analyzed using a frequency table. Qualitative open-ended survey questions were analyzed individually for themes in content. Individual analysis was followed by peer-debriefing to compare individual results and establish trustworthiness. Once specific themes were established, these responses were analyzed again individually to label responses, and then peer debriefed once again to ensure credibility.

#### Results

Only results from the four completed surveys were analyzed. Table 1 shows that there were four cases of improvement in occupational performance between the four participants in three occupational areas. Overall, there were 22 occupational performance difficulties reported between the 4 participants in 10 different occupational performance areas prior to their child

being provided the combined intervention of SD and TL. After administration of the intervention program there were four improvements reported between three participants in three different occupational performance areas. Occupational performance areas that the combined intervention had a positive impact on include dressing, school, and social participation.

Activity	Difficulty (BEFORE)	Improved (AFTER)
Dressing	3	2
Bathing	2	
Toileting	1	
Hygiene Tasks	2	
Eating	2	
Sleeping	3	
School	3	1
Play	2	
Social Participati on	3	1
Other	1	
Total	22	4

Table 1. Improvement in Occupation Areas

Table 2 illustrates that three out of the four participants saw improvements in at least one occupational performance area. According to the data, participant two did not see any occupational improvement and reported that their child only participated in the combined intervention for one to three weeks, providing TL less than once per day and providing sensory diet three to four times per day. Participant three saw improvement in one occupational

performance area and reported that their child participated in the combined intervention for ten weeks, however only provided TL one to two times per day and SD one to two times per day. Participant four saw improvement in one occupational performance area also reported their child participated in the combined intervention for ten weeks and provided TL three to four times per day, however only provided sensory diet one to two times per day. In contrast to the three participants who saw one or no occupational improvement, the participant who saw improvement in two occupational performance areas reported that their child participated in the combined intervention for ten weeks and was provided both TL and sensory diet three to four times per day.

Table 2. Comparison Between Occupational Improvement and Combined InterventionEngagement

Participant	Dx.	# of Occupations Difficult Before	# of Occupations Improved Upon After	Length of time participating in combined intervention (SD and TL)	Frequency of TL	Frequency of SD
1	SPD	4	2	10+ weeks	3-4 times/day	3-4 times/day
2	ASD and SPD	8	0	1-3 weeks	<1 time/day	3-4 times/day
3	ASD and SPD	9	1	10+ weeks	1-2 times/day	1-2 times/day
4	ASD	1	1	10+ weeks	3-4 times/day	1-2 times/day
Total		22	4			

Table 3 displays the themes observed in the qualitative survey responses among the four participants. The first theme identified was difficulty engaging the child in treatment. Participant one noted that "some modules were less engaging for him" when referring to difficulty implementing the combined TL and SD treatment. Participant three noted that "bad days were hard to get involvement". Additionally, the theme of a goal for improvement in formal education was identified by two participants. Participant one stated "we want our child to improve to the point where he could return to school" and participant three noted a goal for "integration into normal education".

In addition to themes noted among participant qualitative responses, certain individual qualitative responses brought valuable insight into caregiver perspectives on TL and SD interventions. Participant one stated "we were skeptical about TL but after a few sessions we really saw an improvement in social connectedness (eye contact and engagement)." Participant three responded to the question regarding how the combined intervention helped the child achieve their previously identified goals with "need more help." This response is very openended, but suggests that the combined TL and SD treatment has not been sufficient in helping the caregiver to achieve their goals for their child.

Themes:	Difficulty Engaging Child in Treatment	Goal for Improvement in Formal Education
Participant 1	"Some modules were less engaging for him"	"We want our child to improve to the point where he could return to school"
Participant 2		
Participant 3	"Bad days were hard to get involvement"	"Integration into normal education"
Participant 4		

 Table 3. Qualitative Response Themes

#### Discussion

Overall, the results of this study show that the implementation of SD and TL as a combined intervention can improve a child's ability to perform occupations such as dressing, going to school, and social participation. The results of this study also show that there is a positive correlation between the outcomes of the combined intervention and the frequency/duration of the combined intervention. In other words, the participants who saw more improvement in their child's occupational performance provided both SD and TL at least one to two times per day for over ten weeks. In contrast, the participant who saw the least improvement in their child's occupational performance provided SD and TL less than once per day for one to three weeks. These results show there is a possible correlation between duration of the combined intervention and occupational improvements. Although 75 percent of the participants were able to see improvement in at least one occupational performance area, this study's results are not statistically significant, due to the small subject pool. These results are consistent with the research study which has been conducted on the combined interventions. Hall & Case-Smith (2007) found that providing sensory diet and therapeutic listening as a combined intervention resulted in behavioral improvements, as well as an average increase of 71 points on the Sensory Profile, and improvements in the Visual Motor Integration assessment and Evaluation Tool of Children's Handwriting. Hall & Case-Smith (2007) also found a significant improvement in the caregivers' perspective on how their child was performing in school and eye contact, as well as decreased behavioral episodes. These overall results are consistent with the results of this study, as both found improvements in occupational performance, specifically in performance in school and social participation.

# Implications for Future Research

This study assists in building a foundation for future research into using the combined inventions as a treatment option to improve client factors and occupational performance. Due to the difficulties in identifying participants using email and social media, future researchers should consider identifying pediatric occupational therapists who are currently implementing the combined treatment interventions with their clients and surveying the caregivers and occupational therapists to gain information on outcomes. Future researchers can also conduct a retroactive study by using previous clients records, such as soap notes or assessment results, of pediatric occupational therapists who have implemented the combined treatment interventions to collect quantitative and/or qualitative data. They may also consider contacting the caregivers in order to gain their perspective on the interventions. By doing so, researchers can gain access to a larger subject pool and potentially gain generalizable results.

Two of the four participants in this study expressed concerns pertaining to integrating their children into formal education. These responses indicate that their current formal education environment is not allowing their child to participate in formal education in the way they desire. Future research investigating the implementation of an SD and TL intervention in a school may be beneficial to address caregiver concerns of children with ASD and/or SPD with regards to improvement in participation in formal education. While this study contains a small study sample and results may not be generalizable, there may be benefit from further investigating what the limitations to accessing desired formal education are for caregivers of children with ASD and/or SPD.

In addition to OT research, this line of inquiry would benefit from additional level I and level II occupational science research. This research would involve studying how various childhood occupations are performed by neurotypical children, and then by children with ASD and/or SPD. A thorough analysis of childhood occupations and relational research about how occupations differ for neurotypical children vs. children with ASD and/or SPD would allow for OT research about interventions such as TL and SD to ask more specific questions about areas targeted by treatment.

# Implications for Occupational Therapy

The results of this study provide evidence for occupational therapists who work with children who have ASD and/or SPD. Because SPD and sensory integration are not classified in the DSM-5, it is imperative for OTs to base their interventions on evidence-based research for the purposes of insurance coverage, as well as for the children and caregivers. This research, in addition to past and future research studying the effects of SD and TL as a combined intervention, will broaden the evidence based interventions that can be implemented in OT.

The qualitative responses from the participants suggests that a barrier to clinical implementation of SD and TL is difficulty with child engagement. In order to remain client-centered and increase client volition to complete the combined SD and TL intervention, practitioners may benefit from modifying these interventions to be more motivating for their client. Practitioners may also survey caregivers and explore the barriers in implementation and child engagement during treatment sessions in order to educate caregivers on a variety of strategies they may use to increase engagement and improve implementation.

#### Strengths and Limitations

A strength of using a survey for data collection is that it removed the need for use of human subjects. This study expanded to surveying individuals outside of the state of Michigan, including anyone in the United States meeting inclusion criteria. Representation in multiple states in the United States makes the survey results more generalizable. The use of a uniform survey ensures that qualitative data collected from each participant targets consistent areas pertaining to understanding outcomes of TL and SD. Lastly, a strength of this study is that it gathered data about the unique perspective from caregivers who evaluate occupational engagement outside of a clinical perspective.

While this study boasts many strengths, it also has several limitations. This study attempted to broaden the previous research (line of inquiry) low response rate in order to be able to generalize the results. Despite broadening the subject pool by using email and social media this study was not able to expand enough to generalize the results. Another limitation of this study is the survey asked caregivers to recall information about their child's treatment. This information is subjective and may be inaccurate due to poor recall, understanding or interpretation of questions posed in the survey. In addition, this survey cannot be tested for reliability because it is new. There is no established criteria in the DSM-5 for SPD, so any diagnosis received is subjective and may interfere with survey results. Lastly, it is unknown what specific sensory-based strategies were used by the OT for the child receiving SD treatment and if these strategies were evidence-based. This calls into question whether the efficacy of the combined TL and SD treatment was successful due to just TL, just SD, or the combined treatment of TL and SD.

#### Conclusion

The results of this study show that the combined intervention of sensory diet and therapeutic listening can be effective in improving occupational performance in children with ASD and/or SPD if the combined intervention is implemented frequently and for an extended period of time. The results also found that sensory diet and therapeutic listening are most effective in improving the occupational performance of dressing, school, and socialization. This study's sample size was too small to produce statistically significant results, which means further research is needed to determine the effectiveness of this combined intervention on children with ASD and/or SPD.

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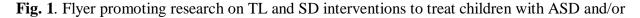
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# Appendix A





SPD.

# Figure Captions

*Figure 1*. Flyer promoting research on TL and SD interventions to treat children with ASD and/or SPD.

# Author Note

Courtney A. Lambesis attended Grand Valley State University as a Masters in Occupational Science and Therapy Student in Grand Rapids, MI in the midwest region of the United States. Lynnette Zulquarinain attended Grand Valley State University as a Masters in Occupational Science and Therapy Student in Las Vegas, NV from the western region of the United States. Mikayla M. Brett attended Grand Valley State University as a Masters of Occupational Science and Therapy Student in Grand Rapids, MI in the midwest region of the United States. Katelyn Ribant COTA attended Grand Valley State University as a Masters of Occupational Science and Therapy Student in Grand Rapids, MI in the midwest region of the United States. Katelyn Ribant COTA attended Grand Valley State University as a Masters of Occupational Science and Therapy Student in Grand Rapids, MI in the midwest region of the United States. Shaunna Kelder DrOT, OTR/L is full time faculty member at Grand Valley State University for the Masters in Occupational Science and Therapy program located in Grand Rapids, MI in the midwest region of the United States.

Courtney A. Lambesis, Lynnette Zulquarinain, Mikayla M. Brett, Katelyn Ribant COTA, and Shaunna Kelder DrOT OTR/L have not changed affiliation subsequent to the time of the study.

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