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Original Article

Sensory Profile of Nepalese Children with or without Autism

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Abstract

Introduction: Sensory Integration Dysfunction (SID) is common in children with Autism Spectrum Disorder. If SID is detected early and intervened, there is a decrease in autistic mannerisms and an improvement in the areas of sensory processing and regulation, social-emotional function, and fine motor skills. Thus, this study was conducted to compare the sensory profile of children with or without autism spectrum disorder (ASD) in Nepal.

Methods: Thirty five parents of children with ASD and 43 parents of children without ASD (non ASD) completed Short Sensory Profile (SSP) questionnaire.

Results: Definitive sensory issue was identified in 66% in ASD and 23% in non ASD group. Common sensory issues in ASD group were auditory filtering sensitivity (74.3%), movement sensitivity (37%), under responsiveness / seeks sensation (45.7%). In non ASD group, common sensory issue was under responsive/seek sensation. The internal consistencies between the sub-scales ranged from 0.70 to 0.83.

Conclusions: Two third of the children with ASD have sensory issues. Identifying different sensory problems with SSP would be helpful for further management of children with ASD.

Introduction

Sensory Integration Dysfunction (SID) is the condition in which the brain is unable to process the information that it receives through different senses. In SID, the brain has difficulty analyzing, organizing and connecting, or integrating sensory messages.[1] This might lead to learning difficulties because of difficulty in using sensory information to plan and organize for the task to be completed.[1] When there is delay and inefficient neurological processing of the sensory signals, they often manifest as inappropriate motor and behavior responses and are misinterpreted as behavioral problems.[1] Whenever the brain is unable to integrate sensory inputs like sights, sounds, touch, body position, or movements that it receives from sensory systems, effective responses cannot be generated.[2] Because of the altered responses and poor behavior, it creates difficulties with academic and motor learning as well.[3] The SID may be tactile, olfactory hypersensitivity, and hypo or hyper-reactivity to sensory stimuli.[4-7] When auditory or vestibular system dysfunctions are present, it affects speech development causing speech delay and articulation disorder.[1] It is seen that young children with speech disorders have reduced functions in the vestibular, proprioceptive, and tactile sensory systems compared to

children without speech disorders.[8]

Individuals with autism spectrum disorder (ASD) often display atypical responses to sensory stimuli and this condition is considered one of autism's defining features.[9] Different kinds of researches show that the prevalence of SID in children with autism ranges from 42% to 88%.[10] When children with autism were compared with children without autism, there was a significant difference in their sensory profile with the greatest differences in under-responsiveness /seeking sensation, auditory filtering, and tactile sensitivity scales.[11] Symptoms of SID are categorized mainly into four patterns: "Visual perception and Auditory- Language Disorders," "Tactile Defensiveness," "Disorders involving the Vestibular System," and "Developmental Dyspraxia". Children with ASD may not display all the symptoms of a certain dysfunction but they usually have several signs of these four patterns.[12] When SID is present in children with autism, it negatively impacts the performance of daily life activities.[13,14]

The recent global data shows the prevalence of ASD is 1 in 100 children.[15] When this data is projected in Nepal's population, there may be about three lakh children with ASD. In these children along with diagnosis of ASD if SID is detected early and intervened, there is a decrease in autistic mannerisms (a component of social responsiveness) and improvement in the areas of sensory processing and regulation, social-emotional function, and fine motor skills.[16] To identify and detect SID in children, the sensory profile can be assessed through clinical examinations and parents' interviews. The sensory profile is a parent-based questionnaire originally developed as a screening tool to identify children with sensory processing difficulties.[13] It includes 125 items in three categories, namely sensory processing, modulation, and behavioral and emotional responses.[17] The shorter version, Short Sensory Profile (SSP) is mostly used for screening programs and research purposes.[11,17] The SSP has good psychometric properties with a satisfactory internal consistency with Cronbach alpha ranging from .68 to .92 and good convergent validity of over 95% in identifying children with and without sensory modulation differences.[18] The tool has been translated into several languages such as Spanish, Arabic, Turkish, Indian, and Chinese.[19] The primary objective of the current study is to assess the sensory profile of children with ASD and compare them with children without ASD using SSP. We also aimed to measure the internal consistency of the questionnaire.

Methods

For the current study, a convenient sample of parents of children with and without ASD was selected from Autism Care Nepal Society (ACNS), a non-governmental organization that provides clinical and social services to families with children with autism, and Tribhuvan University Teaching Hospital (TUTH), a tertiary level hospital, both based in Kathmandu, Nepal. Thirty-five parents of the ASD group were identified from the ACNS registry and the first author's neuro-developmental clinic at TUTH. For comparison, children without ASD (non-ASD group) and any known physical, neurological, or behavioral disorders were identified from well-child visits and pediatric out-patient clinic register at TUTH. Other interested parents were also invited to participate in the study using the researcher's social network. The inclusion criteria for enrollment were children below 16 years in both groups. In the ASD group, children with autism but without any other associated co-morbidities including any physical impairment or disability like cerebral palsy, Down syndrome were excluded. Altogether 48 parents in the non-ASD group agreed to participate in the study. Of them, five children were excluded as three had visual impairment, one child had a motor impairment and one child was recently diagnosed with Asperger's syndrome which was diagnosed after parents completed SSP and sought help. Hence, a total of 43 parents was enrolled in the non-ASD group. Parents completed a demographic questionnaire that included information on the child's age, gender, and any impairment or disability. For children with ASD, an additional question on age at diagnosis of autism was also asked. The SSP is a questionnaire-based screening tool to identify sensory processing difficulties, patterns, and effects on functional performance.[16,17] The SSP consists of 38 items organized into seven subscales; i) tactile sensitivity (7 items), ii) taste / smell sensitivity (4 items), iii) movement sensitivity (3 items), iv) under-responsive / seeks sensation (7 items), v) auditory filtering (6 items), vi) low energy / weak (6 items), and vii) visual / auditory sensitivity (5 items). Each item is rated on a 5-point Likert scale. The response options are from Always =1 to Never = 5. Each item score is summed up to obtain the total score for each subscale which is then classified into one of the three possible ranges: Typical Performance corresponds to 1 SD below the mean (better than the lowest 16%), Probable Difference corresponds to 2 SD below the mean (performed like children in the lowest 14%), and Definite Difference corresponds to 3 SD below the mean (performed like children in the lowest 2%). For the SSP, a total score above 155 indicates typical performance, 142 to 154 indicates probable difference and below 141 indicates a definite difference. Because there is no standardized and validated sensory profile assessment tool in Nepal, the SSP English version was chosen as this tool is simple and easy for parents to respond to. The questionnaire along with the consent form was sent to the parents through closed social messaging tools such as WhatsApp and Viber Chat services. Participants were encouraged to reach out to the research team if they had questions about the survey. The contact information of the research team was provided

in the consent form. Frequencies and descriptive statistics were performed to assess the demographic characteristics of the children. The internal consistency of the total score and subscales were measured using Cronbach's alpha (). The internal consistency is considered high when > 0.80; satisfactory when = 0.60 – 0.80; and moderate when = 0.40 – 0.59. In both groups, children were categorized in a typical performance, probable difference, and definite difference for each of the sensory scales. This was further analyzed in each item of the sensory scales. The analysis was performed in Stata version 16.

Results

A total of 78 parents, 35 in the ASD group and 43 in the non-ASD group participated in the study. The mean age of children was 7.8 (SD = 4.3) and 7.5 (SD = 3.6) years in the ASD group and the non-ASD group, respectively. Majority of the children (80%, n = 35) were males in ASD group while in non-ASD group, 53% (n = 43) were males. Children in the ASD group had a clinical diagnosis as per the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V; American Psychiatric Association 2013). The mean age of diagnosis of ASD was 32.89 months (Range = 18 - 72 months, SD =14.61). More than half of the parents (57%, n = 35) in the ASD group and only 2%, n =43) of parents in the non- ASD group reported that their child may have sensory issues. Almost a quarter of parents in the ASD group were unsure about the presence of sensory issues of their child (Table. 1).

Table1. Demographic characteristics and presence of sensory issue in a child according parents

	ASD Group N = 35	**Non ASD Group N = 43**
Age in years (SD)	7.8 (4.3)	7.5 (3.6)
Gender		
Male (%)	28 (80)	23 (53.4)
Sensory Issue		
Yes	20 (57.2)	1 (2.3)
No	6 (17.1)	37 (86.0)
May be	9 (25.7)	5 (11.6)

Table 2. Standardized Cronbach's alphas[a] for the SSP total score and scores for each subscales for ASD and non-ASD group

	ASD Group	**Non ASD Group**
Tactile sensitivity	0.70	0.76
Taste / Smell sensitivity	0.75	0.80
Movement sensitivity	0.72	0.81
Under-responsive / Seeks sensation	0.68	0.80
Auditory filtering sensitivity	0.70	0.81
Low energy / Weak	0.72	0.83
Visual auditory sensitivity	0.69	0.80
Overall	0.74	0.83

[a] > 0.80 — high; = 0.60–0.80 — satisfactory; and = 0.40 – 0.60 — moderate internal consistency

Table 3: Comparison of subscales of SSP between ASD group and non ASD group

	Typical Performance		**Probable Difference**		**Definite Difference**	
	Autism	Without Autism	Autism	Without Autism	Autism	Without Autism
	N = 35	N = 43	N = 35	N = 43	N = 35	N = 43
	(%)	(%)	(%)	(%)	(%)	(%)
Tactile sensitivity	12 (34.3)	31 (72.2)	11 (31.4)	6 (13.9)	12 (34.2)	6 (13.9)
Taste / Smell sensitivity	18 (51.4)	23 (53.5)	6 (17.1)	8 (18.6)	11 (31.4)	12 (27.9)
Movement sensitivity	12 (34.2)	30 (69.8)	10 (28.5)	8 (18.6)	13 (37.1)	5 (11.6)
Under responsive / Seeks sensation	13 (37.1)	27 (62.8)	6 (17.1)	2 (4.6)	16 (45.7)	14 (32.6)
Auditory filtering sensitivity	7 (20)	32 (74.4)	2 (5.7)	7 (16.3)	26 (74.3)	4 (9.3)
Low energy / Weak	21 (60)	39 (90.8)	2 (5.7)	2 (4.6)	12 (34.3)	2 (4.6)
Visual / Auditory Sensitivity	15	31 (72.2)	12 (34.3)	6 (13.9)	8 (16.3)	6 (13.9)
Total	9 (25.7)	23 (53.6)	3 (8.5)	10 (23.2)	23 (65.7)	10 (23.2)

Table 4: Comparison of individual item in each subscale of SSP between ASD and Non ASD Group

	ASD N = 35 (%)	Non ASD N = 43 (%)
Tactile sensitivity		
a. Expresses distress during grooming e.g. fights or cries during hair-cutting, face washing, finger nail cutting)	9 (25.7)	3 (6.9)
b. Prefers long sleeves when it is warm and short sleeves when it is cold	3 (8.5)	3 (6.9)
c. Avoids barefoot, specially in sand or grass	4 (11.4)	10 (23.2)
d. Reacts emotionally or aggressively to touch	4 (11.4)	3 (4.6)
e. Withdraws from splashing water	3 (8.5)	1 (2.3)
f. Difficulty in standing in line or close to other people	12 (34.3)	2 (4.6)
g. Rubs or scratches out on a spot that has been touched	4 (11.4)	1 (2.3)
Taste / Smell sensitivity		
a. Avoids certain tastes or food smells that are typically part of children's diet	9 (25.7)	7 (16.2)
b. Will only eat certain tastes	13 (37.1)	13 (30.2)
c. Limits self to particular food textures/temperature	11 (51.4)	9 (20.9)
d. Picky eater, especially regarding food textures	8 (22.8)	10 (23.3)
Movement sensitivity		
a. Becomes anxious or distressed when feet leave the ground	6 (17.1)	1 (2.3)
b. Fears falling or heights	11 (31.4)	3 (6.9)
c. Dislikes activities where head is upside down (e.g.; somersaults)	11 (31.4)	1 (2.3)
Under-responsive / Seeks sensation		
a. Enjoys strange noises/seeks to make noise for noise's sake	11 (31.4)	7 (16.3)
b. Seeks all kinds of movement and this interferes with daily routines (figidity)	9 (25.7)	7 (16.3)
c. Becomes overly excitable during movement activity	12 (34.2)	9 (20.9)
d. Touches people and objects	8 (22.8)	7 (16.3)
e. Does not seem to notice when face or hands are messy	5 (14.2)	7 (16.3)
f. Jumps from one activity to another so that it interferes with play	15 (42.8)	5 (11.6)
g. Leaves clothing twisted on body	8 (22.8)	(4.6) 2
Auditory filtering		
a. Is distracted or has trouble functioning if there is a lot of noise around	16 (45.7)	6 (13.9)
b. Appears to not hear what you say (seems to ignore)	15 (42.8)	3 (6.9)
c. Can't work with background noise (fan, freeze)	4 (11.4)	1 (2.3)
d. Has trouble completing task when radio is on	4 (11.4)	2 (4.6)
e. Doesn't respond when name is called but you know child's hearing is OK	10 (28.6)	5 (11.6)
f. Has difficulty paying attention	20 (57.1)	2 (4.6)
Low energy / Weak		
a. Seems to have weak muscle	4 (11.4)	0
b. Tires easily, especially when standing or holding particular body position	3 (8.5)	2 (4.6)
c. Has a weak grasp	5 (14.2)	0
d. Can.t lift heavy objects (weak as compared to other children of that age)	5 (14.2)	0
e. Props to support self (even during activity)	6 (17.1))	4 (9.3)
f. Poor endurance/tires easily	6 (17.1)	0
Visual/ Auditory sensitivity		
a. Responds negatively to unexpected or loud noises (cries or hides at noise from vacuum, dog barking etc)	(20) 7	(4.6) 4
b. Holds hands over ears to protect ears from sound	12 (34.2)	4 (4.6)

?c. Is bothered by bright lights after others have adapted to the light	3 (8.5)	0
d. Watches everyone when they move around the room	8 (22.8)	12 (27.9)
e. Covers eyes or squints to protect eyes from light	3 (8.5)	9 (20.9)

The Cronbach's alphas for the current sample on the SSP was .74 for the ASD group and .83 for the non-ASD group, indicating a satisfactory to high reliability. Cronbach's alphas on all scales for ASD ranged between .76 - .83 whereas it ranged between .68 -.75 for the non-ASD group. In all the subscales, the internal consistency was low in the ASD group as compared to the non-ASD group (Table 2).

Comparison of parent-reported sensory processing scores on the SSP for both groups is summarized in Table 3. About 66% (n = 35) of the children in ASD group had definitive sensory issues compared to 23% (n = 43) in non ASD group. About half of the children (54%, n = 43) in the non-ASD group had typical performance to sensory stimuli as compared to one-quarter (25%, n = 43) of children in the ASD group. In the ASD group, more than 30% (n = 35) had definitive sensitivity to tactile, taste, and smell, movement sensitivity, under-responsive or seek sensation, and low energy scales. Almost 75% of the ASD group had auditory filtering sensitivity. Amongst the non-ASD group, about 30% of them had a definitive sensory problem with taste/smell and under-responsive or seeking sensation scales. However, only a few children in both the groups (ASD group: 16% (n = 35), the non-ASD group: 14% (n = 43) had visual sensitivity issues. When individual items were explored in each sensory scale, about 30% of children in the ASD group had a sensory issue when they come closer to another person in the queue and prefer only certain tastes; they were fearful of height and very excitable during movement. Almost 50% (n = 35) of children in the ASD group had inattention or difficulty in paying attention and jumping from one activity to another. Similarly, about 50%(n = 35) of these children had auditory filtering issues in the form of getting distracted or trouble functioning with noise and sometimes like to produce noise. About 34% (n = 35) also had a habit of closing ears to protect themselves from noise.

Amongst the non-ASD group, about 30% (n = 43) of the children eat only certain tastes and are aware of people around and watch them move.

Discussion

To the best of our knowledge, this is the first study investigating and comparing the sensory profile of Nepali children with or without ASD. The mean age of children in both groups was about seven years. The mean age of diagnosis of ASD was 36 months, indicating a decreased mean age of diagnosis of ASD as compared to the previous findings of 56 - 58 months.[20] The earlier age of diagnosis of autism in recent years might be because there has been an increase in the number of awareness programs conducted by ACNS as well as the increased knowledge about ASD among health professionals and the general public.

Although general awareness about autism is improving, there remains a huge gap of knowledge on sensory processing disorders.[21] Although more than half of parents of the ASD group knew that their child had sensory problems, about one-third of parents were unsure about it. In the non-ASD group, only one-tenth of parents indicated that their child may have some sensory issues. SSP when applied by parents to their children, definite sensory issue was found in about three-quarters of the children in the ASD group. The finding is consistent with many previous SSP studies that stated 42% to 95% of children with autism have a sensory issue reported by parents.[11,22] In the non - ASD group, almost a quarter of the parents reported definitive sensory issues. This finding is comparable with the study from Saudi Arabia that showed similar proportions of their children without autism that displayed definite sensory issues, especially with tactile and under-responsiveness scales.[23] In Indian neuro-typical children also, the definite sensory issue was seen in about 30% of the children.[24] The presence of sensory issues in neuro-typical children from Nepal, India and Saudi Arabia is higher as compared to studies from developed Western countries that ranged from 8.3% in population-based child survey 24 to 5 -13% in elementary school-aged children in the United States.[25] About 16% of neuro-typical children from the US are over-responsive to certain auditory and tactile sensations as compared to Nepalese neuro-typical children who were more sensitive to taste.[26] This difference may be because of cultural differences in parenting style and perception of sensory issues of Nepali parents. Even health care professionals rarely discuss sensory issues as this issue is not integrated into the medical curricula. Along with that, the sensory experiences felt by children are different from how parents perceive them in their children. Parents often find it difficult to understand the actual sensory experiences of their children.[27]

In the current study, we found that about 65% of the children in the ASD group had sensory issues as compared to 83% of the children with ASD in the study from the USA.[11] The most common sensitivity was seen in under-responsiveness and auditory filtering. According to parents' report, children in this study within this group seemed to have problems in standing in a queue, aversion of certain tastes and texture of food, fear of height, inattention, easily distractible and negative response to unexpected sounds and sometimes appearing deaf. Parents also reported that their children got more excited during activities and were easily distractible. However, the visual / auditory sensitivity was found to be in only 16% as compared to about 44% from a study among

children in the US.[11] The visual / auditory sensitivity in ASD and non-ASD was almost similar. Children in the non-ASD group seem to have more negative experiences with certain tastes, and textures of food. As many parents in the ASD group are associated with the autism support group and might have received orientation regarding SID, thus they might have reported only extreme responses and unusual behaviors of autism.

It is seen that many behavioral issues accompany SID and when together, it can cause a high level of stress level in parents with children having SID as compared to children without SID.[28,29] However, when parents are educated regarding SID and when they have a better idea regarding the condition, families can adopt more meaningful family chores avoiding the sensory overload especially in cases of autism. The understanding of sensory issues helped parents to plan and prioritize the family occupations as well. In the case of neurotypical children, parents seem to emphasize more on unpleasant stimuli for the development of problem-solving and coping skills.[30] Thus, a better understanding of the sensory issues of the children and planning accordingly would be helpful for parents to reduce their stress.

When internal consistency of SSP in the Nepalese context (including children with or without autism) was explored, it was found to be above 0.6 in all the scales with satisfactory reliability. Additionally, because SSP is simple and easy to administer, SSP can be filled in for each child with ASD so that the sensory issues can be considered when planning different activities for children. This would also help physicians, teachers, and parents to understand their children better.

The study presents some limitations. Firstly, the findings of the study cannot be generalized. Most of the parents of children with ASD were associated with the autism support group where they have some orientation on SID and who are not associated with the support group, it is not known whether they have received any orientation on SID or not. Secondly, the data was collected through an online portal. Thus, only those parents who have access to the internet and knowledge on using such a portal participated in the study. Thirdly, the data is based on a screening survey instrument. Thus, it is not possible to determine the prevalence rate because of the lack of rigorous study assessing physiological and behavioral manifestations of SID in individuals through screening. It is recommended for more intensive diagnostic assessments for those who are identified to have SID through screening to validate the presence of a sensory processing disorder. Fourthly, the study used a small sample size which was not able to evaluate the presence or absence of other co-morbidities like attention deficit hyperactive disorder or other pure SID. Sensory over responsiveness is often associated with ADHD and anxiety.[24] When treatment is targeted towards sensory modulation associated with hyperactivity and anxiety, sensory over responsiveness might show improvements in function and behaviors. Thus, when SID is explored, other associated co-morbidities should also be explored. The study excluded children with other disabilities like visual, hearing, and physical impairment. In such populations also, identifying and managing SID will help to manage their behaviors. As SID may rise or decline with age, conducting a longitudinal study would be helpful to find out the developmental trajectories of sensory processing disorders.

Conclusions

SID is twice as common in children with ASD as children without ASD. The most common sensory problem seen in children with ASD was auditory filtering sensitivity. Amongst the non-ASD group, the most common sensory problem was taste/smell and under-responsiveness. As SSP is an easy tool to identify the sensory issues, the Nepali version of SSP could be explored for further extensive researches in Nepal.

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