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RESEARCH PAPER

Identifying Parental Needs for Sensory Interventions in Autism Spectrum Disorder

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ABSTRACT

This study aims to evaluate and understand the sensory sensitivities in children with Autism Spectrum Disorder (ASD), identify the challenges faced by their parents, assess the adequacy of current support services, and determine the specific needs of parents for additional guidance and support When a child has sensory sensitivity, it can have a big influence on their everyday life. It can change their comfort level, conduct, and capacity to do normal tasks. These sensitivity might make it difficult to handle day-to-day situations, which can have an impact on growth and general well-being. A quantitative survey design was employed with 125 parents (92 mothers, 33 fathers). Data were collected using a demographic information form and the need assessment Scale. Parents of children with ASD report moderate to high levels of sensory sensitivity, with average scores ranging from 1.98 to 2.32. They have low confidence in present management strategies, scoring between 1.38 and 1.69. They emphasize the need for a new intervention package and express a strong desire for it to be available in Urdu, with mean scores of 2.92 and 2.97, respectively. To effectively treat sensory sensitivity in children with ASD, the government should create user-friendly workshops and manuals, broaden access to professional counsel, and implement bilingual support packages.

KEYWORDS Sensory sensitivities, Parental needs, Children with Autism Spectrum Disorder, Interventional Package

Introduction

Autism Spectrum Disorder (ASD) is a complicated nervous system disorder that affects the developmental abilities and skills of an individual throughout life. A pervasive developmental disorder, autism spectrum disorder (ASD) is typified by impaired social interaction, communication, repetitive behavior, and restricted interests. The symptoms of ASD can differ greatly (Kangas et al., 2011). Most of the parents with children having Autism Spectrum Disorder in the early stages reported issues of sensory symptoms as compared to the parents with developmental delay (McCormick et al, 2016). Sensory sensitivities in autism have been recognized for a long time, and almost 40 years later, they have been included in DSM-5 (Rosen et al., 2021).

Literature Review

Autism Spectrum Disorder is a developmental disorder that is considered extremely disabling and may bring stress and anxiety to parents. The meaning given by parents regarding the concept of disability is commonly described as to "start living in a

different world" a world where life is lived differently by letting go and changing priorities(Veness et al,2021).

Autism was first identified in the 1940s. It is now seen as a spectrum condition defined by problems with social skills, communication, and repetitive behaviours. Diagnosing ASD looks for persistent social and communication issues, along with repetitive behaviors. Diagnosis can range from 'mild' to 'severe' and takes into account verbal ability and intellectual disability. Autism is viewed as a condition that varies in its impact on development throughout life (Chapman, 2020). Most children with ASD exhibit either hyper- or hypo-sensitivity to external stimuli such as light, sound, crowds, and others. Certain people are hyper- and hypo-sensitive. sensory issues may be the fundamental cause of actions like hand flapping, spinning, and rocking. Although the receptors for these senses are found in the peripheral nervous system, it is thought that neurological dysfunction in the brain, or central nervous system, is the cause of these issues (Christopher,2019).

A diagnosis of autism affects not only the life of the diagnosed child but also the emotional well-being of the entire family. Parents who learn of their child's diagnosis report feeling shocked, depressed, shocked, and rejected at first. Realizing that the family, as a holistic schema, must deal with the difficulties of interacting with and supporting their child's social interactions is a fundamental principle (Efstratopoulou et al., 2022).

The ability of parents to advocate for their children with ASD and their level of empowerment can be influenced by factors such as family income and economic status.When it comes to meeting their child's out-of-pocket needs for services and support, parents with higher incomes are better able to do so. Many times, parents will spend large quantities of money to support their kids, which puts them in a difficult financial situation (Smith-Young et al., 2022).

Material and Methods

Research methodology of this research includes research design, the population of the study, the sample of the study, instrument ,reliability of instrument and procedure of the data analysis were discussed.

Nature of Research

In this study quantitative method was used with survey design. Surveys are used to collect structured data on attitudes, beliefs, and actions using standardized questions, allowing for statistical analysis and identifying trends (Fink, 2017).

Population of Research

The population of study was all parents of children with ASD having sensory issues. Research participants were parents (mother and father).

Sample of Research

The convenience sampling technique was used throughout the research process. Convenience sampling is a non-probability technique where participants are selected based on their availability and willingness to participate, rather than through random sampling (Creswell & Creswell, 2018). Among the 125 parents of children with ASD, 92% were mothers and 33% were fathers. Out of 125 parents, 68% were housewives, 28% were

working in private business, 10% were working government jobs, and 19% were special education teachers. The parents were from Lahore (91%), Gujrat (14%), and Okara (20%).

Instrument

To elicit responses from parents of children with ASD, a Self-made Need Assessment Scale for Parents was created. The consent form ensured anonymity and voluntary involvement, with parents able to withdraw at any time. The information page highlighted the study's goal, which was to better understand sensory sensitivities, parent issues, current support resources, and extra guidance requirements. The measure has four sections: sensory sensitivities (touch, smell, hearing, sight, taste, vestibular, and proprioception), parent challenges, existing support resources, and the need for more assistance. The validation methodology solicited expert opinion to confirm the scale's completeness, clarity, and overall applicability.

Reliability of instrument

The Cronbach's Alpha for the Needs Assessment Scale for Parents was 0.829, indicating strong consistency across the 45 items.When normalized, it increased to 0.900, showing extremely high reliability. This meant that the scale could reliably measure what it was designed to measure.

Data analysis technique

Data received from parents of children with ASD was tabulated and classified using SPSS (Statistical Package for Social Sciences). Parametric statistics were used to compare the replies of all parents of children with ASD.

Ethical Consideration

The researcher did his best to conduct this research ethically. When approaching participants and getting access, ethical guidelines were followed. Participants were approached directly, and the researcher scrupulously adhered to **the** principle of informed consent. The researcher properly explained the scope of the study to all participants and assured them that any information they submitted would be kept anonymous and secret.

Results and Discussion

Table 1
Mean scores on sensory sensitivities in children with ASD and management strategies

Questions	Mean	Std. Deviation
Is your child hypo-sensitive in sense of touch (for example: love the deep pressure, like to touch cold and hot things, love to touch different texture)	2.32	.752
Do you use any strategy to manage your child's hypo-sensitivity of touch?	1.69	.584
Is your child hypersensitive in sense of touch (for example:Don't wear coat in winter,Don't touch any wet thing,Don't allow to brush his/her hair,Don't allow brush his/her nail)	2.06	.808
Do you use any strategy to manage your child's hypersensitivity of touch?	1.58	.497
Is your child hypo-sensitive in sense of smell (for example:Like to smell dirty things e.g diaper,dustbin,Like to smell strong odour)	1.98	.857
Do you use any strategy to manage your child's hyposensitivity of smell?	1.38	.490
Is your child hypersensitive in sense of smell (for example:Don't like	2.06	.808

strong odour,don't like strong smell food)		
Do you use any strategy to manage your child's hypersensitivity of smell?	1.58	.497
Is your child hypo-sensitive in sense of hearing (for example:Like loud voices e.g loud music)	2.32	.752
Do you use any strategy to manage your child's hyposensitivity of hearing?	1.69	.584
Is your child hypersensitive in sense of hearing (for example:Put his/her hand at ear to loud voices)	2.06	.808
Do you use any strategy to manage your child's hypersensitivity of hearing?	1.58	.497
Is your child hypo-sensitive in sense of sight (for example:Like bright colours and lights)	1.98	.857
Do you use any strategy to manage your child's hyposensitivity of sight?	1.38	.490
Is your child hypersensitive in sense of sight (for example:Disturb in brights lights,Like to stay in dark rooms)	2.06	.808
Do you use any strategy to manage your child's hypersensitivity of sight?	1.58	.497
Is your child hypo-sensitive in sense of taste (for example:Like to eat spicy food,Like to eat hard thing e.g stone,dust,clay)	2.32	.752
Do you use any strategy to manage your child's hyposensitivity of taste?	1.69	.584
Is your child hypersensitive in sense of taste for example:Like limited range of food,Like bland foods)	2.06	.808
Do you use any strategy to manage your child's hypersensitivity of taste?	1.58	.497
Is your child hypo-sensitive in sense of Vestibular (for example:Cant control his/her movements during any game)	2.05	.891
Do you use any strategy to manage your child's hyposensitivity of vestibular?	1.68	.731
Is your child hypersensitive in sense of Vestibular (for example:don't like to swing,Complain of headache and nausea)	2.29	.701
Do you use any strategy to manage your child's hypersensitivity of vestibular?	1.88	.893
Is your child hypo-sensitive in sense of proprioception(body awareness) (for example:Bump into furniture and people)	2.32	.752
Do you use any strategy to manage your child's hyposensitivity of proprioception?	1.69	.584
Is your child hypersensitive in sense proprioception(body awareness)(for example:Feel difficulty to do such activities which require fine motor skills)	2.06	.808
Do you use any strategy to manage your child's hypersensitivity of proprioception?	1.58	.497

The data from parents provides insights into the sensory sensitivities of children with ASD, as well as the ways parents employ to manage these sensitivities. Children that exhibit hypo-sensitivity, which is defined as a strong inclination towards deep pressure or tactile exploration, have a mean score of 2.32 for touch sensitivity, which indicates a moderate level of hypo-sensitivity. With a mean score of 1.69, the methods used to alleviate this hypo-sensitivity are, nevertheless, somewhat insignificant. On the other hand, children who avoid specific textures or sensations due to their hypersensitivity to touch have a mean score of 2.06, but their usage of techniques to regulate this hypersensitivity is even lower, at 1.58. Children that exhibit hypo-sensitivity, characterized by a strong odor preference, have a mean score of 1.98 in terms of smell sensitivity; yet, there are few solutions to address are low, with a mean score of 1.38 Children who avoid strong odors and are hypersensitive to smells, on the other hand, have a mean score of 2.06.The techniques employed to deal with this hypersensitivity, however, likewise have a poor mean score of 1.58. Children who are hypo sensitive to loud noises have a mean score of 2.32 for hearing sensitivity. There

aren't many strategies for dealing with this hypo-sensitivity; its mean score is 1.69. However, the techniques for controlling this sensitivity are similarly low, with a mean score of 1.58. In contrast, children who exhibit hypersensitivity to hearing and respond strongly to loud stimuli have a mean score of 2.06. Children who are hypersensitive—that is, drawn to bright colors and lights—have a mean sight sensitivity score of 1.98. With a typical score of 1.38, the strategies utilized to remedy this hypo-sensitivity are negligible. With a mean score of 2.06, children who are hypersensitive to light, easily startled by strong lights, and who prefer darker environments also have low-scoring strategies (1.58). Children who exhibit a liking for spicy or unique textures and are hypo sensitive to taste have a mean taste sensitivity score of 2.32. There aren't many strategies to deal with this hypo-sensitivity; the mean score is 1.69. The mean score for children who have hypersensitivity to taste and prefer bland or limited diets is 2.06, and the mean score for management measures is likewise low at 1.58. Children who trouble with vestibular and are hypo sensitive to vestibular sensitivities have a mean score of 2.05. There aren't many strategies for dealing with this hypo-sensitivity; its typical score is 1.68. The mean score for children who are hypersensitive to vestibular stimuli, such as discomfort when swinging or nausea, is 2.29. Their treatment strategies score slightly better, at 1.88, but they are still below average. Lastly, children with a mean proprioception sensitivity score of 2.32 are considered hypo sensitive, frequently knocking into objects. With a mean score of 1.69, the methods employed to correct this hypo-sensitivity are not very effective. Children who struggle with fine motor skills due to hypersensitivity have a mean score of 2.06, and their strategies for managing this sensitivity have a low mean score of 1.58.

Table 2

Mean scores of parents on difficulties caused by their children's sensory sensitivities

Do you face following difficulties due to sensory sensitivities of your child with ASD?	Mean	Std.Deviation
Understanding child's problems	1.37	.486
Understanding your child's Needs	1.94	1.116
Solutions for your child's problems/symptoms	3.09	1.343
Places to look for help	4.26	.906
Family blame or shame	3.02	.696
Stress	3.65	.672
Helplessness	3.77	.996
Less empowerment	3.29	.579

The challenges that parents of children with ASD confront as a result of their children's sensory sensitivity are shown in Table 2. Parents describe differing degrees of difficulty in many domains: The mean scores for comprehending the child's needs and issues are comparatively lower, at 1.94 and 1.37, respectively. As evidenced by the higher standard deviation of 1.116, it appears that parents typically believe they have a solid comprehension of these characteristics, however there is significant heterogeneity in their understanding of needs. With a mean score of 3.09 and a standard deviation of 1.343, parents have a major hard time coming up with remedies for their child's issues and symptoms. This emphasizes a significant difficulty in determining and putting into practice successful tactics. Finding locations to look for aid is the biggest issue mentioned, with a mean score of 4.26 and a standard deviation of 0.906. This implies that parents frequently find it difficult to find the right tools or assistance. Stress and feelings of guilt or blame from the family are particularly noteworthy; mean scores of 3.02 and 3.65, respectively, show a moderate degree of these problems. With a mean score of 3.77 and a standard deviation of 0.996, helplessness is another significant difficulty that reflects a strong feeling of being overpowered by the circumstances. Lastly, parents, with a mean score of 3.29 and a standard deviation of 0.579, indicate a moderately lower sense of

empowerment. This suggests that, in comparison to the other challenges, the experience of lost control is, at most, milder.

Table 3
Mean scores of parents on support for resolving sensory sensitivity issues in children with ASD.

Which support related to sensory sensitivities you have to resolve problems of your child with ASD ?	Mean	Std.Deviation
Parent support group	3.69	1.014
Interventional manuals	3.31	.610
Guidance from professionals	1.37	.486
Training program	3.00	.661
YouTube videos	3.71	.723
Resources on web(Google)	3.69	1.014
Website of international organization	3.31	.610
Books	1.37	.486
School teacher/staff	1.85	1.049

The kinds of assistance parents employ to treat their child's sensory sensitivity when they have an ASD are listed in Table 3. The most helpful options, according to parents, are YouTube videos and parent support groups, with mean scores of 3.69 and 3.71, respectively. These resources are appreciated for their real-time, helpful guidance and parent-to-parent shared experiences. Both have standard deviations of 1.014 and 0.723, which indicate that their perceived usefulness is quite consistent. With mean ratings of 3.31, interventional manuals and Google resources also garner a lot of attention. Though a little less focused than the more interactive aids, these resources offer organized guidance and information. The moderate heterogeneity in their efficiency is indicated by the standard deviations, which stand at 0.610. With mean scores of 1.37, professional guidance and books are less frequently relied upon. This implies that although these sources exist, they might not be as useful or easily accessed for everyday needs. There is agreement on their limited usefulness in this situation based on the low standard deviations of 0.486 for both. The websites of international organizations and training programs had mean scores of 3.31 and 3.00, respectively, indicating modest use and perceived efficacy. The standard deviations, which show variations in opinions on these supports, are 0.661 and 0.610. The mean score for school teacher/staff support is 1.85, meaning that although it is a resource, it is either not used as often or is thought to be less effective. The 1.049 standard deviation indicates a range of experiences with this support.

Table 4
Mean scores of parents on need of interventional package for parents

Questions	Mean	Std. Deviation
Are above support sufficient to resolve your child sensory sensitivities??	1.68	.615
Would you like to have parent support interventional package of children with ASD on Sensory sensitivities?	2.92	.269
If your answer is yes to the above question, in which language should this interventional package be developed? English	2.83	.517
Urdu	2.97	.174
Another	1.00	.000

Parents' opinions on the suitability of the available supports and their desires for a new package of interventions to manage sensory sensitivity in children with ASD are presented in Table 4. With a mean score of 1.68 and a standard deviation of 0.615, parents believe that the current supports are not enough to address their child's sensory sensitivity. This implies a broad agreement that the resources available to them do not completely satisfy their demands. A sizable portion of parents indicate a desire for a

specific parent support intervention package. The low standard deviation of 0.269 and the mean score of 2.92, which show strong agreement on the benefit of such a package, highlight this necessity. With a mean score of 2.97 and a very low standard deviation of 0.174, Urdu is clearly preferred as the language for the planned interventional package. This suggests that Urdu is the preferred language for creating the product, guaranteeing a wider audience may use it. English has a noteworthy 2.83 score as well, albeit with somewhat greater variability. A mean score of 1.00 was assigned to the "Another" language choice, suggesting low interest. Parents really want a customized intervention package, and Urdu is the chosen language for its development, even though they believe that the current assistance are insufficient.

Conclusion

The results of research show a significant gap between the needs of parents managing their children's sensory sensitivity in ASD and the support that is currently available. Furthermore, parents have a clear preference for an interventional package, especially when it involves Urdu. The results also show that parents struggle to obtain helpful resources and assistance for their children's sensory sensitivities, and that present resources are not adequately addressing these issues.

Recommendations

- Provide comprehensive and useful support packages that incorporate practical ideas and approaches for managing different sensory difficulties and handle the varying degrees of sensory sensitivity in children diagnosed with ASD.
- Make certain that new interventional materials are offered in both Urdu and English to accommodate parents' language preferences and improve support accessibility.
- Expand the availability of easily available professional help via internet resources or neighborhood support groups to give parents knowledgeable counsel and doable strategies for handling sensory sensitivity issues.
- Increase the efficacy of currently available resources by creating more dynamic and captivating content that provides helpful advice and community assistance, such as parent support groups and YouTube videos.
- To ensure that parents can easily get helpful information and assistance, make online resources and interventional guides more easily navigable and user-friendly.
- Organize workshops and training sessions that provide parents the know-how and abilities to effectively manage their children's sensory sensitivity, and continue to assist and educate them to increase their efficacy.

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