MEASUREMENT OF BEHAVIOURAL CHARACTERISTICS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS USING INDIAN SCALE FOR ASSESSMENT OF AUTISM (ISAA)

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Abstract:
Back Ground: Autism is a complicated developmental disability and considered as a spectrum of psychological conditions illustrated with extensive abnormalities of social relations and communications, as well as relentlessly limited interests and exceedingly monotonous behavior. Problem behavior is one of the major symptoms associated with autism spectrum disorders.

Objective: Defining the characteristics of children with ASD on Indian Scale for Assessment of Autism (ISAA) and to find the relationship between factors related with diagnosis and problem behaviours.

Methodology: 54 children with ASD diagnosed as per DSM IV were recruited for this observational analysis. Researcher graded the behavior using the standard method as mentioned for ISAA.

Results: Behavioural characteristics of the participants show that no significant difference was observed based on their age and gender however, significant differences in the behaviour problem was observed on participants with different level of ASD diagnosis. A significant relationship was found between medication intake and level of problem behaviours among the participants. Further analysis shows that no significant relationship exists between the age during diagnosis, duration since the diagnosis, number of alternative therapy undertaken and time spent of therapy program.

Conclusion: Different severity of ASD children do have different problems in various aspects of behavioural problems. Reference values for all the domains of ISAA based on age, gender and severity was also established.

Key Words: Autism Spectrum Disorders, Behaviour Measurement, Children, ISAA & Problem Behaviours

Introduction:
Autism spectrum disorders (ASD) is a neuro developmental disorder and is defined by its unique behaviours with many known and unknown causes.[1] Based on the level of impairments in social, communication and adaptive behaviours, these children were usually diagnosed with Autistic disorder, Asperger syndrome, Rett's disorder, Childhood disintegrative disorder or Pervasive developmental disorder – Not otherwise Specified (PDD – NOS).[2] And all these categories of diagnoses were usually classified under the umbrella term Autism Spectrum Disorders.[3] However, the recently released Diagnostic and Statistical Manual of Mental Disorders (5th ed.), has formally clubbed all the sub categories of autism in to one diagnostic term 'Autism Spectrum Disorders'.[4] The prevalence of ASD has increased dramatically these days, due to various factors including expanded diagnostic criteria, increasing awareness, diagnosis at an early age, and the recognition that it is a lifelong condition.[5] Western literature reports the prevalence of PDD in children as 0.67-1.2%.[6, 7] According to a multicentric Indian community study, it is 0.8 - 1.3% in 2- to 9-year-oldchildren.[8]

About 30% to 100% of individual with autism spectrum disorders have sensory processing difficulties which increases the presence of problem behaviours.[9, 10] Problem behaviours, challenging behaviours, mal adaptive behaviours and autistic behaviours are the terms that are used interchangeably to define the unique characteristics of children with ASD. Problem behaviors are typically defined as behaviors that are not socially acceptable, physically dangerous, and those that negatively impact education,[11] limit the development of social relationship,[12-15] and these behaviors can be highly disruptive to classroom, community, and home environments. Problem behaviors observed with autism include physical aggression, self-injury, property destruction, pica, stereotypy, and tantrums. These behaviors are reinforced by the disruption they create and, without intervention; problem behaviours would increase than improve.[3] For planning a better management, it is essential to diagnose the spectrum in a proper way. With the change in the cultural perception and variations in the sociocultural structure it is very challenge in diagnosing autism spectrum disorders with uniform measures. However, researchers have validated certain diagnostic criteria for confirming the diagnosis.

Few internationally validated instruments such as Autism Diagnostic Observation Schedule-Generalized (ADOS-G), Autism Diagnostic Interview-Revised (ADI-R), and Childhood Autism Rating Scale (CARS) are available to measure the characteristics of ASD children.16-18 However, in India it is a challenging task to administer these tests as differences between Eastern and Western culture and parental expectations of behavior and appreciation of symptoms influence the psychometric properties of these instruments.19 The National Trust, Ministry of Health and Family Welfare, and Ministry of Social Justice and Empowerment of the Government of India jointly developed the Indian Scale for Assessment of Autism (ISAA) with a purpose to establish diagnosis, and to rate severity of autism among Indian children.20 This is an objective assessment tool for persons with autism which uses observation, clinical behavioural evaluation, interaction with subjects, and with information from parents or care takers through interview. It is a reliable and valid tool for making diagnosis of person with autism.20 This scale was found to be useful and feasible to use in clinical settings and easy to administer.21 The objective of this study was to describe the characteristics of ASD children using ISAA based on their age, gender & severity. Further the relationship of various diagnosis related factors such as medication intake, age during diagnosis, duration of illness, number of alternative therapies undergoing by the child and total time spent for therapy in a day. with the behavioural characteristics was also studied.

Methodology:
Participants:

This study used a cross-sectional mixed quantitative and qualitative observational research design. The data for this present study come from a two-year prospective study with data collected from 2012 to 2014. Participants were included using convenient sampling design to accommodate all the children enrolled in the institute during the study period. Ethical clearance was obtained from the Institute to carry out this research work. Children diagnosed with autism spectrum disorder based on DSM – IV -TR criteria of both the gender and aged between 3 years and 12 years were selected from an institution (Ergocare Health Rehabilitation Centre). Children with physical disability or with any other comorbid illness were excluded from this study.

Instrument:

Indian Scale for Assessment of Autism (ISAA) is an assessment measure developed to diagnose children based on 40 different items that reflects various problem behaviours seen in ASD. This scale was developed based on CARS, while considering the Indian socio-cultural context. This scale covers six domains – social relationship and reciprocity; emotional responsiveness; speech, language and communication; behavior patterns; sensory aspects and cognitive component. All the 40 items are rated on a Likert scale from 1 to 5 based on history and interviewer observation, and the increasing score indicates increasing severity of the problem. The minimal score that can be obtained is 40 and the maximum score that can be obtained is 200. A score of <70 indicates no autism, 70-106 (mild autism), 107-153 (moderate autism), and >153 (severe autism). It takes about 20 to 30 minutes for administration of ISAA.

Item validity ($p<0.001$) and discriminant validity ($p<0.001$) for this scale is already established in Indian population. ISAA has a high degree of criterion test validity with CARS ($r=0.77$; $p<0.001$), Internal consistency reliability ($\alpha = 0.97$; $p<0.001$), construct validity ($\alpha = 0.93$; $p<0.001$), inter rater reliability ($r=0.83$; $p<0.001$), test-retest reliability ($r=0.83$; $p<0.001$), sensitivity and specificity. A high concordance between ISAA and gold standard of CARS were also observed.22

Procedure:

Children with autism spectrum disorder were diagnosed by pediatrician or psychiatrist and confirmed by clinical psychologist using DSM – IV TR diagnostic criteria for autistic spectrum disorder. Parents were invited to participate in the study and the aims and objectives of the study and its procedures were explained to them. An informed consent form was provided to them, and parents agreed to participate by signing the consent form after understanding the procedures. Totally 54 children were enrolled for this study during the study period. All the parents were asked to fill a profile which collected details including age, gender, age of diagnosis, duration of illness, number of alternative therapies undergoing, time spent on therapy program, medication intake, etc. All children were assessed using Indian Scale for Assessment of Autism (ISAA) to grade the severity of the diagnosis. Researcher rated 40 statements given in this scale after appropriate observation, individual interaction with every child followed by interview with parents about their observation of their child's behaviour. Testing condition was arranged in such way to make parents and children comfortable. Parents were interviewed either in Hindi or in English as per their convenience. Both the Hindi and English versions of ISAA scale were used to elicit the best response from the parent. Some testing material used during the observation and interaction with the children included car, ball (different sizes), doll (different sizes), rattle, picture book, peg board with rings, sorting board, cup, spoon, beads with string, colour card / boards, key, watch, hand bell, paper, crayons, colour pencil, blocks, vegetables and animal toys, mirror, shape sorter and music toys.

Researcher graded the behaviour after observation, individual interaction and interview with parents by marking any one of the 5 ratings of the statement. If the child exhibited the behavioural pattern for up to 20% of the time, then 'Rarely' grade was given and this was assigned the score of 1. When the child exhibited a

International Journal of Multidisciplinary Research and Modern Education (IJMRME)
Impact Factor: 6.725, ISSN (Online): 2454 - 6119
(www.rdmodernresearch.org) Volume 3, Issue 2, 2017

particular behaviour for 21% to 40% of the time, score 2 was given with a grade of 'Sometimes'. 'Frequently' category was marked and score 3 was assigned if the child exhibited a particular behaviour for 41% to 60% of the time. When behaviour occurred for 61% to 80% of the time, score 4 was noted along with 'Mostly' category. A child's behaviour was marked as 'Always' with the highest score of 5 when behavior was exhibited for 81% to 100% of the time. Based on the total scores, children's severity of the condition was noted down as mild, moderate or severe. Score of six components were also calculated by adding the relevant scores.

Statistical Analysis:
Data was analyzed using SPSS (Statistical Package for Social Sciences) version 20.0.23 Quantitative variables were presented as mean and standard deviation. Comparison of mean was done for age, gender and severity of the condition. Student's t-test and ANOVA were used for comparison, appropriately. The categorical variables of the diagnosis related factors were analyzed with Chi-square. $P < 0.05$ was considered statistically significant.

Results:
Table 1 shows the characteristics of the participants for various factors that were found. The average age of the participants was 7.25±3.25yrs. It can be observed that about 80% of the participants were boys. Participant were equally distributed in the age group between 3years to 7 years and 7 years to 12 years. Children with moderate ASD (44.4%) were more than mild and shows that the symptoms in the form of behaviour difficulties remain same across all the age groups. In an earlier study done by Farmer and Aman (2011) on 121 ASD children, no difference was found for different age groups, though younger groups scores more on certain behavioural items.[26] In the present study, small increase in all the components and total measurement was observed for the elder age group participants, however these differences were not statistically significant. These could be due to the environment influence on their characteristics.

Gender:
Further analysis to compare the mean scores based on the gender of the participant reveal no significant difference between male and female participants in all the behaviour symptoms as assessed using ISAA. So it can be inferred that, no difference in persistence of problem behaviour was observed across both the genders. A mild increase in the mean values of all the scores was observed for the female participants though these are not statistically different. Different findings have been reported for the association between gender and problem behavior in children with ASD. Several studies report no gender differences in problem behaviors.[26-28] Other studies have found no sex differences using either parent measures of self-reported measures and interviews.[29-32] In a recent study, Hartley & Sikora (2009) found that girls with ASD showed greater communication deficits than boys and boys evidenced more restricted, repetitive, stereotyped behavior.[33] In a study done on Arab children using ISAA, it was found that boys had greater deficits in emotional responsiveness and the girls had more cognitive problems.[34] Girls with ASD have exhibited more social problems, attention problems and thought problems,[35] sleep problems and anxious or depressed affect than boys.[33] Genetically females have higher tolerance to harmful mutations hence there is less presence of developmental conditions including ASD in females. Because of their higher threshold, when they are diagnosed with ASD, they tend to have more severe symptoms than males.[36]

Severity:
We analysed the data further to see how all the components of the ISAA is seen across the participants when they were classified based on the severity. There was a statistically significant difference between the total ISAA scores of these three groups as determined by one-way ANOVA severe ASD (both about 27.8%). A large number of participants were not taking any medications for ASD. A large number of participants were diagnosed before the age of three years and most of them were receiving two or more alternative therapies and spent more than two hours per day for therapy programs. Mean comparison of various domains of ISAA as per age classification and gender classification are shown in the table 2. It can be inferred from the above table that no significant differences were found between both age groups of participants on all the components of behavioural characteristics as measured by ISAA. Also this shows no significant differences as per the gender of the participants. Mean score comparison of all the domains of ISAA as per the severity of the diagnosis (table 3) show that significant differences in the mean scores among the severity of ASD. Statistical analysis to find out the relationship between various diagnostic related factors and severity of the condition (table 4) show that medication intake has a significant relationship with severity of ASD while other factors such as age during diagnosis, duration since diagnosis, number of alternative therapies undergoing and time spent for therapy per day did not result in any significant relationship.

Figure 1 shows that none of the children with mild ASD were under medication, while about 33% of moderately affected ASD children were undergoing medication and about 13% of the severely affected children were taking medication. 81.5% of the participants were not taking any medication in total.

Discussion:
The main objective of this study was to describe the behavioural characteristics of children with ASD using ISAA. It can be seen that there were more boys among the participants than girls. An increased prevalence

International Journal of Multidisciplinary Research and Modern Education (IJMRME)
Impact Factor: 6.725, ISSN (Online): 2454 - 6119
(www.rdmodernresearch.org) Volume 3, Issue 2, 2017

in males has been observed for all types of Neuro Developmental disorders including ASD.24 A commonly referenced consensus ratio for male: female prevalence in autism spectrum disorder (ASD) is 4:1.25 In this study too, the male female ratio was 4:1 matching with previous prevalence related studies.

Age:

Independent t test results to compare the mean scores of all the domains of ISAA (table 2) show that there are no differences of the behavioural characteristics among various age groups. This (F (2,51) = 212.41 (p<0.05). A Tukey post-hoc test revealed that the problem behaviours of severe ASD (157.33±3.13) is higher than the moderately affected ASD (125.63±10.35). Children with mild ASD (100.07±5.12) scores significantly lower than both these categories. The same phenomena was earlier observed by Jang et al. (2011) in their study.37 Further it can be observed from Table 3 that, the same significant difference was observed on all the components of ISAA. These values also can be used as an individual demarcation factor for components of ISAA in future. The increased amount of symptoms in the severe category demands the need spending more time for addressing these problem behaviours than training them in acquiring new skills. Another objective of the study was to find the association between the severity of ASD and few diagnostic related factors such as medication intake, age during diagnosis, duration of illness, number of alternative therapies undergoing by the child and total time spent for therapy in a day.

Medication:

From the table 1 it can be inferred that about 81.5% of the participants were not under any medication during the study period. Medication use for children with ASD is common,38 and in our study it can be seen that less than 20% participants used medication. This could be because of the awareness among the caregivers, as most of them found therapies as a safest way to deal with their children. Statistical analysis show that there is a significant association between the severity of the condition and medication intake χ (2) = 7.17, p = 0.03. Among those who were under medication (n=10), 80% were children with moderate ASD and 20% were those who were diagnosed with severe ASD. None of the participants who were diagnosed with mild ASD were under medication. It must be noted that all the participants were recruited from a rehabilitation center where they were undergoing alternative therapy programs, hence it could be possible that many of them might have discontinued the medication. Children with ASD exhibit uneven level of symptoms and that could be the reason for different level children having a relationship with the medication consumption. Previous studies on medication use suggest an estimated range from 30% to 70% of people with ASD taking at least one medication.38-41 Risperidone and aripiprazole are the only medication approved by FDA specifically for treatment of aggression and irritability. However, many stimulants medications are long been recommended for various symptoms in individuals with ASD though they are found to be less effective in the treatment of ASD.42,43 Apart from decreased efficacy, some data suggests increased side effects of psychotropic medications in individuals with ASD.44,45 Availability of limited medicines, fear about adverse effects of psychotropic medications, increased awareness about alternative therapies among medical practitioners, and availability of alternative therapies for children with ASD are the few reasons for decreased use of medicines in the treatment by the participants.

Age During Diagnosis:

It can be seen that over 35% of the participants were diagnosed before the age of three. This could be due to the increasing awareness among parents and the medical professionals. The diagnostic criteria are clear than ever before. Pediatricians and psychiatrist believe that early intervention could lead to positive changes in these children. Hence, diagnosis is made at an early stage. Early identification and accurate assessment are vital in the management of ASD.46 Many specialized early intervention programs have reported success in the management of ASD specially in the area of improving the acquisition of skill and facilitating development.47,48. Statistical analysis found no significant relationship between the age in which the child was diagnosed and the severity of the symptoms. This shows that irrespective of the age in which the child was diagnosed, the differences in the severity of symptom is not statistically significant χ (2) = 1.27, p > 0.05.

Duration Since Diagnosed:

Age is an important factor in skill development and training of children. The diagnosis of autism spectrum disorders can be made as early as two years of age.49 Almost 45% participants were diagnosed three or more years before this study. ASD is a life time condition with no cure and the problem behaviours can be managed only by long term programs. Presence of any long term illness such as ASD affect not only the individual but also influences the Quality of Life of their family in a greater way.50 We tried to find f there is any correlation existed between the time since the diagnosis was made and the characteristics of these children with ASD. No significant association was found χ (2) = 2.31, p > 0.05.

Number of Alternative Therapies Undergoing:

From the table 1 it can be seen that more than 68.5% of the participants were receiving more than one alternative therapy program. The attempt to find the association between the severity of condition and the number of alternative therapy treatment showed no significant relationship χ (2) = 1.43, p > 0.05. ASD is a complex spectrum hence no one therapy is effective. Among the participants, most of them were receiving speech therapy, Sensory Integration therapy by occupational therapist, and special education. People with ASDs

have deficits in social communication, and treatment by a speech-language pathologist usually is appropriate. Augmentative and alternative communication modalities, including gestures, sign language, and picture communication programs, often is effective in enhancing communication. Occupational Therapists effectively apply the principles of sensory integration therapy with creativity and bundled with play therapy which supports in the reduction of sensory processing difficulties commonly found in children with ASD. Use of developmental theories based occupational therapy management further helps the child to acquire skills and break the environmental barriers to develop further. Special education program is another preferred program by parents to improve the understanding ability in their children. However, sufficient amounts of 1-on-1 time with low student-to-teacher ratio and small-group instruction to achieve specific individualized goals were lacking. ABA which is used very commonly is USA has not gained popularity among Indian parents. Alternative therapies or otherwise called as Complementary and Alternative Medical Therapy (CAM) is few countries are used more in children with ASD than other illness.51,52 In a survey on 112 families, it was found that 74% were using CAM for their child with ASD.53 Reason for choosing alternatively therapy could be, increasing internet accessibility, absence of side effects, increasing prescription by pediatricians, and a common perception among parents that these therapies are either helpful or without effect but not harmful.

Time Spent for Therapy:
It was observed that about 66.7% of the participants spent more than 2 hours a day for therapy program related to ASD management. Though the statistical analysis showed that there were no significant association between the amount of time spent for therapy programs and the severity of ASD χ (2) = 1.65, p > 0.05, we observed that about 20% of them spent more than 4 hours a day for alternative therapies. Huge time factor is involved in the training of these children. This not only increases burden on the parents but also prevents the children from getting exposure to normal play environment. Care must be taken to plan these unavoidable therapy programs in such a way that these children also get opportunity to play and mingle with other children with typical behaviours.

Conclusion:
This study describes the behavioural characteristics of Indian children with autism spectrum disorders aged between 3 years and 12 years using the Indian Scale for Assessment of Autism (ISAA). Reference values for different domains of this scale based on age, gender and severity was also established in the process. Statistical analysis was aimed at finding association between the severity of the diagnosis and various diagnosis related factors such as medical consumption, age of diagnosis, duration since diagnosis, number of alternative therapies undergoing and time spent for alternative therapies per day.

Limitations:
Participants were enrolled by convenient sampling method, and though the measurement of the behavioural characteristics was done using observation and analysis by the researcher, some part of the measurement dependent on the subjective information provided by the parents.

Recommendation for Future Research:
Future research can be done by doing a longitudinal study on the same. Other factors related with diagnosis, such as role of family and educational level of parents could be studied.

Acknowledgement:

Conflict of Interest:
All the authors declare no conflict of interest.

Author Contributions:
VP, and OL designed the study; VP collected data; VP, and OL analyzed the data and wrote the manuscript. All authors read and approved the final manuscript.

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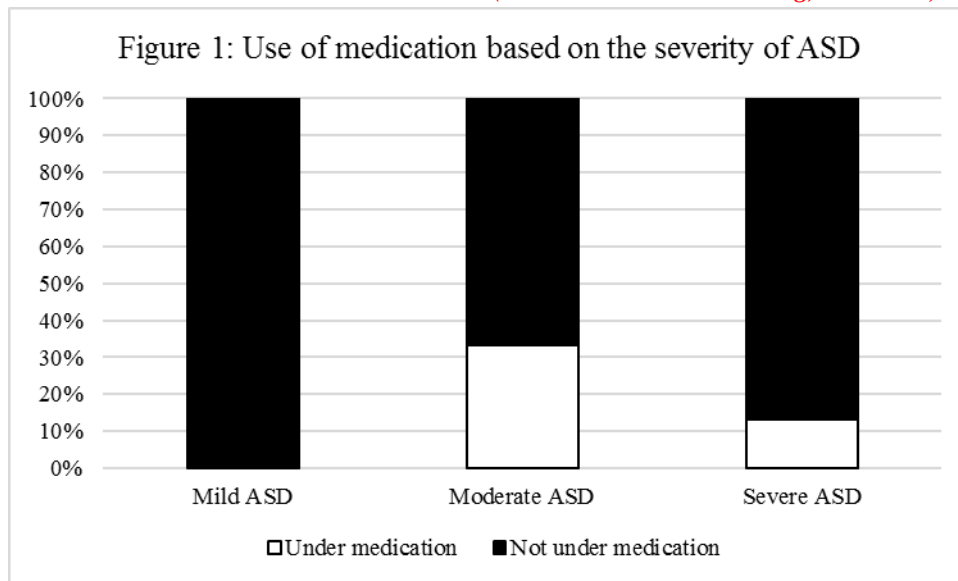
Figure 1: Use of medication based on the severity of ASD

Table 1: Descriptive characteristics of the participants

Variables	Classification	Incidence (N=54)
Gender	Boys	43 (79.6%)
	Girls	11 (20.4%)
Age Group	3yrs to 7 Years	29 (53.7%)
	7yrs to 12 Years	25 (46.3)
Severity	Mild	15 (27.8%)
	Moderate	24 (44.4%)
	Severe	15 (27.8%)
Medication intake	Yes	10 (18.5%)
	No	44 (81.5%)
Age during diagnosis	Less than 3 Years	35 (64.8%)
	3 Years to 8 Years	19 (35.2%)
Duration of diagnosis	Less than 1 Year	3 (5.6%)
	1 Year to 3 Years	27 (50%)
	More than 3 Years	24 (44.4%)
Number of alternative therapies undergoing	One	17 (31.5%)
	Two	25 (46.3%)
	More than two	12 (22.2%)
Total time spent for therapy in a day	Less than 2 Hours	18 (33.3%)
	2 hours to 4 hours	25 (46.3%)
	More than 4 hours	11 (20.4%)

Table 2: Mean scores comparison of different domains of ISAA based on age and gender

Domains of ISAA	Age			Gender		
	3yrs – 7 yrs	7yrs to 12 yrs	t value	Male	Female	t value
Social	35.28±6.175	36.40±4.743	-0.74[NS]	35.70±5.655	36.18±5.288	-0.26 [NS]
Emotional	16.41±3.878	17.56±4.204	-1.04 [NS]	16.77±4.116	17.64±3.802	-0.63 [NS]
Speech	25.52±4.925	27.00±6.265	-0.97 [NS]	25.81±5.616	27.73±5.424	-1.02 [NS]
Behaviour	23.38±4.451	23.48±4.788	-0.08 [NS]	23.21±4.528	24.27±4.839	-0.69 [NS]
Sensory	14.59±4.412	15.84±4.905	-0.99 [NS]	14.81±4.366	16.55±5.628	-1.11 [NS]
Cognition	9.41±1.783	10.24±1.877	-1.66 [NS]	9.67±1.554	10.27±2.796	-0.95 [NS]
Total	124.59±21.712	130.52±24.168	-0.95 [NS]	125.98±22.328	132.64±25.224	-0.86 [NS]

International Journal of Multidisciplinary Research and Modern Education (IJMRME)
Impact Factor: 6.725, ISSN (Online): 2454 - 6119
(www.rdmodernresearch.org) Volume 3, Issue 2, 2017

Note: test – Independent t test; [NS] – Not Significant

Table 3: Mean scores comparison of domains of ISAA based on severity of ASD

Domains of ISAA	Severity of ASD			Significance
	Mild	Moderate	Severe	F
Social	29.67±3.99	35.92±3.13	41.73±2.43	52.36[*]
Emotional	13.13±2.56	16.58±3.27	21.33±1.05	36.85[*]
Speech	20.33±2.80	25.88±3.74	32.60±2.47	55.83[*]
Behaviour	18.47±2.23	22.88±2.01	29.27±1.98	104.2[*]
Sensory	10.53±1.51	14.33±2.94	21.13±1.68	82.18[*]
Cognition	7.93±1.53	10.04±1.37	11.27±1.22	22.63[*]
Total	100.07±5.12	125.63±10.35	157.33±3.13	212.41[*]

Note: Test – ANOVA; [*] – $p < 0.05$, ISAA – Indian Scale for Assessment of Autism, ASD – Autism Spectrum Disorder

Table 4: Relationship between diagnosis related factors with the severity of the condition

Variables	Chi Square value
Medication intake	7.17[*]
Age during diagnosis	1.27[NS]
Duration since diagnosed	2.31[NS]
Number of alternative therapies undergoing	1.43[NS]
Time spent for therapy	1.65[NS]

Test – Chi Square test; [NS] – Non significant ($p>0.05$); [*] – $p < 0.05$