



EFFECT OF PUBLIC EDUCATION ON AWARENESS OF AUTISM SPECTRUM DISORDER IN THE GENERAL PUBLIC: AN INTERVENTIONAL STUDY

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ABSTRACT **Objective:** To study the effect of public education on the level of awareness of autism spectrum disorder (ASD) in general public. **Method:** A powerpoint presentation was developed depicting the characteristics of autism spectrum disorder that was used for public education in the study. Scores of 100 adult participants on pre- and post awareness assessment questionnaires were obtained before and after viewing the presentation and again after one to three months. These were compared using SPSS (Version 20) software. **Results:** Pre awareness questionnaire scores 82.94 out of a maximum possible score of 125 indicated a moderate awareness level about the characteristics of autism spectrum disorder. Mean scores obtained on post awareness questionnaire was 110.50. Comparison of scores on pre and post awareness questionnaires using Wilcoxon sign rank test revealed a highly significant difference between the two scores ($p < 0.001$) indicating that public education was effective in creating awareness about characteristics of autism spectrum disorder. Repeat administration of post awareness questionnaire on 30% of the participants after 1 to 3 months indicated that a significant reduction in the scores ($p < 0.001$), but when compared with pre awareness score of same participants, the difference was significant ($p < 0.001$) indicating that effect of public education presentation was retained but reduced. **Conclusions:** Study reveals that awareness of autism spectrum disorder is moderate in the general public. Public education developed for the study was effective in improving awareness of autism spectrum disorder, however regular follow up awareness programs should be undertaken for retention of the information.

KEYWORDS : Autism spectrum disorders, awareness, public education

INTRODUCTION

Autism spectrum disorder (ASD) refers to a range of conditions characterized by some degree of impaired social behavior, communication and language, and a narrow range of interests and activities that are both unique to the individual and carried out repetitively¹. ASD is a developmental disorder that affects speech-language development and social communication, and emotional reciprocity. Repetitive behaviors and sensory issues leading to impairments in feeding, hearing and visual perception are also seen in these children. The prevalence of ASD in India was 1 in 125 in children between 3 to 6 years and 1 in 85 in children of the 6 to 9 years age range².

In India efforts are underway to create awareness about the condition across various medical professionals, health care workers, therapists, schoolteachers, college and school children and the general public at large. A change is also attempted by the policy makers for inclusion of individuals with ASD in society and in mainstream education. The Rights of Persons with Disabilities Act (2016) included the condition autism spectrum disorder for the first time in India. Government schemes like Sarva Shiksha Abhiyaan in India have worked to bring children with disability into the education system. Also, the introduction of inclusive education has played a part in creating awareness regarding ASD among school teachers. And through word-of-mouth people around these teachers are also becoming aware of ASD. The Indian Pediatric Association is also conducting intensive multiple awareness programs for medical professionals including Pediatricians. In general public, awareness regarding ASD is gradually changing in recent years through exposure via different media like TV shows, movies, newspapers etc. In spite of these multiple level programs, the social stigma and lack of awareness and understanding about the condition persists in India.

Making the general public aware of the characteristics, sensory and communication needs of people with ASD is important so that the general public learns how to respond or react to someone with ASD and cater to their needs if required. This will help individuals with ASD and their families feel more integrated into society. Therefore, creating awareness is important to improve the social quality of life of individuals with ASD in the long run.

Primary Objective Of The Study:

To study the effect of public education on the level of awareness of autism spectrum disorder in the general public.

Secondary Objective Of The Study:

To explore the influence of gender, age and education on the level of

awareness of autism spectrum disorder in the general public.

METHOD

The study was given ethical clearance by the Institution ethical committee.

The study is a part of a larger study that was divided into 2 phases:

Phase 1: Development Of Study Tools

The 1st phase included development of a pre awareness questionnaire, public education (PPT) material and a post awareness questionnaire.

Phase 2: Administration Of Study Tools

The 2nd phase included data collection by administering pre awareness and post awareness questionnaires on the participants of the study before and after the presentation of public education material via power point to check the effectiveness of public education material.

This research paper reports phase 2 of the study. The pre-awareness questionnaire and post awareness questionnaire are given as Appendix 1, and 2 respectively. The public education material is copyrighted.

Participants

Number of participants that were included in the study was 100 and the population was undefined.

Inclusion Criteria For The Participants:

Participants who were 18 years and above, having an educational qualification of 10th Grade and above, and understood and spoke English were included in the study.

Exclusion Criteria For The Participants:

Participants having any known sensory (hearing and vision) and motor impairment impeding use of computer/laptop or having any known neurological/ psychological/ psychiatric condition that can affect cognition and understanding of the questionnaire were excluded from the study.

Procedure

Participants in the study were selected based on the inclusion and exclusion criteria. Selected participants were emailed a participant information sheet and consent form. Consent was taken via email by each participant. An one-to-one meeting on online platform was fixed at a mutually feasible time to carry out the data collection/ administration of study tools. The participants were asked to complete the procedure at one go in the same online meeting and not to interact with anyone during the procedure or browse the internet.

The participant's demographic information was taken. The participants were shown the pre-awareness questionnaire via screen share and were asked to answer each question verbally and the researcher marked the answers. The participants were explained that there are 25 statements about ASD in the pre-awareness questionnaire which had a 5-point rating scale. They were asked to rate each statement after reading them based on how much they agree with the statements. The options were strongly agree, agree, neutral, disagree, and strongly disagree. The participants were asked to rate all the 25 statements. After completing the pre awareness questionnaire, the researcher showed the developed public education PowerPoint Presentation on Autism Spectrum Disorder (ASD) via share screen to the participant. After viewing the PowerPoint presentation, the participants were shown the post awareness questionnaire via screen share. Participants were explained that there are 25 statements on ASD in the post awareness questionnaire and all the 25 statements should be rated on how much they agree with the statement as strongly agree, agree, neutral, disagree, strongly disagree. Participants were asked to rate verbally and researcher marked the response.

Pre and post awareness questionnaires were developed and equivalency of the two was confirmed in Phase 1 of the study by content validation by 5 Speech language pathologists as well as by statistical analysis of scores of individual equivalent questions of the pre and post questionnaires on 10 participants using Mann Whitney U test ($p > 0.05$) without exposure to the public education presentation. Similarly content validation of the presentation for awareness was done by 5 speech language pathologists and suggestions were incorporated before the presentation was used for Phase 2 of the study.

Retention of information from public education material was checked on 30 participants by administering the post awareness questionnaire again after 1 to 3 months of presentation of the education material.

Scores of pre-awareness questionnaire, post awareness questionnaire and post awareness questionnaire administered again after 1 to 3 months of viewing of public education presentation were compared using Statistical Package for Social Sciences (SPSS) version 20.0 (SPSS Inc., Chicago, IL).

RESULTS

100 individuals participated in Phase 2 of the study. Scores obtained of all participants ($n=100$) on the pre awareness questionnaire were first subjected to normality check using Shapiro Wilk test of normality, which revealed that data was normally distributed ($p > 0.05$). Further descriptive analysis of the data was done.

Mean scores obtained were 82.94 out of a maximum possible score of 125, with a SD of 5.12. Mean percentage of scores obtained by the participants is 66.35%. Thus, the level of awareness about ASD among the participants can be said to be moderate.

Pre awareness questionnaire scores of all participants were analyzed further to see if there was any effect of gender, age and level of education on awareness level of ASD.

Awareness About ASD Across Gender

There were 61 males (Mean age: 32.56 years; Range: 18 to 68 years) and 39 females (Mean age: 33.26 years; Range: 19-65 years). Mean and SD of score obtained by males was 82.61 and 12.17 respectively. Mean and SD of scores obtained by females was 83.46 and 11.6 respectively. Unpaired t test was used to compare the mean scores obtained by males and females. Results revealed that there was no difference across the gender as the p value was 0.473, $t = 0.812$, $df = 98$. Hence it was concluded that gender had no effect on the level of awareness of participants in the study.

Awareness About ASD Across Age

Effect of age on level of awareness was studied, by dividing the participants into 4 groups- Group 1- 18 to 25 years ($n=34$), Group 2- 25.1 to 40 years ($n=45$), Group 3- 40.1 to 60 years ($n=17$) and group 4- 60.1 years and above ($n=4$). Group 4 had only 4 participants and hence this group was not included in analysis. Descriptive analysis of scores across age revealed that the mean and SD for Group 1 were 84.64 and 6.05, for Group 2 was 81.6 and 4.27, for Group 3 was 83.12 and 4.62 respectively. One way ANOVA was used to compare scores across the three age groups. One way ANOVA revealed that the main effect was not significant for age ($F = 1.929$, $df = 2$, $p = 0.151$). Hence it was concluded that age has no effect on the level of awareness of ASD

among the participants of the study.

Awareness About ASD Across Level Of Education

Effect of level of education on awareness level of autism spectrum disorder was studied by dividing the participants into 3 groups- Group 1- included individuals having education below or equal to 12th Grade ($n=16$), Group 2 included individuals with education between 12th Grade and Undergraduate degree ($n=54$), Group 3 included individuals with education above Undergraduate degree ($n=30$). Descriptive analysis of scores across levels of education revealed that the mean and SD for Group 1 were 84.50 and 5.06, for Group 2 it was 83.04 and 4.84, and for Group 3 it was 81.93 and 5.57 respectively. One way ANOVA was used to compare scores across the three education groups. One way ANOVA revealed that the main effect was not significant ($F = 1.339$, $df = 2$, $p = 0.267$). Hence it can be concluded that education had no effect on the awareness level of autism spectrum disorder among participants of the study.

Awareness Level About ASD After Presentation Of Public Education Power Point

After viewing the public education Power Point presentation, a post awareness questionnaire was administered on the same 100 participants. The post awareness questionnaire scores were not normally distributed as determined by Shapiro Wilk test of normality ($p < 0.001$). Mean score obtained was 110.50 and median was 110. Range of scores obtained was 100-125. Three participants scored 125, which is the maximum score that could be obtained on the post awareness questionnaire. Mean % scores were 88.4%. Hence it can be concluded that the level of awareness of autism spectrum disorder was high after viewing the public education material.

Effectiveness of public education material was checked by comparing the pre and post questionnaire scores. Pre and post awareness questionnaire scores of 100 participants were compared using Wilcoxon signed rank test. The results revealed that there was a significant difference between pre and post awareness scores ($p < 0.05$). Thus, it can be concluded that public education presentation was effective in educating the participants about ASD.

Retention Of Information Shared Through The Public Education Presentation

Retention of information presented via the public education material was checked by re-administering the post awareness questionnaire on 30% of the participants ($n=30$) 1 to 3 months after first viewing the public education power point presentation. The Median score on post awareness questionnaire (after 1 to 3 months) was 101.5 whereas the median score on post awareness score 1 (immediately after seeing public education power point presentation) was 107. Thus, on descriptive analysis, the post awareness score 2 appeared to be lower as compared to post awareness score 1. Friedman's test was done to compare pre awareness questionnaire score, post awareness questionnaire score 1 and post awareness questionnaire scores 2 of the 30 participants. The p value obtained was < 0.001 hence it was interpreted that there is a significant difference across the scores.

Wilcoxon matched pairs signed rank test was used to do a post hoc analysis to compare the scores. A significant difference was found between post awareness questionnaire score 1 and post awareness questionnaire score 2 ($Z = 3.899$, $p < 0.001$) indicating a significant reduction in scores of post awareness questionnaire after 1-3 months of viewing the public awareness presentation. Thus, the retention of information was significantly lesser after 1 to 3 months.

On comparison on the post awareness questionnaire scores 2 with pre awareness questionnaire scores, it was found that there was a significant difference in the scores ($Z = 4.785$, $p < 0.001$), indicating that the post awareness questionnaire scores 2 were significantly higher than pre awareness questionnaire scores.

Thus, it can be concluded that the public education material is effective for a period of 1-3 months after presentation, but the effect is significantly reduced.

DISCUSSION

As per the results of the study, it is evident that awareness of autism spectrum disorder is moderate. However, in developed nations, awareness of autism spectrum disorder among the general public is higher than among the general public of India. A study conducted by The Northern Ireland Life and Times survey in Ireland reported that

four out of five respondents are aware of autism, and of these, three out of five have family member or friend/ acquaintance with autism. The study concluded that there is a high level of public awareness in Northern Ireland³.

Studies have been conducted in India across different populations including parents of children with special needs⁴, as well as professionals like special educators, speech language pathologists, and nurses. Research aimed to study knowledge of autism among parents and also study the association of knowledge to the demographics of parents revealed that among 50 parents who participated in the study, 52% parents had moderately adequate knowledge, 42% had inadequate knowledge and only 6% parents had adequate knowledge. No significant association between knowledge level and demographics was found. In another study, knowledge and training of special educators about autism was studied⁵. Results of the study showed that special educators had low levels of understanding of autism, classroom behaviors of children with autism and educational programs for autism. Their study laid emphasis on need for improving awareness of autism and training programs for special educators. In another study, knowledge and belief of 219 Speech language pathologists (SLP) was assessed on the assessment and intervention of autism in Indian context. It was a web based online survey⁶. The results of the study show that around 43% of the SLPs who participated in the study obtained a good score on the knowledge section and 27% received a positive rating for the belief section. Factors like "educational qualification," "duration of clinical experience," and "caseload of children with autism" appeared to influence knowledge and beliefs of SLPs about autism. The researchers concluded that SLPs in India show average and below average scores on a questionnaire that assessed their knowledge and beliefs regarding autism. Therefore, there is a need to develop improved training programs and course structures related to assessment and intervention of children with autism for SLPs practicing in India. Knowledge about autism among nurses in Bangalore Karnataka was studied. 52 nurses participated in

Appendix I A

Pre Awareness Questionnaire

Q. no.	Questions	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	People with Autism Spectrum Disorder have problems in communication.					
2	People with Autism Spectrum Disorder give eye contact.					
3	People with Autism Spectrum Disorder have behavior problems.					
4	Autism Spectrum Disorder is caused due to bad parenting.					
5	Autism Spectrum Disorder can be completely cured.					
6	Some People with Autism Spectrum Disorder repeat/imitate what you say without understanding.					
7	People with Autism Spectrum Disorder have feelings/emotions like other people.					
8	Autism Spectrum Disorder is seen only in children and not in Adults.					
9	People with Autism Spectrum Disorder have repetitive behaviors (E.g. Hand flapping, rocking back and forth)					
10	All people with Autism Spectrum Disorder do not have same behavior.					
11	People with Autism Spectrum Disorder use appropriate gestures.					
12	People with Autism Spectrum Disorder (always) respond to their name.					
13	None of the people with Autism Spectrum Disorder can speak					
14	People with Autism Spectrum Disorder can maintain conversations.					
15	Children with Autism Spectrum Disorder have normal play behaviours.					
16	People with Autism Spectrum Disorder find it easy to be in a new environment.					
17	People with Autism Spectrum Disorder may not tolerate loud sounds.					
18	People with Autism Spectrum Disorder may not have perception of danger.					
19	Children with Autism Spectrum Disorder can have emotional and sensory meltdowns (crying, lying on the floor etc) in public places (due to sensitivity to lights and sounds in the mall)					
20	Learning to read and write is difficult for people with Autism Spectrum Disorder.					
21	People with Autism Spectrum Disorder have an unusual attachment towards an activity/toy/object.					
22	Children with Autism Spectrum Disorder cannot be enrolled in school.					
23	ALL children with Autism Spectrum Disorder have some special abilities.					
24	Some people with Autism Spectrum Disorder can be employed.					
25	ALL people with Autism Spectrum Disorder understand jokes and sarcasm.					

the study⁷. The study revealed that most of the participants had a moderate level of knowledge about autism. Thus, the level of awareness among specific populations dealing with ASD also appears to be moderate.

A study similar to the present study was conducted where parents of children attending regular school participated in study⁸. The aim of the study was to develop an ASD awareness program and study its effectiveness. Scores of 200 parents before and after the awareness program were compared. The pretest revealed that most parents were unaware about characteristics of autism spectrum disorder in the domains of social interaction difficulties, speech and language skills delay, motor developmental skills delay and availability of individualized education programs. Awareness program in the form of e-learning with pictorial description on slides and a pamphlet on ASD as a takeaway was provided to the participants of the study. The study reported significantly improved scores of posttest, and hence it was concluded that the awareness program was useful for creating awareness about ASD among the parents of children in general schools. The results of the present study are similar. In addition, in the present study retention of information one to three months post awareness program was also studied. Retention of information was found to be lower than the level of information immediately post awareness program in the present study indicating a need for continuous awareness campaigns and programs for public awareness.

CONCLUSION

The study reveals that the awareness about characteristics of autism spectrum disorders in the general public appears to be moderate and is not affected by age, gender or education. Public education through power point presentation developed by the researchers can be effectively used for creating awareness regarding autism spectrum disorder among people; however regular follow up awareness programs and campaigns should be undertaken for retention of the information.

Post Awareness Questionnaire

Q. No	Questions	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
1	There is a definite cure for Autism Spectrum Disorder.					
2	All people with Autism Spectrum Disorder have different behavior.					
3	Just like others, People with Autism Spectrum Disorder also have feelings/emotions.					
4	Behavior problems are seen in people with Autism Spectrum Disorder.					
5	Communication problems are seen in people with Autism Spectrum Disorder.					
6	Giving eye contact is not difficult for people with Autism Spectrum Disorder.					
7	Bad parenting causes Autism Spectrum Disorder.					
8	Special abilities are present in ALL children with Autism Spectrum Disorder.					
9	Only children have Autism Spectrum Disorder while adults do not.					
10	Schooling is not possible for children with Autism Spectrum Disorder.					
11	ALL people with Autism Spectrum Disorder communicate without speaking.					
12	People with Autism Spectrum Disorder have no difficulty in using appropriate gestures.					
13	Normal play behaviors are seen in children with Autism Spectrum Disorder.					
14	Loud sounds may not be tolerated by people with Autism Spectrum Disorder.					
15	ALL People with Autism Spectrum Disorder have no difficulty understanding jokes and sarcasm.					
16	People with Autism Spectrum Disorder find it difficult to learn to read and write.					
17	Adjusting to a new environment is not difficult for people with Autism Spectrum Disorder.					
18	Maintaining a conversation is not difficult for People with Autism Spectrum Disorder.					
19	When people with Autism Spectrum Disorder are called by their name responding immediately is not difficult.					
20	Repetitive behavior (hand flapping, rocking back and forth etc.) are seen in people with Autism Spectrum Disorder.					
21	Repetition/Imitation without understanding is seen in some people with Autism Spectrum Disorder					
22	Unusual attachment to a certain object/activity/toy may be present in people with Autism Spectrum Disorder.					
23	Employment is possible for some people with Autism Spectrum Disorder.					
24	Going in a public place where there is noise and bright lights is difficult for people with Autism Spectrum Disorder.					
25	Perception of danger may not be present in people with Autism Spectrum Disorder.					

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