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The Social Lives and Work Experience of Adults with High Functioning Autism: An Indian Scenario

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This issue of ***NASET's Autism Spectrum Disorder series*** was written by Sanpalei Nylla Lyngdoh from Texas Tech University. The purpose of this exploratory study is to attempt to understand how ASD affected the social lives and work of individuals at adulthood stage. The ability to attribute mental states to self and others is called Theory of Mind. The lack of theory of mind means that individuals with ASD have difficulty understanding others' points of view; drawing inferences from what others say, and extracting the thoughts and assumptions of others from their words and actions. The study aims at exploring how ASD affects individuals in their social lives and how it affected them at their workplace in India. Findings and implications are discussed.

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Abstract

The purpose of this exploratory study is to attempt to understand how ASD affected the social lives and work of individuals at adulthood stage. The ability to attribute mental states to self and others is called Theory of Mind. The lack of theory of mind means that individuals with ASD have difficulty understanding others' points of view; drawing inferences from what others say, and extracting the thoughts and assumptions of others from their words and actions. The study aims at exploring how ASD affects individuals in their social lives and how it affected them at their workplace in India. Findings and implications are discussed.

Keywords

Autism Spectrum Disorder (ASD), adults, social lives, work experiences, India

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder and individuals with ASD tend to experience sensitivity being in close proximity with others, engaging in eye contact and receiving physical stimulation, failure to understand non-verbal cues all of which are components necessary for successful relationships. There has also been an increase in diagnosis of ASD in adults (e.g., Eriksson et al., 2013 and Pilling et al., 2012) but there is still paucity of research on adults with ASD in India. ASD poses a much greater and serious challenge in countries like India, because of the severity of the impact on the affected individuals and their families, along with the economic burden that it imposes coupled with lack on scientific know how about the disorder (Daley, 2004). Due to lack of awareness about the condition, often, misdiagnosis or inclusion of ASD under the general category of mental retardation and/or speech and language disorders is commonly noticed (Singhi & Malhi, 2001). A total of only eight articles have been published on adults with autism (Bannerjee, 1975; Abhyankar et al., 1981; Duggal et al., 2001a, 2001b; Chaudhari et al., 2008; Arora et al., 2011; Barua, 2007; Sharma et al., 2013). Yet, there are no significant studies focusing on social lives and work experiences of these adults. Only one study (Daley et al. 2014) looked into the daily routines and activities during a typical day of adults with autism in India. So the purpose of this exploratory study is to attempt to understand how ASD affected the social lives and work of individuals at adulthood stage.

The present paper is based on the 'theory of mind' (ToM).The term 'theory of mind' (ToM) comes from the work of Premack and Woodruff (Parsons & Mitchell, 2002), who used it to described the ability to attribute mental states to self and others. Howlin (2008) defines Theory of Mind as "the ability to attribute mental states - intentions, beliefs, desires, pretense, knowledge, understanding etc. to oneself and others. It enables an individual to understand that mental states affect others behavior and actions and can thus both explain and predict their behavior. It also involves the ability to understand that other people's mental representations of the world do not necessarily reflect reality and can be different from one's own." Lacking theory of mind means that individuals with ASD have difficulty understanding others' points of view; drawing inferences from what others say, and extracting the thoughts and assumptions of others from their words and actions (Baron- Cohen, 1999). Baron-Cohen (1995) used the term 'mind-blindness' to described this deficit. Difficulty with theory of mind may make it difficult for individuals with ASD to place themselves in the perspective of another. Feeling emotional reactions to others' circumstances may lessen the ability of individuals with ASD to feel empathy towards others.

ASD can also be hidden in adulthood when an individual's intellectual ability is high and environmental support is good; however, over time and in unexpected situations, the façade of normality cannot be maintained (Frith, 2004). Many of these individuals described themselves as feeling like "outsiders" often being excluded educationally and socially and knowing they are different without understanding why (Portway and Johnson, 2003). Griffin et al (2012) found that social interaction was perceived by participants as being fraught with potential problems, such as maintaining eye contact, knowing when and how to join and/or conclude a conversation, and also understanding social nuances. Additionally, some reported sensory overload problems: noise, strong lights, and smells could become so overwhelming it was difficult to focus on anything.

In the work setting, adults with ASD can be excellent employees in terms of job performance, but may be perceived as difficult due to poor people skills and behavior challenges. Even though they may have good job training, attention to detail, and a dedication to work, they are frequently under employed (Schall, 2010). Many are employed only with the help of supported employment programs (Hagner & Cooney, 2005; Howlin et al., 2005). Sensory issues persist in adulthood and carry over to affect performance in all areas including the ability to be successful in a typical work environment.

Method

Participants consisted of three male and one female adults already diagnosed with ASD. They were recruited from the autism center situated in New Delhi (India). All were adult participants, who were eligible and currently in the work force (work in the center). Criteria for inclusion in this study included a prior diagnosis of ASD and at the high functioning end of the spectrum, age over 18 years, had attended school before and willingness to participate. It was important that a diagnosis of ASD had been received by each of the participants. In order for the researcher to be able to identify that all the potential participants had this diagnosis, a clinical psychologist who worked with them gave a confirmation of their diagnosis. An informed consent was taken from the participants after detailed explanation of the rationale behind the study and about the questions in the questionnaire.

Care was taken to ensure confidentiality of the data collected for the study. The study protocol was reviewed and approved by the autism center IRB. In this study, self-reports, observation checklist, observation, informal conversational interviews of short duration and review of archival records was used.

Self-reports was also used in order to address the participants' discomfort with direct, face-to-face interaction which they cannot sustain for long. The written response format of the self-report is seen as complementary to the spoken format of a semi-structured interview. Hence quotes from the self-report were used. Content validity procedure was followed to ensure validity of this tool. The tool was inexpensive, easy to use and allowed respondents to fill them out privately, in their own time. In this study too, the researcher made use of observation checklist by coworkers of the participants in the study to assess environmental characteristics, that is, characteristics of the participants observed at workplace. The main aim of using a coworkers' checklist was to determine the degree to which each participant exhibit the traits or behavior or quality of that behavior and each trait was rated on a continuum from 0 to 4: 0 indicated not at all/does not apply, 1 indicated mild/sometimes observed/applies to some extent, 2 indicated moderate/often observed/certainly applies and 3 indicated severe/frequently observed/strongly applies. The role of the observation checklist was to assess the characteristics, strengths and weaknesses of the participants seen at workplace. This tool allowed the researcher to get the views of someone who knew the person well and who had greater opportunity than the researcher to observe him or her in a natural setting. The researcher also observed during a summer break camp where the participants of the study had volunteered. She observed their interaction with other children with autism, their non-verbal cues, body language and postures and their interaction with other volunteers.

Open-coding was used in the data analysis to identify common themes, identifying, naming, categorizing, and describing phenomena (Glaser, 1992; Creswell and Miller, 2000; Strauss and Corbin, 1990).

Findings

All participants have ASD, are over 18 years and had attended school before. The participants are referred to as Mr. A, Mr. B, Mr. C and Miss. D. Three participants are single and only one is married.

Social experiences

Voice, gesture and body language. The participants' lack of body language was rated by coworkers as sometimes observed or often observed at the workplace. The researcher also observed that two of the participants displayed an unusual gait. This was also confirmed by the coworkers' checklists. In terms of gestures, Mr. B incorporated the use of his hands to enhance the meaning of his verbal explanations on what the items he was selling was all about, although he managed to give only short explanations. Similarly, during summer camp, Mr. C used gestures to indicate to the researcher to sit properly and not cross her legs. He indicated to the other staffs to do the same. He got furious when the researcher accidently crossed her legs again.

Eye contact. The participants lacked appropriate eye contacts during social interactions. When the researcher smiled at him, it was not reciprocated; instead Mr. B looked around himself. This observation was also confirmed as frequently observed by his coworkers. It was also noticed that Mr. A and Mr. C maintained minimal eye contact during conversation which was also sometimes observed by his coworkers. However, in case of females, researchers have suggested that characteristics, such as lack of social interaction, are less intense than that expressed in males with ASD (Kopp & Gillberg, 1992; Hully & Larmar, 2006). This was seen in Ms. D's case, where she initiated conversations with the researcher, trying to know who she was and what the purpose of the researcher's visit was. But her eye contact was fleeting throughout her interaction. Yule (2008) suggested that eye contact is avoided because people with ASD are highly sensitive and fear what they may encounter when meeting another person's eye.

Social life. Participants in this study have few social contacts. For instance, Mr. B said that he lived with his dog. In terms of friendship, all the participants in the study were keen in making friends and reported that they need help in making friends and it was difficult for them to make new friends. One participant had no best friend and the others have one or two persons whom they called best friends. Two preferred working out their own problems while the other male wanted to try and forget about the problem. Miss D liked to share her problems with friends and liked going out with her friends once a month. Orsmond,

Wyngaarden-Krauss & Seltzer (2004) reported that the participants in his study showed absence of peer relationships outside pre-arranged settings, for example, outside of workplace. This was echoed in the study too when one of the participants reported – 'I like to interact with people but my circle of friends continues to be limited and most of my friends are from AFA (workplace).'

Workplace experiences

Social interaction. Participants experienced workplace difficulties due to deficits in social and communication skills. Avoiding eye contact was observed by the researcher as well as coworkers in all the participants. The coworkers also reported that they sometimes observed that 3 participants preferred solitary activities. Two participants were reported that they were unable to focus on group goals when they are members of that group. Two participants did not initiate/join in activities, for instance during activities Mr. A stares intensely at people/objects. One participant had difficulty with the social interactions and understanding how to interact with others, he said, 'I have difficulties in social understanding because of which I have had difficulties at home, at school and also later at work'.

Workplace conflicts. The participants often experienced high levels of anxiety in response to criticism and conflict do aroused because of their difficulties in coping with change in work schedule or activities.
Mr. A: 'Sometimes, it is difficult for me to handle negative remarks, harsh words and anger around me'.
Mr. B: 'When I get hurt or done wrong I scold with someone'.
Mr. C:' I am unhappy or sad when nobody listens to me'.
Ms. D: 'I get unhappy or sad if anybody underestimates me or humiliates me near other people or if anybody discourages me'.

Working style. Three participants (A, B and C) preferred to sit in one location at their workplace. Coworkers in this study also observed that the participants have difficulties coping with change, with Mr. B being frequently observed that he had difficulties with any change in the daily routine followed by Mr. A and Ms. D. Mr. B was also noted that he liked to arrange objects in a specific way. These participants preferred sticking to routines and all of them needed a lot of preparation when routines were changed. Moreover, all participants showed difficulty with task initiation and task completion so they worked better if the work was explained to them clearly and broken down the task into small steps.

Mr. A said, 'I work better when the job is explained to me in a clear direct manner and I am given a time frame. The work can be easy or tough but breaking it into small simple steps makes it less complicated'. Mr. A was also sometimes observed that he did things over and over to make them right. The researcher observed that the participants in the study arrived at work on time which can be seen as strength among workers.

Sensory sensitivity. Adults with ASD have sensory sensitivities, especially to noise which can cause difficulty in work settings. Mr. A stated: 'Sometimes, it is difficult for me to handle loud and unwanted sounds…Sometimes going out for a walk helps me de-stress'. All the participants disliked particular sounds and smells. It was seen that something as simple as a clothing tag or a certain fabric or a crowded room can induce a full-blown meltdown tantrum because the child is overwhelmed. Although the reasons for her meltdowns were unknown to the researcher, Ms. D wanted to mitigate and control her reactions. She said, 'I want to stop throwing tantrums at home with mom and at times I am rude to people'.

In the area of motor functioning, Mr. B and Mr. C showed problems with handwriting, cutting and drawing and both have unusual ways of walking.

Discussion

Results from this study showed that the participants in this study vary widely in terms of their abilities and disabilities, problems and needs. Some appeared awkward in their interaction with the researcher, forgetting to make eye contact or to smile; others used gestures instead of talking or used it to enhance their explanation. Lack of theory of mind meant that individuals with ASD have difficulty understanding others from their words and actions (Baron- Cohen, 1999).

The participants in the study lacked eye contact when making conversations. Their difficulties in reading social cues and understand others actions and perspectives meant that they do lack theory of mind.

Happé (1993), in her research into the connections between pragmatics and theory of mind, noted that people with Asperger's syndrome tend to make literal interpretations of what someone says and may not understand when someone is joking. This would suggest that people with ASD, who were described as lacking Theory of Mind, would have difficulty with certain aspects of humor such as jokes and sarcasm. However, the present study showed that most of them understand jokes. When asked what made them laugh, Mr. A and Mr. B replied watching movies which are funny. Mr. C said "when somebody jokes or a thing is funny" and Ms. D also replied "jokes and at times I laugh for no reason".

Regarding sensory sensitivities, their sensory issues have not been dealt with when they were children; hence it was a difficult time for them fitting into the roles of adults now which was seen in the problems they have at their workplace. Mr. A's hypersensitivity to sound made him valued a quite environment. Sensory issues induced tantrums and Ms. D had problems with meltdowns and tantrums. These sensory problems were undiagnosed during their childhood and adolescence lives which interfere with their ability to attend and learn at times. Because their sensory problems were not addressed as children or adolescents, they still struggle with their problems as adults and it affected their work too.

The positive aspects of these participants were also not overlooked in this study. In terms of memory power, they have a good rote memory. Mr. B and Ms. D were very attentive to details. The researcher felt Mr. B's propensity of giving detailed descriptions may be useful in providing directions to visitors in the workplace. He gave the researcher directions too. The participants have strong work ethics; they arrived at work on time, tidy their work area before starting their day and focus on their work. Participants channeled their special interests in computers to help them with the job such as Mr. A, who is very much interested in computer applications used it for his work in calculations and maintaining accounts. Ms. D was interested teaching computers and finding worksheets for her children in school from the internet. Her use of language in interaction and in her self-report was stronger as compared to the male participants. Moreover, the participants were not totally isolating themselves; they have different leisure activities at weekends.

Thus, the data gathered confirmed that the participants had difficulties in social interaction; difficulties at workplace but the data also refute the claim that people with ASD lacked the use of gestures and body language, did not understand jokes and preferred isolation. Based on the results of this study, it also appeared that they long for friendship and social connectedness, and derived satisfaction from making contributions at workplace.

Participants stressed the importance of attitudinal supports from family members and coworkers which includes a patient and caring attitude and an understanding and respect towards them. For instance, Mr. B was unhappy when others did not understand him and Ms. D felt unhappy when others underestimated and humiliated her. Positive attitude towards people with ASD will go a long way in terms of alleviating their feelings of isolation and social estrangement.

Limitations of the study

Three limitations were found. First, because the sample was small, the findings of this study were related only to the cases involved and generalizations to the wider population of people with ASD in India cannot be made. Second, biases may be present in the participants in reporting themselves as well as the coworkers rating them. And third, the participants were taken from one geographical area and from one specific site, hence the study could not give more diverse insights as there was no cross comparisons of geographical areas or sites.

Implication for future research

Very little information is known concerning the study of how ASD affects the adults and those around them in the workplace in India. However, the insights expressed by the participants in this study provided a glimpse into the lives of adults with ASD, the impact it has had on their lives, and what they want others to know about being an adult with ASD. More research is needed to illuminate the study in a larger, more ethnically diverse sample; further research might also include executive functions, social/emotional functioning, and quality of life of persons with ASD. Also, more information is needed about best practice in the systems of which these individuals are a part such as families, schools and places of work. Further research could assist in development of information that would inform families and professionals about

ways to remove barriers to their success in school, work and other social settings. Finally, there is also a need for further qualitative research to be conducted to provide 'insider' views from persons with ASD so that a greater understanding of the challenges and difficulties faced by these people can be drawn, thus enabling professionals to better understand and meet their special individual needs.

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