

Specific Challenges Faced by Girls with Autism Spectrum Disorder A Case Study

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Abstract

Autistic girls face complex and diverse challenges. The present study aimed to study the specific challenges faced by girls with autism spectrum disorder. The investigator had used the case study method, for which a seventeen-year-old autistic girl, along with her mother, was purposely selected for the data collection. Results based on the data collection had listed various challenges that this autistic girl has been going through.

Keywords: Autism, Specific challenges, Autistic girl, Menstrual Cycle, Discrimination

Introduction

I was attached to a special school for data collection purposes for my PhD thesis when this beautiful little girl, named Allen, an autistic girl, intrigued my interest. She had a habit of eating salt, a bowl full of salt. She would cry or shout at the top of her lungs whenever that bowl was taken away. Staff at the school were instructed to hide bottles/packets of salt, which were used in the small kitchen of the school. Later, I observed that the same girl had some sort of itching issues in her vaginal area. I heard once a lady staff member saying that either Allen eats salt all day, or she keeps itching her private parts (which bruises her vagina). I don't know why, but after hearing this, I realised that there is some connection between itching with the salt. After searching for many websites and research papers, I understood that some autistic children may eat excessive amounts of salt due to sensory sensitivities, preference for intense flavours, or as a way to self-soothe or cope with stress, which in turn causes hypernatremia. "Hypernatremia" is a condition where there is too much sodium in the blood, which can affect urination patterns and potentially cause itching in the vagina. I kept on thinking about the pain and uneasiness this little autistic girl, Allen, must be bearing/holding due to the condition. Though, as per the data, autism spectrum disorder is more prevalent in boys than girls (Wilson et al., 2016), the ratio is 4:1 (Baron-Cohen et al., 2014). But after coming across Allen, the need to address specific challenges faced by autistic girls sparked in my brain.

Autism Spectrum Disorder

Autism is a developmental disability. Individuals with ASD often have difficulties with social communication and interaction, and restricted or repetitive behaviours or interests. It creates a miscellaneous group of conditions and symptoms related to the progress of the brain. About 1 in 100 (WHO,2023) children have autism. Individuals with autism often have comorbid conditions (WHO, 2023), including epilepsy, depression, hyperthermia, anxiety, attention deficit hyperactivity disorder, difficulty in sleeping, and are prone to self-injury. The comorbidity makes their life way too challenging, as many times in the presence of one condition, the symptoms of another condition get camouflaged.

Autism in Girls

Females are more likely to display concealing or masking (Schuck et al., 2019) the symptoms of autism than boys, often leading to delayed diagnosis. Sex differences have been reported in autistic traits and systemising (male advantage), and empathising (female advantage) among typically developing individuals (Baron-Cohen et al., 2014). While boys may display more apparent behavioural challenges, girls are more likely to internalise their symptoms, experiencing anxiety, depression, and social difficulties that may be unnoticed. In the dearth of timely identification, detection and intervention, the challenges faced by girls are explicitly specific. They are specific in all sorts of dimensions, viz, mental, physical, physiological, social, and anatomical.

Significance of the Study

The present study is central and decisive because this study will help in understanding the exclusive challenges a girl with autism must be living with, also the study will assist in understanding the necessity of support systems. This research is especially significant because autistic females are often underdiagnosed or misdiagnosed, leading to a lack of appropriate support and increased vulnerability to mental health issues, physical health issues, abuse, mishandling, exploitation and other challenges.

Objective of the Study

1. To study the specific challenges faced by girls with autism spectrum disorder.
2. To provide suggestions for overcoming the challenges faced by girls with autism spectrum disorder.

Delimitation

1. Only a 17-year-old girl with ASD was selected for the study.

2. A girl with ASD who was already labelled and studying in a special school in Lucknow city was selected for the study.
3. A girl with level-1 autism was selected for the study.
4. Only 01 parent, the mothers of the girl, was selected for the study.

Methodology

As a case study, this is a preliminary investigation of a phenomenon over which we had little control (Yin, 2017). According to Miles et al. (2019), a case is “a phenomenon of some sort occurring in a bounded context”. As the researcher seeks an exploration of specific challenges faced by girls with ASD, the Case study method was used in the study. Furthermore, this is an exploratory case study given that it was not intended to test a particular hypothesis (Yin, 2017). As noted by Hancock and Algozzine (2011), exploratory case studies serve as a prelude for more expansive investigations that might seek to work with a concept in a more in-depth manner. Given the small sample size, our findings are not generalizable.

Population

All the girls who are labelled as autistic make up the population of the present study.

Sample

Keeping in mind the onset of puberty, menstrual cycle and various bodily changes (so that specific challenges can be studied), a seventeen-year-old autistic girl was selected for the present case study. As the girls remain close to their mother and generally mothers look after the child, so mother of this girl was also selected for the study.

Sampling

The Purposive sampling technique was employed by the investigator to select the sample. Firstly, a list of all the autistic girls studying in the Rainbow Society for autism was made by the researcher. Secondly, out of the above list, the investigator has purposely selected a 17-year-old girl who was labelled as level-1 autistic.

Tools

As the investigator has to collect the data, keeping in mind the specificity of the challenges faced by autistic girls. There weren't any standardised tools available, so investigators had developed an interview schedule for collecting data from the mothers of the autistic girl.

Theoretical Framework

The present case study is framed around the “Social Role Theory”. This theory impacts the course of socialisation and personality development through the person's input in increasingly diverse and intricate social roles. Social role theory claims that gender differences in behaviour

stem from the division of labour in society and the parts that men and women inhabit. It assumes that societal roles, shaped by biological factors and then reinforced by cultural norms and expectations, influence how individuals perceive themselves and others, leading to distinct gender roles and stereotypes. The investigator has noted that the idea of specific challenges faced by women in societal settings is not a new one; it has been documented throughout history.

Context

The case study was carried out at a private special school for autistic children approved by RCI. Though the school is specifically for autistic children, children with other types of disabilities are also enrolled there. The total of this school is 108, out of which 37 are autistic children. It was found that out of these 37 autistic children, only 07 were girls, as the prevalence of autism is higher in boys. Out of these 07 autistic girls, only 02 girls were teenagers, i.e. puberty had hit. Out of these two girls, only one parent permitted the collection of the data.

The school is run by a lady, the principal of the school. The staff of the school is predominantly female, including teachers and Aya Didi. A few male therapists were also working there. The school runs its school bus; the driver and conductor are male.

Participant

The participant is a seventeen-year-old autistic girl who lives with her mother, brother and grandmother. She had lost her father a few years back. As per her mother, she was born normal- a chirpy little girl. She danced on her first birthday, and everything was going well. Before her second birthday, she started showing the symptoms of autism. She attends the school regularly, along with the therapies being provided at the school itself. A cafe is being run by this school, and the participant is among the few special children of this school who are being trained to run this cafe.

Data Collection

A total of eleven visits were carried out by the investigator, with seven at school and four at the cafe run by the school. Visits were typically on Mondays and Wednesdays, though one of the visits was on other days of the week due to events at the school, due to which the investigator was unable to meet the mother of the child or observe the child. The researcher has chosen Monday and Wednesday because, as per the timetable, the child had to undergo the therapy sessions as well, along with the regular classes. The mother had permitted the investigator to video record the interview session. In the entire eleven-day visit, interview sessions lasted around two hours every day. There was not a single problem encountered by the investigator

while interviewing the mother of the participant, as she was regularly accompanying her daughter to school, and remained sitting outside the classroom till the school day was over. Besides, this mother was very genial with the investigator. The investigator also tracked/observed the frequency of certain behaviours exhibited by the autistic girl in the school and cafe.

Limitations

Case studies, predominantly those that are exploratory and utilise within-case investigation, are not generalizable as they concentrate in-depth on one particular case to thoroughly comprehend some facet of that case. Added time observing the participant and leading the study over an extensive period of time would have given a more vigorous set of data. The investigator could not get permission to interview the brother and grandmother of the autistic girl. Also, the investigator could not observe the child at her home because of a personal reason, as quoted by the mother.

Data Analysis

Miles et al.'s (2019) method on qualitative data analysis is followed in the present study. The investigator had analysed in two phases of coding on the interviews. The first cycle of coding employed numerous kinds of coding, including descriptive, in vivo, and emotion coding. The purpose of the first cycle of coding was to précis the obtained data. The second cycle of coding helped to recognise outlines in those codes. Codes were then assembled into groups or themes. Later investigator marked down the themes. Following the use of jottings of marked themes, analytic memoing was designed, which assisted in “synthesize (descriptive summaries of data) into advanced level analytic meanings”. Analytical memos spread and join numerous data with theory and the researcher's observations.

To formalise and organise the answers given by the mother of the autistic girl and observations made by the investigator, the investigator had produced assertions and propositions (based on both sources of data). These statements allowed the investigator to look at the findings broadly and better determine the entire picture, based on the available data.

Results, Findings and Discussion

Being a woman is beautiful. But it can be challenging being a woman at times. It could be more challenging when a womanhood is co-morbid with autism. Based on the data collected from interviewing the mother of an autistic girl and observation done by the investigator, the following findings are analysed by the investigator-

I) Menstrual Cycle Related challenges:

The inception of menses (menarche) is a significant—and often challenging (Burrows and Johnson,2005)—transition in any woman’s life. This is especially the case for developmentally-disabled women, who may experience menarche and menstruation contrarily—and more undesirably—related to non-disabled women (Ditchfield and Burns, 2004; Rodgers and Lipscombe, 2005). While there are no significant differences in the age of menarche between autistic girls and girls with other developmental conditions (Burke et al., 2010), there are several reports (including case studies) of marked changes linked to menarche and menstruation in autistic girls and women (the majority with additional intellectual disabilities), including cyclical self-injurious behaviours (Lee, 2004), mood symptoms and emotional dysregulation (Burke et al.,2010; Hamilton et al.,2011; Lee,2004; Obaydi and Puri,2008), and an amplification of autistic symptoms (sensory issues and repetitive behaviours; Hamilton et al.,2011; Lee,2004).

1) Track of Menstrual Cycle:

Keeping track of the menstrual cycle is the whole and sole responsibility of the girl's mother. The autistic girl has no idea that she will undergo this process every month. Mother quoted- “Generally, I set an alarm on a mobile application, but in case of being early or delayed cycle, things get messed up. Mother cited that many times her daughter had returned home unaware that her menses had started during school hours in dirty menstrual clothes.”

2) Irregular Menstrual Cycle:

As per the data obtained from the girl’s mother, the participant generally experiences irregular menstrual cycles, including missed periods, longer or shorter cycles. Mother quoted- “It is very difficult for her/ school staff to predict the onset of girls' menstrual cycle, which could be due to hormonal changes or medications”

3) Pattern of Bleeding:

Menorrhagia, or heavy or excessive menstrual bleeding, is noted by the mother. Despite taking medicines from a gynaecologist, no marked changes had been observed in the pattern of bleeding. Sometimes she is required to change 5-8 sanitary pads.

4) Cramps during Menses:

On asking this particular question girl’s mother started crying and said, “It must be difficult to handle a special child, but it is way more difficult to handle an autistic child, that too going through a menstrual cycle”. She mentioned first three days of every cycle remain very painful, full of cramps, which her daughter could not even communicate to her. All they could do as a

family was arranged for hot water bottles, which sometimes her daughter wouldn't allow her to apply. Mother cited-

"Our family could never forget her first menstrual cycle and cramps, she was so restless that even our neighbours noticed that something was unusual with my daughter".

5) Management of Sanitary Napkins:

The girl has not yet learnt to use and change a sanitary napkin; this is done by her mother only. Mother quoted-

"Of late, her daughter has started wrapping up used napkins after proper direction."

Mother has to look after the menstrual hygiene of her daughter as her daughter experiences heightened sensitivity to the physical sensations associated with such as blood flow or the discomfort of sanitary products.

II. Abuse and Molestation Related Challenges:

The majority of research literature to date has fixated on the peril and pervasiveness of victimisation in autistic youth. Autistic adults experience more relational ill-treatment than non-autistic adults, and the collective pervasiveness rate for poly-victimisation across the lifetime in autism is 84% (Weiss & Fardella, 2018; Thrundle et al., 2022). Autistic youth are three to four times more likely than non-autistic youth to experience sexual victimisation, and between 40% and 50% of autistic adults report experiences of sexual abuse during childhood (Thrundle et al., 2022; Weiss & Fardella, 2018). Similarly, autistic adults report a higher prevalence of sexual harassment and abuse than the neurotypical population (Gibbs et al., 2021). It is critical to note that victimisation is more common among autistic females than autistic males and the neurotypical population (Cooke et al., 2025).

1. Difference between Good touch and bad touch

As per the data gathered, the autistic child was able to differentiate between good touch and bad touch. The mother explained this by saying that she has observed her daughter generally avoid going near unknown people, especially males. But nothing firm can be uttered on this, as such children lack communication.

2. Autistic girls are more prone to sexual abuse:

As per the details obtained, no such thing had happened with the participant. But her mother accepted that the probability of coming across such abuse is higher with her daughter, as she is autistic. Being autistic brings her more chances of repeated sexual assault or abuse, as she lacks any kind of communication. Her daughter even lacks speech; in that case, she can't ask for help if such a situation arises.

“Mother has mentioned this very clearly. When it comes to the safety of my autistic daughter, I can't rely on anybody. I daily accompany her to school and remain seated outside her classroom. I make sure her therapy sessions are done right in front of my eyes, as many males are working there as therapists”.

The mother of the girl showed her concern while mentioning that sometimes her daughter starts removing her clothes in front of anyone, further she added that it could be due to an allergy to sensory issues. Mother cited-

“I want to make sure that my daughter learn as soon as possible that she must not remove her clothes only in her room”

3. Safety Concerns at Public Places:

As per the data, the participant remains at high risk of exploitation and difficulties in navigating social situations in the absence of communication and social impairment, which are the core characteristics of autism. It had been observed by the mother that her daughter either starts shouting or puts her hands on her ears might be due to sensory overload from noise, crowds, and bright lights.

The mother of the participant mentioned-

“A very good initiative by the school has been taken to run a café, where they train special children for public dealing. My daughter is also being trained there, but I again accompany her there as I don't have faith in anyone”.

4. Lack of ability to commute independently:

Due to a lack of social interaction, navigating public transport is difficult for the participant. Public transport has difficulties with spatial awareness, potentially leading to safety concerns in crowded or unfamiliar environments.

The mother of the participant cited-

“I don't allow my daughter to commute by bus provided by the school bus, as it lacks any female staff”.

III. Discrimination-Related Challenges:

People with autism may happenstance countless instances of discrimination (Cleary et al., 2023). For example, tertiary students with autism who, after revealing their diagnosis, report being rejected from real-world placements because of a reluctance to accommodate autism or other disabilities in practice-based settings (Sullivan, 2021).

1. Discrimination in the family:

As per the information provided by the mother, the participant's grandmother and brother are very caring and look after her whenever and wherever needed. But a lot of discrimination has been faced by the family when it comes to the extended family, as they never fail to realise them by posing fake concerns. Mother with utter grief on her face quoted-

“I have heard people saying kuch bure karm kiye honge in hone (some bad deeds must be done by them)’

“Hey Bhagwan!!Ek to ladki, upar se autistic, kya hoga iska (oh god, what will happen to this poor autistic girl)”

“Is pagal ladki se shadi kon Karega (who will marry this mad girl)”

The Mother of the participant very firmly mentioned that we have stopped going to such family/social gatherings, which only demotivate us. We remain happy in our world. The mother also recalled that one of his relatives had changed his residence when they were expecting their first baby, as they believed that the shadow of my daughter might bring misfortune for their unborn child.

2. Discrimination in Education:

Research has constantly reported discrimination across all levels of education. Discrimination can take the form of rejection to enrol the child, dismissal from the school, elimination from the class setting to another location, deferral from school, exclusion from educational activities, or refusal to make reasonable adjustments to accommodate an autistic person's needs (WHO,2022). At its worst, there have been instances of autistic students being locked inside a small room by teachers to provide ‘time out’ (9News, 2015) and, in one instance, even being locked inside a cage during times the autistic student exhibited extreme distress (Cleary et al., 2023b).

In the present study, though no discrimination at her present school is observed, but mother expects more avenues for such children, as present schools are not well equipped, lack trained teachers, and a curriculum. One thing that this mother kept on mentioning is the need for special safety for such girls in and out of school premises.

IV. Challenges related to healthcare

Discrimination can be found in the processes that support autistic people to access health care, and the responses of health professionals. Discrimination by the health system and staff is often the result of a lack of knowledge and skills relating to various disabilities, including autism (WHO, 2022).

In the present case study, time-to-time anxiety, depression, mood swings, sleep disorders, and eating disorders have been reported in the case of the participant, which could be attributed to hormonal fluctuations and sensory sensitivities. But no proper test/ medication is available.

Also, again, it is very risky for such girls to visit any kind of healthcare with proper assistance, despite attaining the age of seventeen.

V) Future-related Challenges:

1) Marriage:

Marriage or relationship or having a family for such girls is a taboo in society, as nobody would take the chance of marrying her. The first statement mentioned by the mother on the question related to marriage, and she became emotional; she took a long pause. Later, on her own, she again started this topic and said-

“Her grandmother and I both are willing to marry her; there must be someone for my daughter as well. God must have sent her soulmate. I don’t have big dreams; I am looking for a suitable boy, maybe an autistic or disabled one. Maybe in future, when we are not here to look after her, they both will be there for each other.”

2) Employment:

It is very difficult for the autistic girl to find any job or run any sort of business because of her symptoms. The family is spending a lot on the autistic girl; the amount is so much that they have to cut the spending on their second child. They want this girl to get trained in some sort of skills, so that she can fulfil her common needs herself. Mother mentioned-

“I keep on looking for a job advertisement, but found none suitable for my daughter”

Conclusion

The life of an autistic girl can be diverse and complex. They may experience significant challenges in leading their lives because of their symptoms. The social and communication impairment is the biggest hurdle when it comes to their safety. The current study also suggests that autistic people’s menstrual experiences (Burke et al.,2010; Hamilton et al., 2011; Lee, 2004; Obaydi and Puri, 2008) are in some ways dissimilar from those of non-autistic people, placing extra strain on what can be challenging lives. Such girls undergo many types of social boycotts in the form of unsuitable education, healthcare issues, and various forms of discrimination. The future of an autistic girl remains unpredictable in the dearth of suitable life partners and job prospects.

Suggestion:

I. For Addressing Menstrual Challenges

1. Education and awareness

On the part of the Government/schools/ NGOs, regular drives should be run to increase awareness about menstruation and its potential impact on autistic individuals among families, educators, and healthcare professionals. Such a drive should focus on providing intervention to autistic girls before reaching puberty, specifically designed for the use of sanitary napkins, their proper disposal, and hygiene to be maintained during the menstrual cycle. Early interventions, precisely focusing on the menstrual cycle, will help in preparing the autistic girls to be ready in the future for handling it.

2. Individualised support:

As per the need and level of autism, tailored support should be provided at school/ healthcare services.

II) For Addressing Abuse

1. At School

- Every school should employ female staff when and where required. As in the present case study, there was a sufficient number of female teachers, but therapies were conducted by male staff. In that case school must provide a lady's assistance, proper installation of CCTV camera, and also it should be taken care of by the school that the room allotted for such activity is not in a secluded place.
- Schools must hire at least one female staff member for school buses/vans.

2. At Home

- Parents must keep a track of visitors at home. Other than family members, nobody should be allowed to take the autistic child anywhere without proper permission. Probably, an appropriate installation of a CCTV camera should be maintained at the house.
- Only female help should be employed to take care of the autistic girl from the start.
- Parents must teach their autistic girls to change their clothes in private rooms.

III) Discrimination Related:

- By promoting equal access to quality education, healthcare and employment discrimination related challenges can be lessen. It can be done by conducting public awareness campaigns and educational programs.
- Encourage and involve men and boys in the conversation that are related to gender equality.

- Promote inclusive workplace, school and communities that value diversity and respect for all gender.

IV) Future

- Government/NGOs/Schools should provide trainings designed specially for autistic children. Parents should make sure their child get as much as exposure so that they can learn newer skills.
- Marriage should not be considered as a taboo for autistic girls. Families of such children can come forward through various online platform to find out suitable match. It is not necessary that only non-disabled can get married. In case of not finding suitable match, families of disabled person can find suitable matches within.

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