

## Psychosocial intervention in the family with an individual with autism spectrum disorder: A case study

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### ABSTRACT

**Background:** Autism is a complex neurodevelopmental disorder with onset and diagnosis during the first three years of life. Mental retardation (MR) is a varied group of conditions characterized by cognitive limitations due to organic brain dysfunction, with onset no later than 18 years of age. **Assessment and Management:** The case presented here is that of 16 years old, an unmarried, male, belonging to a Hindu nuclear family of lower socioeconomic status from Chandigarh presented with childhood autism with moderate mental retardation and his family was struggling with various associated psychosocial problems. Through an in-depth case study using behavioural intervention with the patient and face-to-face interview with his family members, a psychosocial formulation was made and a plan for psychosocial intervention was carried out. As per the progress of the sessions, further associated issues were discussed. Consent was taken from the patient's family members for future possible reporting of this case in any journal. **Outcome:** After the psychosocial intervention, understanding and awareness about illness and PSI was enhanced in the patient and family, they actively participated in the psychosocial intervention and made positive efforts to achieve set goals; the patient's sister restarted studies, appeared for her senior secondary examination; the family burden was reduced; the patient was successfully improved in his condition and his family took him back into their house. On follow-up, they reported improvement in his behaviour. **Conclusion:** The case study illustrates the nature and extent of psychosocial problems in a child of Autism with moderate mental retardation along with his family caregivers' burden and financial issues. It also demonstrated that psychosocial intervention plays a key role in the treatment of autism.

**Keywords:** Children, autism, psychosocial intervention

### BACKGROUND

Autism once believed to be a rare disorder, is a complex developmental disorder with onset and diagnosis during the first three years of life.<sup>[1]</sup> Mental retardation (MR) is a varied group of conditions characterized by cognitive limitations due to organic brain dysfunction, with onset no later than 18-22 years of age.<sup>[2]</sup> Autism is a pervasive developmental disorder (PDD) with early childhood onset. It is characterized by abnormal development in social interaction and communication; a stereotypical, repetitive range of ritualized behaviours such as rocking, toe-walking flapping, clapping, and whirling and an obsessive desire for sameness.<sup>[3]</sup> Mental retardation (MR) is a complex diagnosis that takes into account a person's interaction with

his or her environment. The current diagnosis of MR uses the level of adaptive functioning as well as IQ.<sup>[3]</sup>

Present case report is of a child with autism who was struggling with various psychosocial problems with his family. It was dealt with psychosocial intervention; a psychosocial formulation was made and a psychosocial intervention was accomplished with the patient and his family members. So, to demonstrate the scope, feasibility and possible outcome of the psychosocial intervention in a case of a child with autism and associated psychosocial problems formed the background of this case report. The positive outcome of this case also allowed us to critically assess the feasibility of the psychosocial intervention in a facility named "Psychosocial Intervention Clinic"

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**How to Cite the Article:** Zaid M, Pandey S, Chandrabala, Mehta S, Sahu KK. Psychosocial intervention in the family with an individual with autism spectrum disorder: A case study. Indian J Psychiatr Soc Work 2022;13(1):45-51.

#### Access the Article Online

##### DOI:

10.29120/IJPSW.2022.v13.i1.464

##### Quick Response Code



Website: [www.pswjournal.org](http://www.pswjournal.org)



which has started functioning recently in the Department of Psychiatry, Government Medical College and Hospital, Chandigarh.<sup>[4]</sup>

## ASSESSMENT

**Case Introduction:** The case presented here is that of 16 years old, an unmarried, male, belonging to a Hindu nuclear family of lower socioeconomic status from Chandigarh.

**Source of Information:** The information was collected from the patient's sister and mother and case records, which were reliable, adequate and complete.

**Reason for referral:** Psychosocial assessment and family intervention.

**Clinical Diagnosis:** According to ICD-10, F84.0 and F71 (Childhood autism and moderate mental retardation).<sup>[5]</sup>

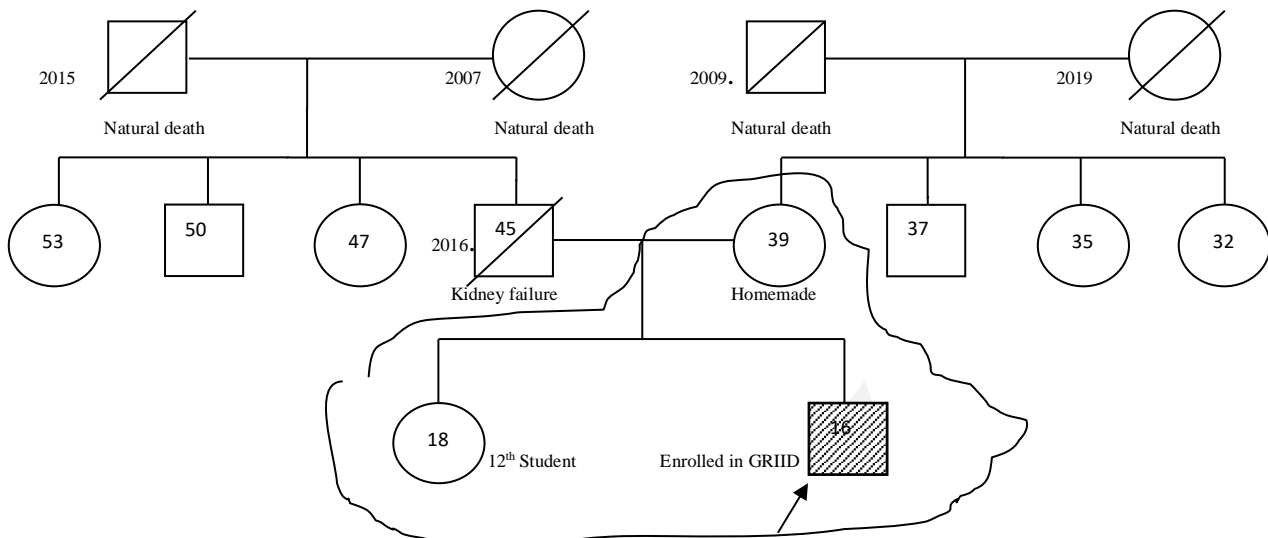
## Brief Clinical History

The patient has had difficulties since his childhood; his developmental milestones were delayed: delayed birth cry, holding things, delayed sitting and walking, but he was not able to speak a word despite family members insisting him to do so. His parents noticed that he has impaired language, social interaction, communication and maintain eye to eye contact as compared to other children. The patient was sent to a regular play school at the age of three years in 2010. As the patient grew up, he would not adjust to school with other children and teachers because he was unable to speak and understand. He used to tear off his clothes at school; so, the school principal called the parents and sent him back home with termination in the year 2013. He was maintaining well with the family members but at the age of 9 years in 2016, after the death of his father, he was found with an unusual touch towards his sister and mother, on denying he tore off his clothes and try to hit them. When it happens multiple times then his mother admitted him to the psychiatric ward in GMCH. After some time, he improved with medication and was referred to Government Rehabilitation Institute for Intellectual Disabilities (GRIID) in 2017. He was enrolled in the day care section in GRIID and engaged in drawing classes, and games. Again, he was admitted to GMCH on 4<sup>th</sup> May 2019, when he started getting angry with family members and discharge after one month of treatment with improvement in his behaviour, later he was admitted again on 20<sup>th</sup>

Aug and 12<sup>th</sup> Dec in 2019. In 2020, GRIID was shut down due to Covid-19 lockdown and his symptoms of aggression and inappropriate behaviour increased then he was admitted on 19<sup>th</sup> Feb for psychosocial intervention and discharged after one month. He was last admitted on 27<sup>th</sup> December 2020 with complaints of non-compliance to medications, irritability towards family members particularly towards his sister, shouting aloud without any reason, tearing off his clothes, instances of keeping himself isolated and physical aggression. He was admitted for more than 2 months and discharged in a satisfactory condition on 10<sup>th</sup> March 2021. As per the patient's sister, a few days after discharge, he would shout without any apparent reason. He would also punch walls without any reason. He would get irritable when he was prohibited from stomping on the stairs while going up/down. He would also knock on neighbours' doors and windows, keep making weird gestures at neighbours, and would repeatedly greet them, to which the neighbours would object and get angry. He would only stop for a few seconds when asked by family but would resume doing the same again. He would sometimes get angry and break household articles. He would also insist to be taken to his mother at work. If his request/demand was denied, he would get irritable and tear off his mask. On many occasions, he also tore off his clothes. When he was taken with his mother to her workplace, he would initially remain calm and manageable. But recently, he started disturbing his mother while at work and hence, she was, asked by her employer not to bring him along with her at work. There was also an incident where the patient got aggressive towards his sister. He pulled her hair and kept on laughing while doing so. Due to all these things his sister needs to take care of the patient and her study gets stopped due to financial issues and a negative environment, she also reports depressive thoughts, helplessness and need for counselling. During all this time, he was compliant with medication. Due to repeated complaints by neighbours and unmanageability at home, the patient was brought to GMCH emergency and was admitted on 10<sup>th</sup> May 2021. He got admission six times to the psychiatric ward during last five years (2016-21) for two to three months. No history of head injury/loss of control/seizure/high fever or substance use.

## Family History

Genogram [6]



## Family Composition

**Mother:** Ms S, 38 years old, female, 5<sup>th</sup> pass, working as a housemaid.

**Sister:** Ms H, 18 years old, female, 10<sup>th</sup> pass, currently pursuing 12<sup>th</sup> arts via National Institute of Open Schooling (NIOS).

**Patient Index:** Mr V, 16 years old, male, 5<sup>th</sup> pass, currently studying in GRIID.

## Family Interaction Pattern

**Interaction between parents:** The parents shared a cordial relationship. The patient's father died in the year 2016. They used to share most of the things with each other.

**Interaction with parents:** The patient used nonverbal communication with his mother and conveys his needs. The mother interacted verbal and nonverbally with the patient and shared an affectionate relationship with a strong emotional bond.

**Interaction between siblings:** The interaction pattern between the patient and his sister is not cordial. The patient uses physical aggression and unusual gestures on the sister which disturbs her, that affect the sister in her study and overall behaviour due to which she faces a lot of difficulties and feels ashamed to share it

## Family Dynamics

**Boundaries:** Family boundaries are found to be enmeshed. The mother gives little independence to the daughter to make her decisions and the mother is found to be over-

involved with his son (the patient) as she was always available for the patient and tries to fulfil the patient's desire even if it is not an essential need. This had affected the daughter's schooling as she was taking care of the patient. Over-involvement with the son has affected the work of the patient's mother. Internal boundaries are open as the patient can convey his message to the family members. External boundaries are also open and clear as the patient was connected with neighbours and other people outside. Two subsystems operate in the family. The parent-child subsystem was well-formed as they shared a cordial relationship but the sibling subsystem has some issues. There was disengagement from his sister's side; she felt she had to scarify to take care of the patient.

**Family development stage:** As per Duvall's classification<sup>[7]</sup> the family is stuck at the fourth stage of the family development stage i.e., family with school-age children.

## Leadership

**Power Structure:** The patient's mother is the nominal and functional head of the family. This is accepted by family members. She prefers to discuss most of the family matters with her daughter.

**Decision-making:** The family follows the democratic decision-making process in the family. The patient's sister participates in the decision-making. Sometimes family has to take the help of the treating team when consensus is not reached between mother and sister in making a decision.

**Role Structure and Functioning:** A multiplicity of roles present as the mother has to earn money and take care of household chores. Mother has to look after the patient after coming from work. Role strain is evident in the mother. The complementary role is present from the sister's side but during the relapse of the symptoms of the patient, the sister feels helpless and the mother has to leave work to take care of the patient. The patient is unable to play his role due to his illness as he is unable to study or support with mother in her household chores. The caregiver burden is high on both mother and sister. The patient fractured his right leg in the ward when he fell which resulted in a long bed stay.

**Communication:** Verbal and nonverbal communication exist in the family as the mother and daughter use verbal communication while the patient uses nonverbal communication and can convey his message to his family members. The noise level is high in the family as the patient's sister raised her voice toward the mother and the patient situation is even worsened whenever there were worsening symptoms in the patient. The mother's over-involvement is evident towards the patient as the mother leaves her work during the patient's hospital stay even when the sister can manage with the help of hospital staff.

**Reinforcement:** Some form of positive reinforcement is present in the family in the form of clapping and smiling at the patient when the patient performs his activities. Positive reinforcement is also provided by PSW trainees during activity time.

**Cohesiveness:** There is healthy connectedness among all family members and the family has a 'We' feeling as they have love and concern for each other. Sometimes patient's sister shows detachment towards her mother and brother when her demands are not met. They engage in social and personal activities together.

**Family Rituals:** Any family rituals could not be found.

**Adaptive Pattern:** The family's problem-solving ability is inadequate, though they could only manage to deal with problems with the help of the treating team when the problem persists. The family member found it difficult to cope with and withdraw from the difficult situation and entirely depends on the treating

team to the extent that the financial expenses on treatment have to be borne from the poor patient fund. The family's coping pattern is inadequate as they depend on every stressor to be dealt with by the treating team.

### Social Support

**Primary Support:** In terms of instrumental, appraisal, emotional support systems are adequate for financial to some extent depending on relatives and poor patient funds.

**Secondary Support:** The family has relatives but the patient is not accepted whereas the sister is welcomed. Mother is not given financial or emotional support from them.

**Tertiary Support:** Tertiary social support is adequate and the family can avail of it as and when needs arise.

### Personal History

**Birth and early developmental history:** The patient was born with a full-time normal delivery at home in 2004 and delayed cries at birth. He has breastfed only for 2 months the reason that his mother was busy with domestic work and would spend less time with the patient. The patient had delayed developmental milestones.

**Educational history:** The patient attained to a regular school from 2010 to 2013, till class fifth, where he was not able to speak and understand other children. When he tried to interact through gestures in the form of non-verbal communication with other students then get irritated with them when they could not understand his message and started tearing his clothes. Later he was sent to PRAYAAS (A Centre that offers free of cost services to children suffering from Cerebral Palsy, Autism, Neurological Development Disorder, Hearing & Speech Impairment, Mental Retardation and Psychological Counselling) for the period of 4 years (2013-2017) and then was admitted to GRIID in 2017.

**Occupational History:** The patient is attaining day-care section in GRIID since 2017 and getting monthly disability pension of Rs. 2500.

**Sexual and Marital History:** No sexual history or masturbation practice was reported.

**Present Living Conditions:** The patient lives with his mother and sister in rental accommodation in one room set which rent is 2500 per month. The mother is working as a housemaid, there is no steady income.

## Psychosocial Formulation

Mr. V., a 16-year-old male child, educated up to 5<sup>th</sup> std., attaining day-care, belonging to a Hindu nuclear family of lower socioeconomic status from a rural area of Chandigarh presented with insidious childhood onset, continuous progressive course, with no apparent precipitating factors, characterized by shouting, demanding behaviour, irritability, physical aggression towards family members, tearing clothes.

Family assessment reveals that boundaries are enmeshed, inadequate role structure, unhealthy communication, poor adaptive pattern, and inadequate secondary social support, high caregivers' burden and over involvement.

## INTERVENTION

### Goals and Interventions

1. To establish a rapport with the patient and family.
2. To enhance the activities of daily living of the patient.
3. To enhance the knowledge and awareness about illness among family members
4. To ease the caregiver's burden.
5. To utilize the resources and support system available in the family.
6. To cope with over-involvement as a kind of expressing emotion.
7. To restart the sister's study.

### Interventions Offered

**I Rapport Building:** Therapeutic relationship refers to the interpersonal process dynamic that emerges between therapist and patient in the context of a psychosocial intervention.<sup>[8]</sup> These relationships are complex and multifaceted, but a substantial body of research indicates that they are a common treatment factor that contributes to a small but significant amount of variation in individual,<sup>[9]</sup> group,<sup>[10]</sup> family,<sup>[11]</sup> and child-focused therapy,<sup>[12,13]</sup> as well as other therapeutic modalities. The therapeutic alliance, or the perceived or observed agreement between patient and therapist on therapeutic goals, tasks, and a sense of bond, is the therapeutic relationship that has received the most research. A rapport was established with the patient in different sessions gradually. In the first session, the trainee introduced himself to the family member. In the second session trainee engaged with the family

member and it was achieved through active listening and play activities<sup>[14]</sup> with the patient.

**II Engaging the patient in ADL:** People with ASD frequently struggle with social communication issues. Impairments include difficulties with appropriate modulation of non-verbal behaviour (such as eye contact or gestures), lack of awareness, and/or literal interpretation of, social norms and conventions, as well as idiosyncratic use of language and speech (WHO, 1992).<sup>[5]</sup> Depending on the severity of the symptoms, impairments may only be occasionally observed (e.g., only showing up in novel social interactions), or they may occur in a variety of contexts and circumstances.

At the time of admission, the patient has not maintained activities of daily living properly. As per the interest of the patient, an activity schedule was prepared with the consultation of his sister to engage the patient in some work. PSW trainee engages the patient in different activities through play through gestures. Later patient started maintaining his ADL on persuasion and supervision by his family members as guided by the trainee. Some playing instruments like a ball, colouring sheet and puzzle etc. As the patient got a fracture in his leg then he was engaged in walking through a walker. Due to the fracture, he was very irritable, so, at that time he was engaged in watching cartoons on TV to divert his preoccupation with injury.<sup>[15]</sup>

### III Psychoeducation to the Family Members:

The patient's mother was very concern regarding the illness of the patient and her sister was very disturbed regarding her brother's irritable and aggressive behaviour as he hit her many times when getting aggressive due to his illness and mostly when the blood sample was taken by the medical staff, they were educated regarding the illness and issues with the patient through multiple psychoeducation sessions. They were educated about the illness and its nature. Sometimes patient's sister hit the patient in response to the patient's irritable act then the mother gets upset about it. So, both of them were educated regarding this behaviour that sister is concerned about her brother, she cares a lot for him but sometimes if she gets irritated that does not mean that she hates him. Sister was motivated to focus more on her studies and career.<sup>[16]</sup>

#### **IV Addressing the Family Caregivers' Burden:**

As the family belong to a lower socio-economic status and facing lots of burdens, the sister was losing her study time due to giving more and more time to care the patient; she was spending time at the hospital for taking care of her brother and also doing house hold work as her mother was also very much disturbed for her child (patient). The patient's home visit was done to look after the situation of poor financial status. With lots of support and encouragement patient's sister was successfully enrolled in class 12<sup>th</sup> through NIOS; support was also provided to purchase books from the fund arranged. This has a significant positive impact to ease the burden on the patient's sister.

#### **V Utilization of the Resources and Support System Available in the Family:**

It is the technique to provide better solutions through emotional and social support. Trainee supportive session was conducted with the patient's sister regarding the illness of the patient, family burden and plan of study. The family was facing a lot of crises and internal problems were at their peak due to lack of finance, study loss of the patient's sister, and instrumental problem. The family was provided sessions regarding all of their problems and help in the form of instrumental support as provided walker to the patient, his medical testing and expenses of medicine, diet free, admission of patient's sister in NIOS and suggest looking for a better option after study for career settlement. The patient's sister gets irritated regarding the patient's behaviour and gets aggressive at her mother to not work as a caretaker anymore with the patient then she had been provided session and resolve the matter among them.<sup>[17]</sup>

**VI Addressing Expressed Emotion:** The patient's mother has emotional over-involvement towards her son as she left her job as a housemaid during the patient's hospital stay even if her sister can manage with the help of medical staff. She was educated that patient's sister can take care of the patient at an extraordinary level and if she is spending her crucial time with the patient then sometimes, she feels irritated but that doesn't mean that she wants to harm the patient, later on, patient's sister was convinced to stay at her maternal aunt's home in Bangalore for some time to reduce her burden and enhance her wellbeing by the change in the environment.

#### **VII Restart the study of the patient's sister:**

PSW trainee visited the patient's home to look at the situation of the patient financial status. On finding the poor status in form of finance, the patient's sister enrolled in class 12<sup>th</sup> through NIOS. The fund was arranged from the poor patient fund to pay the fees for her study.

#### **OUTCOME**

- Increase in understanding and awareness about the illness to the family member.
- Motivated for activities of daily living.
- Reduce the family burden.
- Restart the patient's sister's study.
- Secondary support was enhanced.
- Respite care for the patient's sister (she was sent to her maternal aunt's home).

#### **DISCUSSION**

Studies have indicated that individuals with ASD experience challenges and difficulties as they enter adulthood<sup>[18]</sup> which are not adequately addressed by the treatments and services currently available.<sup>[19]</sup> ASD impose lots of burdens (viz financial burden, disruption of routine family activities, disruption of routine family leisure, disruption of routine family interaction, effect on physical health of others, effect on mental health of others on family members of the affected individuals);<sup>[20]</sup> the present case report demonstrated that psychosocial intervention could be effective in reducing family burden significantly which can positively impact e.g. it can be respite care for some family members so that they can get some relief and better engagement in their work. In the current case, the patient's sister was sent to relatives' place and later restarted her study with intervention. Reduction in subjective burden may work positively in overall family function which in

Though psychosocial interventions were vital in the index case, pharmacotherapy, psychological services, inpatient services, and other services also played an important role, the details of which are not discussed in this case study. Psychosocial interventions adjunct to pharmacotherapy and other services have been shown to have a better outcome than anyone alone. Indeed, the case presented here demonstrates the complex interplay between features of ASD (rigidity, repetitive behaviours, comfort-seeking etc.) and psychosocial support and intervention.

## CONCLUSION

The present case report demonstrated that psychosocial intervention could be effective in reducing family burden significantly along with other areas like level of awareness and knowledge about illness in the family members and better engagement of the individual affected by the ASD. Thus, while managing ASD a multidisciplinary team focusing on a bio-psycho-social approach can demonstrate a better outcome than a unidisciplinary.

**Funding Source:** None

**Conflict of Interest:** None

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**Submitted on:** 24-08-2021

**Revised on:** 31-07-2022

**Accepted on:** 05-08-2022

**Published on:** 13-08-2022