Silence Misdiagnosed: Mutism, Autism or Submissiveness? Diagnostic Bias in Collectivistic Culture

by Syeda Namrah Mahmood Ayesha Jabeen

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ABSTRACT

Introduction: Selective Mutism (SM) is a rare condition which is even rarer in collectivistic cultures. Firstly, SM is most often mistaken and misdiagnosed as Autism Spectrum Disorder (ASD) and other related conditions due to lack of awareness of SM and the presence of mimicking characteristics of Autistic behaviors in SM. Secondly, submissive behaviors in collectivistic societies further veil this rare condition by considering SM rather desirable than a problem. Especially in situations where Intellectual Disability Disorder (IDD) is a comorbid condition it became a great challenge to correctly diagnose among related conditions.

Aims and Objectives: The current study includes a case of twelve years old girl with IDD who remained falsely diagnosed with ASD for five years. A detailed structured assessment using indirect measures was done to reach accurate diagnosis. The intervention plan devised on the basis of new diagnosis of SM which proved efficient in improving client's functioning. The goal of this study is to highlight the diagnostic issues in SM and other related conditions especially ASD that might hinder the development of an inappropriate management plan.

Recommendations: The study emphasized the need to develop a standardized assessment tool to diagnose SM considering cultural aspects into account. Furthermore, the study also supports the idea of using modern technology in the management of SM.

Key words

selective mutism; autism spectrum disorder; submissiveness; intellectual disability disorder; collectivisticic culture

INTRODUCTION

The historical origin of the concept of Selective Mutism (SM) is dated back to 19th century where it was first named as *aphasia voluntaria* describing a disorder in which individual appears to avoid speaking voluntarily in specific situations [1]. The term was renamed as *elective mutism* in initial versions of Diagnostic and Statistical Manual of Mental Disorders (DSM-III; DSM-III-TR) in early 1930's to favor the voluntary nature of SM [2]. However, in latest two versions of DSM (DSM IV- TR; DSM V) the term *elective* was finally modified to *selective* to reflect that the persistence failure to speak is selective to social settings unlike the previous terms emphasizing the intentional withholding of speech [3]. The latest description of SM in DSM-V explains it as a childhood condition specified by a consistence failure to speak in selective social situations where the speech is expected [4]. Children having SM appear to exhibit normal communication at home with parents and siblings, however, consistence failure to speak occurs mostly at school setting or any other less familiar social setting [5].

The analysis of available literature suggests that SM is most often inaccurately misdiagnosed with Autism Spectrum Disorder (ASD) due to mimicking of certain behavior characteristics present in both SM and ASD children including shyness, lack of social interaction and verbal speech, being fearful and often oppositional etc. [6, 7]. Furthermore, the role of culture also plays a crucial role in the fate diagnosis. It is a well-established fact that cultural

norms provide the perspective which defines either a childhood behavior is problematic or not [8]. In a collectivistic culture like ours, shyness or submissiveness is not only considered desirable but also determines adults' attitude with a child which promotes limited participation and shyness among children in such societies [9]. Therefore, it would not be wrong to say that an already rare condition (SM) is even rarer in developing world because: first most of the professionals are unaware about the condition, second they prefer more glamourized disorders like ASD over SM and last, they simply do not consider it a problem as it contains characteristics which are more desirable in collectivistic culture.

More importantly, the diagnosis became more challenging and confusing in the presence of Intellectual Disability Disorder (IDD) as SM most commonly co-occur with developmental delays. It is a well-established fact that IDD already affects child's speech development suggesting less use of verbal communication which is further exacerbated by SM. Furthermore, another notion is becoming popular that SM may serve as a protective factor helping children conceal their developmental disabilities under their silence [10]. This is the irony of fate that lack of standardized assessment of SM especially in the face of IDD and paucity of empirical research along with lack of general awareness of SM create crucial hurdles in assisting children with SM and comorbid conditions. The data suggests that such children misdiagnosed as autistic, language delayed etc. saddle them with inappropriate or ineffective interventions leading towards far-reaching psychological consequences [11].

AIMS AND OBJECTIVES

The aim of the current study is to divert attention of the professionals towards the current diagnostic issues of SM and to develop a standardized assessment to make an accurate diagnosis by eliminating existing confusions.

CASE PRESENTATION

The detailed evaluation revealed strong genetic and postnatal history contributing in the disability of client. The consanguineous marriages had been practicing for generations in client's family which resulted in a number of cases of disabilities among children of her family. The postnatal history of client elucidated that she was found to be a Down syndrome child soon after her birth and she also suffered from high grade fever within a month of her birth. During infancy her mother was not being able to breastfeed client as due to Down syndrome it was difficult for her to coordinate suck-swallow-breathe actions. The client also reported to have delayed developmental milestones. The problems of incontinence, poor self-help and social skills and temper tantrums persisted till the time she started schooling. However, all her presenting problems gradually faded away within 2 to 3 years except for her social skills which mainly included poor eye contact and lack of social reciprocity in terms of both verbal and non-verbal communication. The client at the time of admission at school was perceived as deaf-mute and hence her assessment and management ignored the area of social skills. However, after few years she was suspected of being capable of speaking but keeping her social skills into consideration she was again misdiagnosed with Autism Spectrum Disorder. The teacher of the client stated that although client was an aloof child but it did bother her teachers as she was most submissive among all students of her class and never gave tough time to teachers. Moreover, client continued to take speech therapy sessions since she was admitted to the school but no improvement was reported by her speech therapist in client's speech and social reciprocity. However, it was reported that client was witnessed a few times while secretly talking with her first cousin who studied in the same school. At the time of recent referral of client to therapist she was presented with the complaints of being shy and non-participative in school activities,

avoidance of interaction with other school mates, unable to establish and maintain eye contact, lack of social reciprocity in terms of non-verbal communication and total absence of verbal communication.

CLINICAL ASSESSMENT

A multimodal and comprehensive approach had been adopted in order to assess client's presenting problems which was majorly divided into two types; informal (including observations and interviews of family members and professionals) and formal (assessment of client through standardized measures). Initially, detailed account of client's medical history, including comprehensive review of prenatal and perinatal course and developmental milestones were taken by client's family. The reporting of observation of client's teachers and other staff members also helped gain valuable insight into client's speaking habits and overall temperament in school environment. Beyond the information gained from parents and teachers of client other available health professionals in school including audiologist, psychiatrist and speech pathologist were consulted and involved in comprehensive multidimensional assessment. Last but not least, the direct and indirect observation of client by the therapist in a number of settings (from classroom to playground) provided an extended understanding about client's level of social interaction. The informal evaluation, precisely, revealed that client exhibited two to three words speech with no hearing impairment and marked avoidance of verbal communication and participation in social activities at school but not at home. The client attempted to communicate nonverbally but seemed shy in using non-verbal means of communication with less familiar people. The potential determinants unmasking SM from the shadow of ASD in case of client included; lack of awareness of SM among professionals, glamorization of ASD, comorbid IDD and most

importantly lack of concern of school personnel about client's lacking in social skills as client's shyness was praised by her teachers.

The formal evaluation of client's presenting problems involved the administration of Childhood Autism Rating Scale (CARS) [12], Portage Guide to Early Education (PGEE) [13] and Bender Gestalt Test (BGT) [14]. The administration of CARS involved the rating of both parents and teachers, separately. Interestingly, a significant discrepancy was found between the ratings of parents and teachers. According to the ratings by parents client fell in the category of minimal to no symptoms of ASD whereas the ratings by teacher suggested the presence of mild to moderate symptoms of ASD (Table 1). The potential differences of ratings lied on items; relating to people, imitation and verbal and non-verbal communication. However, ratings of both parents and teacher were almost similar on other items related to the distinguishing symptoms of ASD suggesting them to be absent including body use, object use, adaptation to change and so on.

PGEE was administered to assess client's development on five areas of PGEE which include socialization, language, self-help, cognitive skills and motor skills in order to plan intervention, accordingly [13]. The profile of client showed that except for cognitive and language areas other areas of PGEE are developed till 5-6 years of age (Figure 1). The analysis of client's profile revealed that the profile was unusual and inconsistent, for example, a significant discrepancy was found between socialization area and other two areas closely related to socialization i.e. cognitive and language. This difference might be due to less verbal skills involved in most of the tasks for age 5-6 years in socialization area of PGEE in comparison of the language skills required in cognitive area.

The significant discrepancy between client's functional level and her chronological age suspected the presence of brain organicity. This suspicion led to the administration of BGT to identify any possible organic brain damage and the degree of maturation of the nervous system using the scoring system for children developed by Koppitz [14, 15] (Table 2). The BGT profile reflected the developmental maturation of client to fall between five to seven years or above in some designs suggesting a little discrepancy with the outcomes of PGEE. This discrepancy of 2-3 years in both measures provided a strong explanation of unusual profile of client on PGEE. It could be assumed that client performed low on cognitive area of PGEE as it required verbal skills whereas BGT did not require any verbal ability she scored better in developmental maturation. Therefore, it provided substantial evidence that lack of generalizability of speech had affected client's performance in cognitive area rather than her cognitive area had been affecting her language abilities. Furthermore, client's better performance on social area of PGEE as compared to language and cognitive area supports the notion that there exists a need of communication in client negating the presence of ASD. So, it could be concluded that poor performance on language area was not due to the absence of speech or social reciprocity but due to the lack of generalizability of her verbal and non-verbal communication skills into different settings.

SYSTEMIC CASE CONCEPTUALISATION

The client's case formulation was conceptualized on bio-psychosocial model eliciting the biological, psychological and social causes acting as precipitating, predisposing, maintaining and protective factors in client's presenting problems. The biological factors that might have predisposed client towards developing a disability (Down syndrome) could be genetic predisposition as well as consanguinity. Both are well-known risk factor for genetic disorders,

including diseases and syndromes that present with intellectual and developmental disabilities [16, 17]. Furthermore, previous literature suggests that development of 'triadic' (person-person-world) social interactions may be influenced by limited information-processing capacities in infants with Down syndrome, through a complex socially-mediated developmental trajectory [18]. So, it could be assumed that this limited information processing capacities might have initially served as a precipitating factor in the development of SM in client. However, later on client might use SM as a protecting factor in concealing her developmental problems or weaknesses [10]. Moreover, other social factors that seemed to influence her anxiety and speech problem include the lack of exposure or encouragement, absence of proper management previously and interaction of client with her cousin. The observation revealed that client was not encouraged to speak in school or to participate in social activities as she was already considered either deaf and dumb or having ASD. Similarly, client was too closed with her cousin who also had IDD and spent most of her time with her cousin. This shows that client might not feel a need to interact with strangers which seemed threatening to her. This way rather than learning from other children as well, she only tried to model her cousin who was having speech problems too.

MANAGEMENT APPROACH

In present case, management modality was another challenge as previous intervention plan was based on techniques to deal with ASD not SM along with speech therapy interventions. The former management plan seemed to bring no improvement in client's presenting problems since she commenced her school. A completely new plan was devised for client majorly dealing with her anxiety to improve her verbal and nonverbal communication skills. Exposure therapy techniques were mainly employed including stimulus fading and desensitization. For this purpose a complete ladder of verbal and non-verbal tasks was devised to gradually desensitize

client's anxiety. Moreover, social skills training was also used with client to help her improve non-verbal social skills such as maintaining eye contact or shaking hand. Furthermore, abundant use of technology was made to achieve success in goals such as Talking Tom app was used to motivate client imitate words and actions.

RESULTS

The total number of sessions with the client was 13 and the duration of each session was approximately 40 minutes. The major focus of intervention was the generalization of already acquired verbal and non-verbal communication skills in school and other inhibited settings. A significant improvement has been achieved in client's social skills especially the non-verbal ones (Table 3). The execution of Stimulus Fading by using Talking Tom app proved best and a fun way in helping client reduce her anxiety.

DISCUSSION

The current case study highlighted how destructive cultural aspects could prove from the creation of diagnostic bias to the development of an inappropriate management plan. It is an irony of fate that such important aspects are still ignored in clinical practice in developing world posing devastating consequences not only for such children but also for the caregivers [19]. Globally overdiagnosis of ASD has been observed in recent years, though, published statistics suggest low prevalence of ASD in developing countries but we should not ignore the fact that documentation of mental disorders is not a trend in these countries [20]. Besides, lack of awareness among practitioner and caregivers about rare conditions like SM in developing countries further complicate the diagnosis as they confuse it with other more common conditions especially ASD [6, 7]. Furthermore, characteristics of SM including shyness or lack of interaction might not consider as problematic in collectivistic cultures rather such behaviors are

encouraged, therefore, SM is often overlooked [9]. So precisely this could be said that we have glamourized ASD so much and covered Mutism under the veil of culture that it is still invisible in our culture.

Moreover, currently the diagnosis of SM relied on indirect assessment measures including behavioral observation, functional assessment, interviews with parents and teachers and adherence to diagnostic criteria. The unavailability of standardized assessment often mislead to false diagnosis especially in the presence of Intellectual Disability (ID). The case study highlights the need of a reliable scale to correctly assess SM in a shorter time span helping devising an efficient intervention plan and aiding faster improvement in symptoms. The presence of ID in client posed challenges in making a diagnosis and formulating intervention plan. Literature has suggested that ID undermines the presence of other comorbid conditions leading to inefficient diagnosis [21]. The detailed and structured assessment focusing on predisposing, precipitating and maintaining factors in client's problems helped in reaching the appropriate diagnosis. The diagnosis helped therapist devising an efficient intervention plan which brought significant improvement in client's social skills for the first time. The improvement in client's functioning was another evidence favoring the accuracy of diagnosis and intervention plan specifically planned to deal with SM.

CONCLUSION AND RECOMENDATION

The case highlighted the diagnostic dilemma in the assessment of SM due to cultural aspects presenting devastating consequences for a child and caregivers. Such cultural aspects should be considered during diagnostic process along with a careful search of SM in other related conditions such as ASD. There is a need to create awareness of such rare conditions in the professionals of developing countries. Also s standardized assessment tool for SM especially

in the presence of IDD is needed to avoid any misdiagnosis. Other indirect but systematic measures should also be used to overcome diagnostic issues and reaching an effective management plan.

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TABLE 1: Category Ratings by Teacher and Parents of Client on CARS

Category	Ratings by Teacher	Ratings by Parents
Relating to People	4	2.5
Imitation	4	2
Emotional Response	3.5	2
Body Use	0	0
Object Use	1	0
Adaptation to Change	0	0
Visual Response	0	0
Listening Response	2.5	0
Taste, Smell and Touch Response and Use	0	0
Fear or Nervousness	1	2
Verbal Communication	3.5	2
NonVerbal Communication	3	1.5
Activity Level	2	0
Level and Consistency of Intellectual Response	3.5	3.5
General Impression	2.5	1
Total Score	31 (Mild to Moderate Symptoms of ASD)	16.5 (Minimal to No Symptoms of ASD)

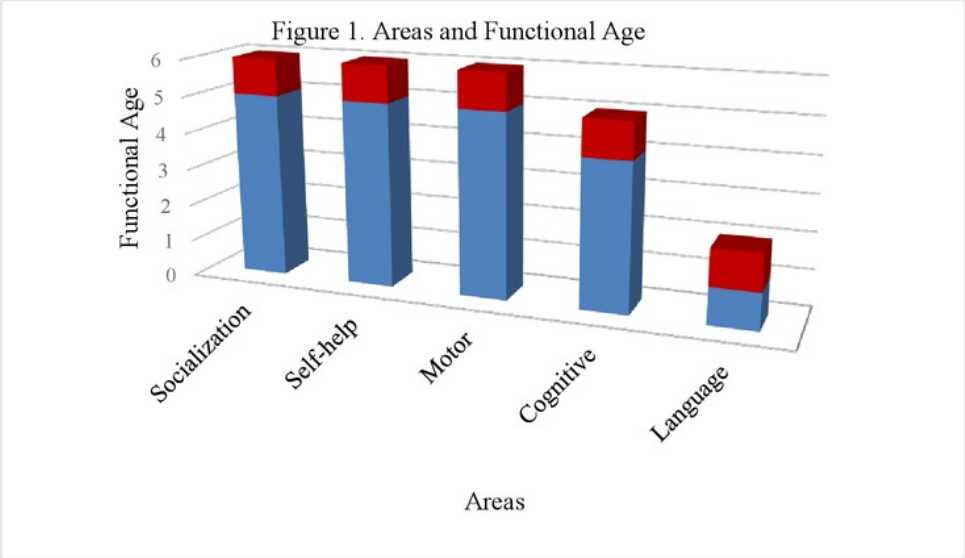

Fig 1: Areas and Functional Level of Client on Five Areas of PGEE

TABLE 2: Pattern of Reproduction of Figures, Scores and Corresponding Developmental Maturation

Pattern of Reproduction	Raw Score	Corresponding Age
Figure A	6	5 years
Figure 1	7	6 years
Figure 2	18	6 years
Figure 3	28	6 years
Figure 4	23	5 years
Figure 5	15	7 years
Figure 6	15	7 years
Figure 7	27	6 years
Figure 8	27	6 years
Total	166	6 years

TABLE 3: Functional Assessment of Client's Performance on Selected Goals on Pre and Post Management Level

Goals	Pre-Assessment	Post-Assessment	Percentage of Achievement
Shake head	0 out of 10 times WOR	7 out of 10 times WOR	70%
Play with other kids	0 out of 5 days WOR	3 out of 5 days WOR	60%
Shake hand with others	3 out of 10 times WR	8 out of 10 times WR	50%
Imitate Tom Cat	0 out of 10 trials WR	5 out of 10 trials WOR	50%
Establish eye contact	10% of the time WOR	25% of the time WOR	15%

Note. WOR=Without Reminder and WR=With Reminder.

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