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Medical report: not to be disclosed without permission of author.

Private and confidential

Regarding: Abrar Mahmood Al Monthery

DOB: 24/1/2014

MRN No 10069376

This report is based on appointments on the following sessions:

1. 05/07/2018 (30 minutes)
2. 08/07/2018 (1.5 hour)
3. 18/07/2018 (1.5 hours)
4. 29/07/2018 (40 min discussion and 1 hour for draft and typing)

DIAGNOSIS:

1. **AUTISM SPECTRUM DISORDER (High level of symptoms)**
2. **Likely Learning difficulties (needs educational psychology assessment)**
3. **Bilateral spastic paraplegia (including milder upper limb involvement Right>Left)**
4. **Ex premature 27 week gestation, Twin pregnancy with chronic lung disease or prematurity**
5. **Possible mild cortical visual impairment (needs further investigation)**

Reason for referral presenting complaint

- Concerns about understanding/attention
- Speech delay

Birth history / Medical history: Abrar was born at the Tawaam Hospital at 27 weeks gestation as Twin1. She was intubated and ventilated soon after birth. She was ventilated for a prolonged period and went through a stormy neonatal course. She was referred to the SKMC hospital for delayed development and physical findings of stiffness in her limbs. An MRI of her brain revealed changes supporting a diagnosis of bilateral spastic paraplegia.

Feeding habits: Abrar was tube fed for the first few months with mixed feeds and then moved on to formula feeds. Xhe does not eat any fruits or salads but will eat sandwiches. She needs assistance to eat with cutlery. She tends to mouth any object she finds.

Family history: Abrar lives with her parents and her twin sister. She also has 2 younger siblings. There is no family history of any neurodevelopmental problems but her maternal uncle had epilepsy and was diagnosed with severe mental health problems. He passed away unexpectedly at the age of 39.

Developmental history: Abrar presented with delayed milestones. She walked at 3 years of age. Has less than 5 words used for communication but does tend to copy tunes and rhymes although not clearly.

Qualitative abnormalities in reciprocal social interaction

Eye – gaze, facial expression, body posture and gesture to regulate social interaction

It was reported that Abrar's eye contact is limited. She will only give eye contact to her mother /nanny when she needs something. Abrar is reported to show 'happy' facial expressions when she is enjoying herself or look sad when unhappy. No other facial expressions were reported. There is no social smile for greeting and no use of gestures.

Peer relationships: Abrar generally is not interested much in other children in her nursery. Overall, she generally tends to ignore children. She may snatch toys from children.

Socio – emotional reciprocity: Abrar is not reported to acknowledge if a family member is upset or respond with any actions to comfort them. If she is upset or has hurt herself by falling she will not approach anybody but tends to sit and cry and needs to be picked up; she does not seek unprompted comfort as hugs and cuddles. She will generally tend to ignore people if they try and talk to her.

Spontaneous seeking to share enjoyment: She does not tend to share her emotions. She generally seems to be happy when on her own agenda or when engaged in physical repetitive play. She is not known to share anything. She does not point or indicate her needs but tends to cry.

Qualitative abnormality of communication

Development of spoken language

Abrar is reported to have less than 5 words. She does not point at things at all. She will often use her mother's hands as tools for specific tasks like opening things.

Reciprocal conversation

There are no examples of reciprocal conversations.

Stereotyped and repetitive use of language: Abrar tends to make noises and vocalizations a lot.

Varied spontaneous make-believe social play: Abrar is not reported to have any imaginative or pretend play. She loves to watch balls roll on the floor and will keep on doing this repetitively. She does like to play with sand and water. She does not spontaneously imitate anybody's actions

Restricted repetitive and stereo-typed patterns of behavior

Interests: Abrar generally tends to like to play with water and is difficult to get her to move away when she is doing so.

Routines / rituals: No obvious ritualistic. Generally, she manages changes in her routine or environments quite well.

Stereotyped and repetitive motor mannerisms: Abrar is not reported to display any stereotypical movements. She does tend to lick and mouth everything.

Abrar's family have had concerns about Abrar's behavior since about 1 years of age. She has had therapy input since the last few months. Abrar is not toilet trained now. There is no evidence of Abrar having any special skills. There are no reports of Abrar having any seizure like episodes. She has now started hitting out and is reported to be very difficult to manage even for the family and the nanny. She is reported to hit her head when she is frustrated. She will often bite herself.

Autism Diagnostic Observational Schedule (ADOS) conducted on 18th of July, 2018

The ADOS (module one) was primarily used to gain further information about Abrar's skills in play and Social communication. The choice of the module was influenced by language skills that Abrar has attained as well as her age. Her mother was present in the clinic room throughout the assessment.

Language and communication

Abrar did not use any recognizable single words or word approximations. She did make a lot of vocalisations and noises. The speech was too limited to comment on echolalia. She was not noted to spontaneously communicate with carer or examiner during the assessment. There were no instances of pointing with her index finger for requesting or sharing attention and no examples of usage of gestures to communicate.

Reciprocal social interaction

Abrar quite clearly had poorly modulated eye contact. She did not demonstrate any responsive social smile. She was not noted to direct any facial expressions towards her nanny or the examiner. She did not display any communicative overtures.

She did respond not to her name being called by the examiner or her mother but only looked up briefly to a familiar vocalisation. There was no requesting behavior: no evidence of 'showing' or 'sharing'. There were no examples of spontaneous initiation of joint attention or response to prompts of joint attention.

Overall the quality of social responsiveness is deemed to be quite limited. The child was not engaged even when the examiner made efforts to attract the child's attention. There was relatively little concern as to whether the examiner or the mother was paying her any attention. The examination was markedly uncomfortable with reference to maintaining rapport.

Play

There was no evidence of appropriate spontaneous functional play with toys. There were no instances of spontaneous pretend play.

Stereotyped behaviors and restricted interests

There were multiple episodes of unusual sensory interests or sensory seeking behaviors noted today. Abrar was noted to be licking and biting many of the toys in the room. She was noted to lick and try to bite the sink as well. There were no episodes of obvious hand or finger mannerisms noted in clinic today. There were many instances of self-injurious behavior noted. She was constantly attracted to the tap on the sink. She was mouthing and biting all toys and was flinching when the bubbles play was introduced. She tended to poke at the dolls eye for some time but showed no other interest in the toys.

Other abnormal behaviors

Abrar would certainly be deemed more active than other children of her age. Abrar was noted to move about and fidget a lot and it was difficult to get her to sit still at all.

Abrar scored 20 in the Social Affect ratings and 4 in the Restricted and Repetitive Behaviour ratings. The total score was 24 out of a possible total of 28. The ADOS algorithm is supportive of a diagnosis of AUTISM SPECTRUM DISORDER. Her level of Autism related symptoms is noted to be HIGH according to the Algorithm.

CONCLUSION

The detailed history and the evidence from the ADOS assessment highlights significant concerns about Abrar's communication skills.

1. The most appropriate diagnosis for Abrar's presentation would be **AUTISM SPECTRUM DISORDER.** This would be in keeping with both the ICD 10 and DSM V criteria for diagnosis.
2. It is also felt that given Abrar's lack of understanding of instructions, no obvious play noted today and no demonstration of problems solving skills it is imperative that a diagnosis of **LEARNING DIFFICULTIES** must also be considered.

RECOMMENDATIONS : Abrar needs to be assessed by a multi-disciplinary therapy team.

1. Abrar definitely needs input from Applied Behaviour Analysis techniques. She will need therapy coordinated by a Board Certified Behavioral Analyst (BCBA) and delivered by a supervised therapist. Given the severity of her presentation during this assessment I would suggest that Abrar would benefit from intensive (i.e. if possible daily) sessions of 1 hour.
2. A Speech and Language Therapy review would be necessary to improve speech and communication skills (twice weekly)
3. Abrar would certainly benefit from a sensory assessment given the various sensory symptoms she has displayed today. She should receive input from an paediatric occupational therapist (twice weekly).
4. Abrar would need an educational psychology assessment to establish her learning ability level; she would benefit from a specialized learning environment tailored to her needs. She may need support from a shadow teacher and might require specialized schooling environments if much progress is not noted.
5. Given her physical issues of spasticity she will need physiotherapy input on a regular basis(twice weekly)
6. Medically, Abrar should be under the care of neurodevelopmental paediatrican. This would be for monitoring of the neurological issues as well as worsening behaviour, adequate nutrition and sleep along with surveillance of bowel habit for constipation which is more common in children with Autism Spectrum Disorder. Also any abnormal movements need to reported and if possible parents to obtain a video recording of the same for review at clinic appointments.
7. I would also recommend support from social services/governmental organizations in providing house help trained in managing children with severe developmental issues like Abrar. This will

provide much needed respite for the mother and the family as the child's physical problems and behavioral issues would require constant support. **I would recommend home nursing support for Abrar given her physical issues, learning difficulties and behavioral problems.**



Dr Binu George MBBS, FRCPCH(UK)
Consultant Paediatrician
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Dated : 9th August, 2018