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AN OVERVIEW OF AUTISM: IS IT TREATABLE IN PAKISTAN?

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Autism Spectrum Disorder (ASD) is a clinically complex, pervasive neurodevelopmental disorder with early appearing social communication deficits and repetitive sensory–motor behaviors.¹ Although affected individuals differ significantly from one another, typically the disorder is characterized by impairment in social reciprocity and communication. Children usually have speech delays or lack of social interaction including: lack of eye contact, limited response to name, decreased interest in peers, and restricted shared attention with parents.¹ Autistic individuals also exhibit repetitive behaviors like flapping, lining, or stacking objects and narrowly focused rigid interests such as paying particular attention to spinning objects.¹ It usually manifests before 3 years of age and has a male predominance.² Unavailability of reliable biomarkers makes it a purely clinical diagnosis³ and interestingly social skills impairment and inflexible behaviors are universally present in autistic children from different ethnic, social and cultural backgrounds including those diagnosed in Pakistan.

A combination of genetic and environmental factors are believed to cause autism and extensive research on causative factors such as infections, maternal health and pregnancy complications, pollution and medications has been carried out mostly in the western world.⁴ Data on prevalence, etiological factors, presenting symptomatology, and treatment are limited in lower middle income countries like Pakistan. The Centers for Disease Control and Prevention (CDC) statistics in their press release published in April 2018 estimated that 1 in 59 children in multiple communities in the United States had been identified with ASD as compared to 1 in 150 children in 2007.² The increase in numbers can be partially due to better understanding and diagnostic skills of physicians in conjunction with Diagnostic and Statistical Manual 5 (DSM V) consolidating all pervasive developmental disorders (Aspergers, PDD NOS) under the umbrella of ASD.¹ Nevertheless the concern is that unknown environmental factors are contributing to this increase. Contribution of vaccines specifically Measles, Mumps and Rubella Vaccine (MMR) as a causative factor was implicated in the past but there is strong evidence contrary to that research. Luke et al in a recent meta-analysis have again established the fact that MMR vaccine does not increase ASD rates.⁵

Individuals with ASD can develop psychiatric, psychosocial, and medical difficulties. Baio et al reported that 31% of children with ASD have intellectual disability and 25% are in the borderline range.² Social anxiety disorder, attention deficit hyperactivity disorder (ADHD) and schizophrenia also have higher prevalence in people suffering from autism according to Luigi et al.⁶ Medical conditions may include neurology, immunology and gastroenterology associated problems in ASD.⁷ Henceforth, though some autistic individuals can lead independent lives, many have symptoms that interfere greatly with their quality of life, thus requiring extensive caregiving which can be emotionally and financially draining for families. In countries like Pakistan where poverty is rampant and government initiated support services for mental health are almost nonexistent, these stressors make an even greater impact.

There is no curative treatment for autism and management involves therapies which help develop social, communication and academic skills.⁸ Medication can aid with specific symptoms or co-morbidities. Early initiation of speech therapy conducted multiple times a week, ideally before age 3, along with developing communication skills in the form of signing and picture/symbol cards are recommended. Physical and occupational therapy can help develop gross and fine motor skills. Testing for academic performance, remedial tuitions, individualized academic plans, and resource teachers for individualized help in a regular school are other ways to help. Therapies to develop social skills like Applied Behavioral Analysis are utilized to teach social norms to children.⁸ However Pakistan's collectivistic culture with larger families and extended family living setups can help with social development of autistic children by utilizing family members. Specific social skills can be divided amongst individual members; for example one person can work

on eye contact and another on greeting a guest in an encouraging environment.

In Pakistan the services available for autistic individuals and their families are limited and expensive. Most services are limited to big cities primarily Lahore, Karachi and Rawalpindi/Islamabad. In Karachi a few expensive private hospitals like Ziauddin Hospital in Clifton, Aga Khan University Hospital (Stadium Road Campus) and some other smaller private institutes provide therapies. Institute of Physical Medicine and Rehabilitation (IPM&R) at Dow University of Health Sciences (DUHS), Karachi has an autism program available at subsidized rates. The Sind government has also inaugurated a Centre for Autism rehabilitation and training in Karachi but it is not completely functional yet. Unfortunately Government schools in the country are not equipped to handle Autistic children and only a few private schools are willing to be inclusive. Therefore it is necessary to advocate for promoting education for all, in an inclusive environment, at a government level. This will allow each differently abled individual to reach their potential.

Ultimately educating and building capacity of family members to appropriately handle autistic children is also very important. Each ASD individual will have different needs at different stages in life and it is crucial to have a long term doctor/patient and family relationship. Making contextualized guidelines and treatment protocols is also required for better management.

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Tania Nadeem; concept, data collection, data analysis, manuscript writing, manuscript review

Rabeeka Aftab; data collection, data analysis, manuscript writing, manuscript review

Nargis Asad; data analysis, manuscript writing, manuscript review