

Challenges in Care of Individuals with Autism Spectrum Disorder during the COVID-19 Pandemic: A Perspective from UK, India and Nepal

Dear Editor,

Social distancing, lockdowns, and changes in routines have adversely affected the care of children with Autism Spectrum Disorders (ASD) during the COVID-19 era. A recent online survey showed the COVID-19 pandemic to be a challenging period for families of autistic children with increased difficulties in managing daily activities, especially free time and structured activities, and children showing more intense and frequent behavioral problems. The rising stress and anxiety during the pandemic, and alteration in service delivery could be the reasons for the exacerbation of behavioral symptoms [1]. Access to treatment has significantly reduced due to the disruption of services secondary to care provider's illness, unwillingness for home-based care to those who are quarantined, and limited reimbursement for tele-behavioral health. These interruptions may have short and long-term consequences, including worsening of autism symptoms and an increase in other mental health issues (e.g., anxiety and suicidal ideation) secondary to psychosocial impact (e.g., social isolation) of the COVID-19 pandemic. The recent National Institute for Health and Care Excellence guidance on criteria for admission to critical wards was perceived to disadvantage autistic patients and was subsequently reworded to address these concerns [2]. Individuals with ASD are a particularly vulnerable group during the COVID-19 pandemic due to fixation with routine, ritualized behavior, and the need for highly individualized and intensive interventions. Changes in routine secondary to school closure, lockdown, need for physical distancing, and COVID-19 in self/ families during the pandemic are likely to result in meltdowns and significant behavioral challenges [3]. Besides, increasing pressure on the mental health services and other relevant services including speech-language therapy, occupational therapy, and behavioral therapy may result in a significant supply-demand mismatch, disproportionately affecting this

vulnerable population. Differential access to educational and health care systems for patients with ASD has been noted even before this pandemic. The pandemic appears to have significantly compounded these difficulties in individuals with ASD facing significant barriers in accessing appropriate health care. However, different measures have been taken in different countries to combat these difficulties. Here, we try to detail the state of health services for individuals with ASD as witnessed by managing practitioners in the United Kingdom (UK), Nepal, and India.

In the UK, most of the assessments including observation modules and assessment questionnaires, feedback, and behavioral management have transitioned to virtual or online care. It is heartening to note that a wide range of resources has been developed by the Royal College of Psychiatry, National Autistic Society, and Challenging Behaviors Foundation to support individuals with ASD as well as their caregivers. Easy read guides with a focus on techniques like social stories and social narratives form the bulk of these resources. Furthermore, some charities like 'Contact a Family' run free helpline services as well. Similarly, access to appropriate educational services has been a challenge for children and adolescents with ASD due to manpower constraints and difficulty in ensuring appropriate COVID-19 measures in specialized educational settings for ASD [3].

However, the condition has been altogether different in Nepal and India. In most of the developing South Asian countries including India, the telemedicine services were in infantile stages when the pandemic struck. However, the burden of ASD is huge. The reported prevalence of ASD in South Asia ranges from 0.09% (India) to 1.07% (Sri Lanka) and it is estimated that one in 93 children have ASD in this region [4]. These factors have further increased the problems here. There has been a drastic decrease in the time given for assessment and management by the clinicians to avoid the significant contact time and most consultations are tele-consults. Telephonic calls, encrypted smartphone applications like WhatsApp, Viber are being used for teleconsultations. However, large population residing in rural areas are not aware regarding tele-mental health services and they also have limited speed internet facilities required for video conferencing. Assessment tools such as AIIMS modified INDT- ASD tool, Indian scale for Autism assessment, etc. are being used

during virtual consults [5]. Some parents have got a break from their busy schedule and have been able to give time to the children and act as co-therapist over online sessions especially in the urban areas whereas some parents are struggling due to limited engagement activities. The training programs for psycho-social workers and paramedics have partly come to halt due to minimal physical visits. In a nutshell, autism care has been hampered due to the current pandemic in addition to ongoing challenges that were present before the pandemic.

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Declarations

None

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