AUTISM- TOWARDS COMPREHENSIVE ASSESSMENT AND MANAGEMENT

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ABSTRACT

Autism is a pervasive, neurodevelopmental disorder characterized by stereotyped movements and impairment in social skills and communication patterns. Prevalence patterns show an increasing burden of about 1 in 150 children affected by the disorder. Most affected individuals have symptoms that interfere greatly with quality of life. Although a burgeoning concern, research on the prevalence, etiological factors and presentation patterns is limited in LAMI countries, leading to a minimal understanding of the disorder at individual, professional and societal level. There is an urgent need to enhance awareness and education to decrease stigma that maybe associated with autism. Partnering with entities like Autism Speaks is a potential step forward as they partner with local stakeholders to develop a culturally appropriate campaign focusing on the need for early diagnosis and intervention. For a country with very limited local resources, a collaborative approach with international partners is imperative to develop research, training and services for developmental disorders within our current and existing health systems.Autism is a pervasive, neurodevelopmental, clinically complex disorder that interferes with a person's ability to communicate and relate to others. It require multiple and timely interventions to alleviate common clinical targets, such as impaired social skills and communication, executive functioning, empathy and perspective taking, sensory perception, and motor skills, along with restricted and circumscribed interests and often co-occurring psychiatric disorders [1]. While some individuals are able to lead independent lives, most of those affected by the disorder have symptoms that interfere greatly with quality of life. Although new research is working on developing screening and diagnostic measures for children as young as 12-18 months, ASDs can be reliably diagnosed behaviorally by age 2. ASD screening is recommended for all children at age 18 and 24 months. Early intervention in an educational/therapeutic setting is shown to bring about considerable improvement in areas of language, social skills as well as cognitive ability. While there is no known cure for ASDs, research has shown that improvement in language is directly associated with better prognosis.Prevalence Since the earliest epidemiological surveys in the 1960s, a wealth of data has become available, indicating a much higher prevalence of the condition than previously thought [2,3,4]. Some estimates show that autism affects 1 in every 150 children in the United States. This makes it more prevalent than pediatric cancer, diabetes and Aids combined. Globally, a number of surveys have been published since 2000, and the majority since 2006. The diagnostic criteria reflect reliance on modern diagnostic schemes and indicate similar epidemiological findings. As ASD is believed to cut across racial, ethnic, socio cultural and geographic boundaries, it is estimated that 67 million children maybe affected worldwide. The highest rate of PDD internationally comes from a recent Korean study estimating the prevalence to be 189/10 000 [4] followed by a Japanese study estimating the prevalence to be 181.1/10 000 [5]. Robust research from the developing and low-income countries focusing on ASD prevalence, etiological risk factors and presentation patterns is still lacking. A few reports from the South East Asian and the Eastern Mediterranean region, show a prevalence of 100/ 10 000 in Sri Lanka [6], 29/10 000 in the United Arab Emirates [7], 1.4/10 000 in Oman [8], and 6.3/10 000 in Iran [9]. Some smaller studies done in India also show a high but variable male-female ratio.Focusing on a broader context than autism, the Movement for Global Mental Health has identified a clear treatment gap, particularly pronounced in low- and middle-income countries [http://www.globalmentalhealth.org; 10,11]. Epidemiological data on the burden of mental and neurological disorders and systematic mapping of relevant services in low- and middle-income countries encouraged World Health Organization (WHO) to launch the mental health Gap Action Programme (mhGAP) [12]. Around the same time Autism Speaks, an organization dedicated to changing the lives of all those who struggle with Autism around the globe, launched the Global Autism Public health (GAPH) Initiative. This is an international advocacy effort designed to: (1) enhance public and professional awareness of autism, (2) increase clinical and scientific expertise/capacity and promote international research collaboration, (3) enable service development and training in early detection and intervention around the world. To this end, Auism Speaks has worked collaboratively with a number of countries in the Middle east, Latin America and Asia in areas of training, technical development and awareness campaign. Epidemiological surveys have been carried out that go beyond providing robust prevalence data to resulting in systematic information regarding existing services and may help in assessing the

needs and priorities for each community.Characterization of PDD Over time, the definitions of autism have changed as illustrated by the numerous diagnostic criteria that were used in both epidemiological and clinical settings. Starting with the narrowly defined Kanner's autism, definitions have progressively broadened in the criteria, moving from the International Classification of Diseases (ICD)-9 [WHO, 1975, Diagnostic and Statistical Manual of Mental Disorders (DSM)-III [American Psychiatric Association, 1980] and DSM-III-R [American Psychiatric Association, 1987], the ICD-10 [WHO, 1992] and DSM-IV [American Psychiatric Association, 1994]/DSM-IV-TR [American Psychiatric Association, 2000] and most recently the DSM V [American Psychiatric Association, 2013]. The first diagnostic criteria reflected the more qualitatively severe forms of the phenotype of autism, usually associated with severe delays in language and cognitive skills. Less severe forms of autism started being recognized in the 1980s, and Asperger disorder was not officially recognized until the 1990's. DSM- V, published in 2013, has removed both the diagnosis of Asperger's and the various subtypes of ASDs. Instead ASD appears as a singular diagnosis, with various qualifiers for severity, whereas a diagnosis of Social (Pragmatic) communication disorder aims to cover the symptomatology for those with impairments only in communication. This is important to know as the international nosology offers a standardized methodology in both clinical, training and research endeavors.Phenotypic presentation of PDDOverall, very few studies have examined the impact of geographical, economic, social and cultural factors directly on the presentation patterns of ASDs; the few that have been done indicate little impact. Across some smaller studies done in India, the concern that most commonly led to referral from medical professionals was language delay or regression in language skills, followed by social difficulties and hyperactivity. Most children received the diagnosis of ASD between 3 and 6 years [13, 14]. The time between recognition of symptoms by caregivers and diagnosis averaged about 2 years. It appears that the majority of the families that access care in the developing countries come from middle class backgrounds. This maybe because the higher socioeconomic families do not attend state-run facilities while the lower socioeconomic groups may not access care unless the child is acutely ill. Most often the associated symptoms include seizures, regression of skills and intellectual disabilities; in some reports, intellectual disabilities have been found to be present in about 95% of children with ASD.There is a striking absence of controlled studies examining the potential impact of environmental and socio-cultural factors on the understanding, experience, expression, and help- seeking for autism, especially in the developing countries. There appears to be an improvement in the identification of autism in low-resource countries, as inferred from the increase in referrals and identified cases. Studies continue to point out that variation in parental education determines their help seeking for autism [15] and that it is predominantly severe cases that are currently being identified in poor communities [16,13, 17].Pakistan: The Challenge Ahead Advances in autism research are clearly needed to bridge the gap between evidence and practice, especially in developing countries where the gap remains large. To date, robust data on the epidemiological burden of ASD in Pakistan remains absent. Literature from developing countries gives a clear indication that the burden is considerable; scattered efforts in pediatrics, pediatric neurology and child mental health arena to address the increasing clinical need also point to a burgeoning concern. There is minimal understanding of the disorder at individual, professional and societal level and therefore an urgent need to enhance awareness and education to decrease stigma that maybe associated with autism. Partnering with charities like Autism Speaks is a potential step forward as they partner with local stakeholders to develop a culturally appropriate campaign focusing on the need for early diagnosis and intervention. They also provide access to a wide range of educational and informational materials that may be adapted to local needs.It continues to be imperative that we invest in research endeavors; one of the main objectives of global initiatives is to shed light on the impact of autism on the community. GAPH initiative has developed a number of funding mechanisms designed to support the growth of epidemiological research activity and promote international collaborative efforts. Similarly, since autism is diagnosed behaviorally, culturally validated and adopted instruments are essential for scientific and clinical efforts. Locally translated versions of ADOS and ADI-R would act as gold standard instruments and maybe used for research and training purposes.Similarly, joining hands with international partners in service development for patients with ASDs is an essential aspect of addressing the increasing burden of the disorder. Services in Pakistan are minimal at their best and continue to be of inconsistent quality due to an acute shortage of clinicians with sufficient experience in diagnosing and managing autism. There is an urgent need to build capacity for services by providing professional development, technical assistance, content development and education. These would focus both on clinical-based services as well community-bases interventions, encompassing stakeholders that include parents, health professionals as well as early and special education professionals.WHO mhGAP has recently included evidence based and simple interventions for ASD and intellectual disabilities that are being tested out in low and middle income countries. It is important that as a country with very limited local resources, we utilize a collaborative approach with international partners to develop research, training and services for developmental disorders within our current and existing health systems.

REFERENCES

1. Drahota A1, Aarons GA, Stahmer AC. Developing the Autism Model of Implementation for autism spectrum disorder community providers: study protocol. Implement Sci. 2012 Sep 10;7:85. doi: 10.1186/1748-5908-7-85.
2. Fombonne E. Modern views of autism. Can J Psychiatry. 2003 Sep;48(8):503-5.
3. Fombonne E. Epidemiology of autistic disorder and other pervasive developmental disorders. J Clin Psychiatry. 2005;66 Suppl 10:3-8.
4. Kim YS1, Leventhal BL, Koh YJ, Fombonne E, Laska E, Lim EC, Cheon KA, Kim SJ, Kim YK, Lee H, Song DH, Grinker RR. Prevalence of autism spectrum disorders in a total population sample.Am JPsychiatry.2011Sep;168(9):904-12.doi:10.1176/api.ajp.2011.10101532.Epub 2011May 9.
5. Kawamura Y1, Takahashi O, Ishii T. Reevaluating the incidence of pervasive developmental disorders: impact of elevated rates of detection through implementation of an integrated system of screening in Toyota, Japan. Psychiatry Clin Neurosci.2008 Apr;62(2):152-9.doi: 10.1111/j.1440-1819.2008.01748.x.
6. Perera H1, Wijewardena K, Aluthwelage R. Screening of 18-24-month-old children for autism in a semi-urban community in Sri Lanka. J Trop Pediatr. 2009 Dec;55(6):402-5. doi: 10.1093/tropej/fmp031. Epub 2009 Apr 28.
7. Eapen V1, Mabrouk AA, Zoubeidi T, Yunis F. Prevalence of pervasive developmental disorders in preschool children in the UAE. J Trop Pediatr. 2007 Jun;53(3):202-5.Epub 2007 Jan 23.
8. Al-Farsi YM1, Al-Sharbati MM, Al-Farsi OA, Al-Shafaee MS, Brooks DR, Waly MI. Brief report: Prevalence of autistic spectrum disorders in the Sultanate of Oman. J Autism Dev Disord. 2011 Jun;41(6): 821-5.doi:10.1007/s10803-010-1094-8.
9. Samadi SA1, Mahmoodizadeh A, McConkey R. A national study of the prevalence of autism among five-year-old children in Iran. Autism. 2012Jan;16(1):5-14.
10. [http://www.globalmentalhealth.org
11. Patel V1, Garrison P, de Jesus Mari J, Minas H, Prince M, Saxena S; Advisory group of the Movement for Global Mental Health. The Lancet's series on global mental health: 1 year on. Lancet. 2008 Oct 11;372(9646):1354-7. doi:10.1016/S0140-6736(08)61556-1.
12. http://www.who.int/mental_health/mhgap/en/
13. Juneja M1, Mukherjee SB, Sharma S. A descriptive hospital based study of children with autism. Indian Pediatr. 2005 May;42(5):453-8.
14. Kalra V1, Seth R, Sapra S. Autism -- experiences in a tertiary care hospital. Indian J Pediatr. 2005 Mar;72(3):227-30.
15. Seif Eldin A1, Habib D, Noufal A, Farrag S, Bazaid K, Al-Sharbati M, Badr H, Moussa S, Essali A, Gaddour N. Use of M-CHAT for a multi national screening of young children with autism in the Arab countries. Int Rev Psychiatry. 2008 Jun;20[3]: 281-9. doi:10. 1080 / 09540260801990324.
16. Daley TC. From symptom recognition to diagnosis: children with autism in urban India. Soc Sci Med. 2004 Apr;58(7):1323-35.
17. Malhi P1, Singhi P. Patterns of development in young children with autism. Indian J Pediatr. 2005 Jul;72(7):553-6.