



PREVALENCE OF AUTISM SPECTRUM DISORDER: A SYSTEMATIC REVIEW

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ABSTRACT

Background: Autism Spectrum Disorders (ASDs) are a group of neurodevelopmental conditions, the prevalence of which in a South Asian country like Pakistan is still not completely known. This study was conducted with the aim to review the available epidemiological studies of ASDs in Pakistan in order to identify gaps in our current knowledge. **Materials and Methods:** A search for relevant studies was conducted using the key words “Autism” “Prevalence” and “Pakistan”, among others, and articles reporting prevalence of ASDs in Pakistan, published between January 2000 and March 2019, were reviewed and evaluated. The search was conducted in line with PRISMA guidelines. **Results:** Out of the 83 articles found, we identified 6 articles that met our predefined inclusion criteria. The articles reported prevalence of ASDs in Pakistan ranging from 2.4% to 8.6%, showing a trend of increasing prevalence over the years. A high prevalence (8.6%) was reported in Rawalpindi in the study conducted by Khan et al., in 2019. Study sample sizes ranged from 200 in Karachi to 1889 in Rawalpindi. The age range varied between 4 years to 18 years of age. The studies showed a higher prevalence of ASDs in males than in females. **Conclusions:** In this study, we attempted to methodically review all the available evidence of prevalence surveys of ASDs in Pakistan. An evidence gap is identified in a region where need of availability of services is much needed. In light of the fact that sparse data exists, our conclusion is limited. ASDs are on the rise but multiple barriers in the way of understanding exist. We can only hope this study attracts the attention of organizations interested in health welfare to arrange well planned epidemiological surveys in this region, the results of which can be applied at a larger scale, and promote research regarding ASDs.

KEYWORDS: Autism, Prevalence, Frequency, Pakistan, Autism Spectrum Disorder, Pervasive Developmental Disorder.

INTRODUCTION

Autism, better referred to as Autism Spectrum Disorder (ASD), is a group of neurodevelopmental conditions characterized by persistent deficits in social communication and interaction across multiple contexts.¹ Also seen in ASD, is a lack of social reciprocity and non-verbal communicative behaviours.^[1] ASD typically manifests early in development and produces impairments of social, personal, academic and occupational functioning.

The prevalence of children with ASD is on a constant rise. According to estimates from the Center for Disease Control and Prevention (CDC)'s Autism and Developmental Disabilities Monitoring (ADDM)

Network, approximately one in 59 children aged 8 years are identified with ASD in the United States.^[2] However, there is a lack of epidemiological data available from low- and middle-income countries, which necessitates the need for more research.^[3,4,5]

Pakistan, a developing country in Southeast Asia, with a population of around 200.6 million,^[6] is the sixth most populous nation in the world (Population Reference Bureau 2018)^[6] and around 33% of this population is under the age of 15,^[6] which means a large number of undiagnosed cases can be rationally expected. Rafiq et al. noted Autism like features and agenetic predisposition in families with Cohen Syndrome indicating latent developments in Autism.^[7] Examples of comprehensive

studies that have calculated and analysed the prevalence of ASDs in Pakistan are few, but from the knowledge that has been gathered from some hospital-based studies conducted in the past, the following percentages of new patients were diagnosed with Autism: 2.5% and 4.5% in two separate studies conducted in Karachi (2007 and 2009)^[8] 5.3% in Rawalpindi (2009)⁸ 5.3% and 3.2 % in Lahore (2012).^[8]

As for now, a significant knowledge gap about Autism exists in Pakistan. In addition, the studies that have been conducted in order to assess the baseline knowledge of Autism among healthcare professionals have not given promising results.^[9,10] Different systematic reviews conducted globally have given different estimates for ASD.^[11,12,13,14] however, the data on South Asian countries like Pakistan is currently lacking. The aim of this present study is to systematically review the prevalence of ASD in Pakistan and identify the gaps in our current knowledge. The absence of significant research output for Low and Middle Income countries (LMICs) results in stunting of the growth of evidence based practice in LMICs.^[15] We have conducted this review with the aim to provide more information on the epidemiology of ASD so that health professionals and policy makers can prioritize relevant research and improve services in Pakistan.

Objectives

- To conduct a systematic review of the available epidemiological studies on ASDs in Pakistan in order to identify gaps in our current knowledge.

METHODS AND MATERIALS

Case definition of ASD

Autism is a neurodevelopmental Disorder characterised by certain symptoms that are a part of specific diagnostic criteria whereby the diagnosis is made clinically. In this review, articles that were selected were those that defined ASDs using the diagnostic criteria presented in DSM-IV, DSM-V and ICD-10.

Search Strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used in the search strategy and adherence to the PRISMA guidelines and methodology was ensured. Four electronic databases were searched (Google Scholar, PubMed, MedLine and DOAJ) for the relevant articles that had been published about the prevalence of ASDs. The search terms that were employed included: “Autism” OR “Autism Spectrum Disorder” OR “Pervasive Developmental Disorder” AND “Prevalence” OR “Frequency” AND “Pakistan”. We also conducted a manual search for the articles listed in the references to identify additional articles and citations were organized using Mendeley.

Inclusion and Exclusion Criteria

The inclusion criteria was adapted and modified from Wing L., 1993^[16] and Williams JG, 2006^[17] and is as

follows: We included articles based on the following facts:

(i) Primary Research (ii) Studies conducted on Pakistani population or sample including Pakistani population (iii) Studies including frequency/prevalence Data for Autism (iv) Study designs considered were cross-sectional or first phase of a longitudinal study (v) Defined diagnostic criteria stated for autism or ASD (vi) Initial selection in a wide range of children in the general population, or in a clinical setting (vii) Final identification of cases based on clinical or other diagnostic assessment of selected children (viii) Only researches published in English were considered

Quality Assessment

After the literature search, each article found was assessed by going through the Title and Abstract in order to determine whether the inclusion criteria was met or not. If any article failed to meet the criteria, the full text was not retrieved and the article was excluded from the study. In case of any disagreement in the quality assessment of a certain article, three authors discussed and reached an agreement on the inclusion or exclusion of that particular article. The quality of the selected articles was assessed using the JBI critical appraisal checklist for the studies selected.^[19]

Tabulation

After a thorough review, we arranged the articles, extracted data from each study and tabulated it by (i) first author, (ii) year of publication, (iii) country and city (iv) Setting (v) Place of Study (vi) sample size (vii) age range (viii) gender (ix) outcome measures and instruments and (x) reported prevalence of ASD. The selection process of the articles is displayed in **Figure 1**.

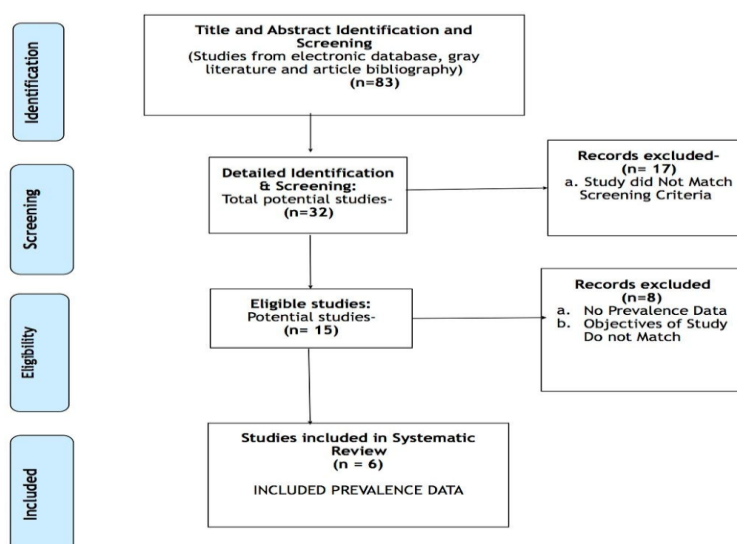


Figure 1

Ethical Considerations

Ethical Clearance was granted by the Institutional Review Board of King Edward Medical University.

RESULTS

Selection of Literature

After the initial search of databases, 83 articles related to our study were identified. After exclusion through comparison of the titles and abstracts against the inclusion criteria, we identified 32 potential articles for a detailed examination. Out of those, we excluded 17 articles as they were deemed not relevant to the review and the contents did not match the screening criteria. Further evaluation and screening of the 32 articles identified 15 eligible articles for a comprehensive analysis. Out of the 15 articles, 8 articles were further excluded as the objectives of those studies did not match the inclusion criteria and they failed to report prevalence data on ASDs. Finally, 6 studies met the inclusion criteria

for the review and were analysed in detail.

Prevalence of ASDs in Pakistan

The summary of the 6 studies that reported the prevalence of ASDs in Pakistan that were systematically reviewed is presented in **Table 1**. The Prevalence of ASDs in Pakistan that were found in the 6 studies reviewed are presented in a Bar Chart, labelled as **Figure 2**. The articles reported prevalence of ASDs in Pakistan ranging from 2.4% to 8.6%, showing a trend of increasing prevalence over the years, as shown in the chart labelled as **Figure 3**. A high prevalence (8.6%) was reported in Rawalpindi in the study conducted by Khan *et al.*, in 2019. Study sample sizes ranged from 200 in Karachi to 1889 in Rawalpindi. The age range varied between 4 years to 18 years of age. The studies showed a higher prevalence of ASDs in males than in females, as shown in the chart labelled **Figure 4**.

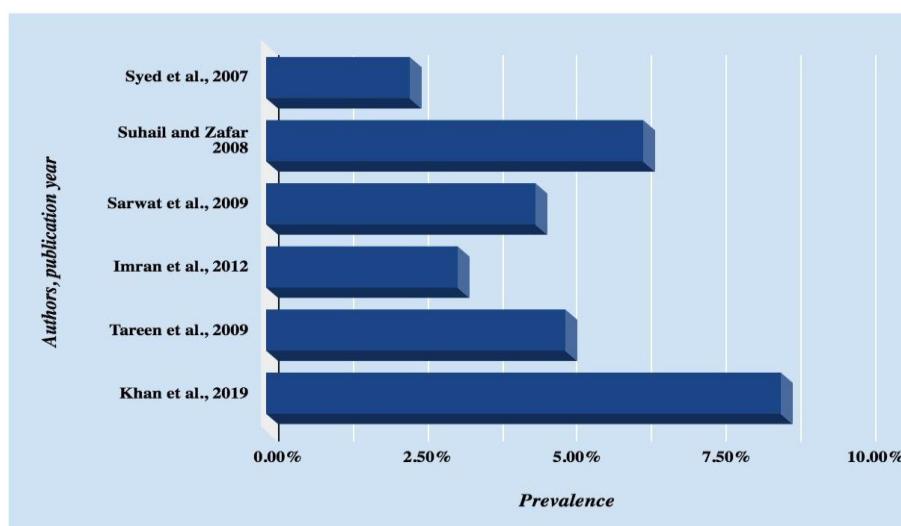


Figure 2:

Table 1

Authors, publication year and reference.	City,Country	Setting	Place of study	n (sample size)	Age range	Gender	Outcome measures and Instruments	Prevalence
Syed et al., 2007	Karachi, Pakistan	Urban and rural	Community	290	Below 15 years old.	M/F	DSM-IV criteria	2.4%
Suhail and Zafar 2008	Lahore, Pakistan	Urban	Community	1633	4-18 years	M/F	DSM-IV-TR CARS	6.31%
Sarwat et al., 2009	Karachi, Pakistan	Urban and rural	Community	200	Upto 14 years	M/F	P-CHIPS DSM4	4.5%
Imran et al., 2012	Lahore, Pakistan	Urban and rural	Community	1000	Mean age of 8.46(S.D $\pm$ 4.51)	M/F	ICD-10 criteria	3.2%
Tareen et al., 2009	Rawalpindi, Pakistan	Urban and rural	Community	169	Mean age of 6.5(S.D. $\pm$ 3.3)	M/F	ICD10	5%
Khan et al., 2019	Rawalpindi, Pakistan	Urban	Community	1889	18-59 years	M and F	AQ ASRS-V1.1 DSM5	8.6% after screening the sample(1518 were found negative on both screening scales)

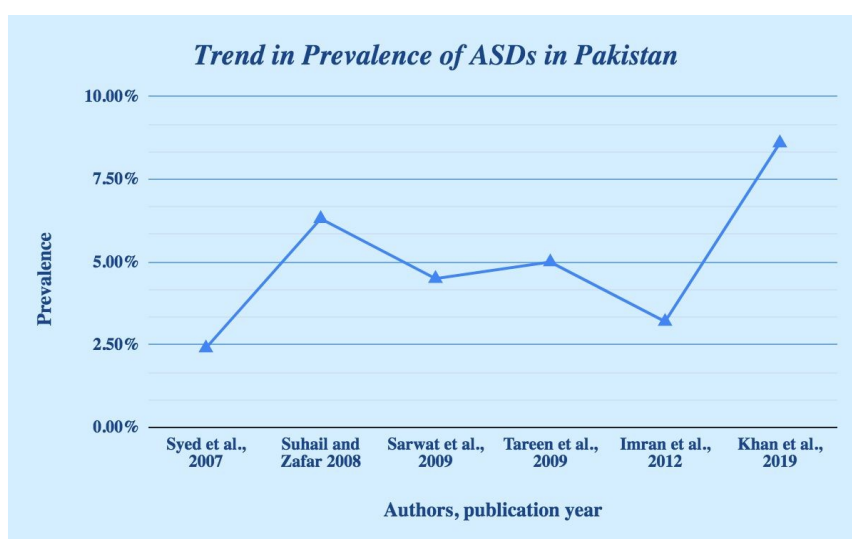


Figure 3:



Figure 3:

DISCUSSION

Summary of Evidence

This paper compares the epidemiological data that has been reported on the Prevalence of ASDs in Pakistan from January 2000 to March 2019. There are very few articles available reporting the frequency of ASDs in Pakistan over a large scale. Most studies that are conducted are either hospital-based or community based or are conducted among children in a particular Autism school, so it's very difficult to compare the frequencies obtained and apply the data over the entire population or other settings. However, out of all the 6 studies selected, the average prevalence obtained was around 5.0% and the ages varied from infants to adolescents, to adults.

In the study conducted by Syed et al. (2007)²⁰ a total of 290 children were assessed at the clinic in the period between March 2002 and March 2005.²⁰ The reasons that most commonly led to the referral were aggressive behavior toward others (n 1/4 73, 25.1%), other oppositional behaviors (n 1/4 39, 13.4%), poor attention and overactivity (combined n 1/4 74, 25.2%), and learning difficulties (n 1/4 29, 10.0%).^[20] The prevalence of Pervasive Developmental Disorder reported after provisional diagnosis under DSM-IV was 2.4%.^[20] This

was a descriptive study presenting the activity data from the first 3 years of the service, and the emerging referral and clinical trends, in order to predict and plan further service development. As mentioned in other studies, data about mental health from developing countries such as Pakistan is extremely scarce. The limited evidence arises from either school surveys or small-scale clinical samples. However, some observations on the links between societal changes and child mental health can be drawn from the wider international literature. There are also certain protective factors specific to society in Pakistan, particularly the extended family setup that takes care of some parenting issues such as supervision of the child, relief from burden, and respite if necessary. Deeply religious faith and belief in destiny can protect people from total despair and suicide. Our school system does not have a mental health philosophy, and so our teachers are not trained to identify children with problems in learning and emotions. Most children who have mental health problems or learning difficulties are simply ignored or labelled as 'slow', 'disobedient' or 'problem children', and schools can be too keen to exclude them rather than help them address these issues. Another issue is the shortage of child mental health professionals, with specialist occupational and speech

therapists also being rare. Another striking finding of this study was that most of the children were referred because of behavioral problems but not diagnosed with disruptive disorders. This seems to indicate that mental health or developmental problems were masked by the behaviour and that the behavior was misinterpreted as naughtiness. The article used the results to devise a future strategy for the betterment of child mental health services in Pakistan.^[20]

The study conducted by Suhail K et al.^[21] determined the prevalence of Autism in special education schools of Lahore. The sample consisted of prospective children with Autism from nearly all special Education institutes of Lahore. 5 out of the 36 schools found were not functional and hence were excluded from the list. The final list consisted of 29 schools. The age range of the sample was from 4-18 years.^[21] An initial screening was carried out using the DSM-IV criteria during which 142 out of 1633 children were identified as probable cases of Autism.^[21] Among all the associated features of the disorder, a poor social relationship was found to be the most prominent one.^[21] This study filled the gap in the prevalence data available and emphasized the need for separate schools offering specialized instructional and educational programmes for children with Autism in order to effectively manage this disorder. The prevalence rate obtained was 6.31% and this rate is greater than that found previously but unfortunately, the study did not assess the intellectual functioning of these children and the quoted figures were only based on the information obtained from the schools.^[21] Even though Autism was more prevalent among boys, the difference was not statistically significant.^[21] The study had a lot of limitations: The study only assessed prevalence of Autism in special education schools of Lahore and could not cover the other areas of Pakistan, which makes the generalizations difficult.^[21] Next, there was no way to include untreated cases of Autism which, in the absence of visible verbal or intellectual deficits may not be easily detected and thus may be studying in normal schools.^[21] Thirdly, the intellectual level of the children was not assessed so no assumptions can be made about the comorbidities. Fourthly, parents evaluations was not taken, which is important.^[21]

Tareen et al. (2009)^[22] conducted the study in order to document the presentation of various psychiatric conditions in adolescents and children so as to gain enough data to develop a model to build a child and adolescent mental health service in a low income country such as Pakistan.^[22] The article's aim was not particularly directed at reporting the prevalence of ASDs in Pakistan, however, the objectives of the study were in line with that of ours i.e. filling the gaps in the epidemiological data available on the prevalence of Autism in LMICs so that next steps can be taken in order to provide better services to such patients in Pakistan. In the training clinic, 169 new patients were seen over a period of one year, out of which 9% of the patients

presented with newly diagnosed cases of Autism.^[22] The mean age of presentation was 6.5 years $\pm$ 3.3 and there was a higher prevalence among boys as shown by the bar chart presented in Figure 4, with a boy: girl ratio of 5:4.^[22] However, the most common diagnosis reported was not Autism, but was intellectual disability (31.95%), and only 2.9% had depression and 1.7% had attention-deficit hyperactivity disorder in contrast to the frequencies reported by ICD-10.^[22] Approximately 18% of their patients had behavioral problems. This difference may be a reflection of differences in the population accessing the service, such as socioeconomic status and accessibility to rural population.^[22]

The study conducted by Sarwat et al.(2009) was a cross-sectional study conducted at the psychiatric clinic of Paediatric OPD at civil hospital Karachi. The sample size was 200 and the children up to 14 years of age were included in the study.^[23] Assessment of the children was done using a semi-structured interview based on P-CHIPS (Child Interview for Psychiatric Syndrome), the parents version and diagnosis of various psychiatric illnesses was further confirmed by comparing it with the DSM-IV diagnostic criteria. The study showed that psychiatric disorders in general were more frequent in males (63%) as compared to females (37%), which is in line with the other studies showing a gender based prevalence.^[23] Majority of patients affected were between 5-10 years of age (62.5%).^[23] Among the psychiatric disorders, oppositional defiant disorders were (20%), ADHD (17%), elimination disorders and anxiety disorders were (11%) each.^[23] Other less frequent psychiatric problems were mood disorders, somatoform disorders, specific developmental disorders, emotional and habit disorders. Out of the total 200 cases, the prevalence of Pervasive Developmental Disorder was 4.5%, with a higher prevalence in males, exhibiting a 2:1 ratio.^[23] This study identified the need for epidemiological studies about child and adolescent psychiatric illnesses in order to develop appropriate healthcare services across Pakistan, which are currently lacking. The main feature of this study was to determine the frequency, age and gender distribution of psychiatric illnesses in children attending the psychiatric clinic. The study suggested that there may be several causes that may contribute to the mental health problems in Pakistan, including inter-family marriages, high rates of birth injuries economic decline and high rates of unemployment, and so on. However, the limitation of this study was that it was a hospital based study with a sample size of only 200 and community based surveys should be carried out on a larger scale in order to find out the depth of the disease burden in children.^[23]

Imran N et al. (2012) conducted the study with the aim to determine the pattern of referrals, socio-demographic factors, frequency of psychiatric diagnosis, and help offered to children presenting in Child Psychiatry Department outpatient clinic of a tertiary care hospital in Lahore. A cross sectional study was

conducted and 1000 consecutive new referrals were assessed after interviewing the child and the parent. Diagnosis was made using ICD-10. Out of the 1000, referrals, there was a male predominance (65%) and the average age of presentation was 8.46 (SD 4.51).^[24] Among the various sources of referral, self-referral was the highest (84.7%) followed by referral from Pediatrics (8.4%). Among the various psychiatric diagnoses observed, the prevalence of Autism was reported to be 3.2% and that of speech Related Difficulties including speech delay, articulation problems and specific developmental delays of speech & language} was 46.5% , and that of Learning Disability was 43.3%.^[24] The findings illustrate the importance of multidisciplinary approach and to assess the different dimensions of psychopathology in children for future service planning. The limitations of this study, however, were as follows: limitations. It was based in a hospital setting and data was collected from one hospital only thus the results cannot not generalized. Furthermore, this data was collected on the first visit and included the most probable diagnosis after team assessment. In some cases, diagnosis may have been reviewed when further information from multiple sources became available. The study highlighted the importance of collecting data on a structured basis in order to identify the need & planning of the services. Future studies should include hospitals in multiple sites across the country encompassing both urban and rural settings as well as community based epidemiological studies would be very helpful.

Finally, Khan S et al. 2019 reported the undiagnosed burden of ASDs and ADHD (Attention Deficit Hyperactivity Disorder) among adult psychiatric patients reporting at a tertiary care hospital in Pakistan in her study. The sample size used in this study was the largest (1889), hence making this study the most reliable one out of all the 6 that were reviewed. Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder were screened by using screening tools which are the Adult Autism Spectrum Quotient (AQ) and ADHD Self-Report Scale-V1.1 (ASRS-V1.1) respectively.^[25] Out of 1889 adult patients screened through AQ and ASRS, 78.9% were screened negative on both the screening tools while 12.5% were positive on AQ and 13.5% were positive on ASRS.^[25] 8.6% of the screening positive patients had diagnosis of ASD and 11% had a diagnosis of ADHD after clinical interview with the consultant psychiatrist. Ten patients had both ASD and ADHD.^[25] Psychiatric diagnosis was made according to the DSM V criteria by a consultant psychiatrist. Upon applying the logistic regression, the study found that male gender, illicit substance use, low education and inadequate response to treatment had significant association with the presence of ASD and ADHD among the adult psychiatric patients.^[25] This study showed a high prevalence of ASD and ADHD among adult psychiatric patients of Pakistan reporting for the psychiatric evaluation. Like the high prevalence of ASDs among males shown by previous studies, this study also associated the male gender with

the presence of ASDs and ADHD in adults. Illicit substance use and poor response to treatment also emerged as independent risk factors linked with the presence of ASD and ADHD among the target population. The study had no conflict of interest to be declared by the author and there were a few limitations of the study. Despite a lot of strengths, it was carried out on the psychiatric patients of a tertiary care psychiatric facility so neither generalizable for the whole adult population nor for the psychiatric patients as many psychiatric patients with less severe symptoms managed at primary and secondary care level would have been missed. Secondly bio- logical screening was not done so these symptoms might be due to some organic pathology missed at the psychiatric clinics. Use of psychometric screening tools poses methodological issues as well as study participants may under report or over report symptoms on them. More- over if final diagnosis has been made by one consultant psychiatrist and that too after blind-ing, results would have been more accurate. Large multi-center or community based studies in future with more sophisticated study design may generate more generalizable results.^[25]

Limitations

Very few studies were found after extensive search. Studies conducted were few and far between which means epidemiological vigilance has suffered excessive neglect. Certain studies had a much smaller sample size which affects accuracy of results negatively. A clear lack of resources can be seen which puts analysis of thus gathered data in uncertainty. Most importantly, all the studies conducted were either conducted in a hospital-based setting, community-based setting or conducted among children who are a part of special Autism Schools, making generalizations of the results obtained to other settings much difficult.

CONCLUSION

In this systematic review, we attempted to methodically review all the available evidence of prevalence surveys of ASD in Pakistan. An evidence gap is identified in a region where need of availability of services is much needed. In light of the fact that sparse data exists, our conclusion is limited. ASDs are on the rise but multiple barriers in the way of understanding exist. We can only hope this study attracts the attention of policy makers and Non-Government Organizations or any organization interested in health welfare to arrange well planned epidemiological surveys in this region, the results of which can be applied at a larger scale, and promote research regarding ASDs. This may help the health sector to adopt the present screening and diagnostic tools and regionally optimize them and work towards making the disorder culturally acceptable to help early diagnosis and improve treatment in a large population with a large potential undiagnosed burden.

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