



Autism Spectrum Disorder in Children: The Disparities between the Developed and Developing Countries

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Abstract

This review aims to appraise the disparities in the prevalence and management of childhood autism in developed and developing countries, and to discuss strategies that will possibly close the gaps. Autism is one of the pervasive developmental disorders or autism spectrum disorders which are characterized by developmental delays in socialization and communication. Following the revised definition by the Diagnostic and Statistical Manual of mental disorders, Fifth edition (DSM-V), the term 'autism spectrum disorder' (ASD) is now used as the nomenclature to identify children with autism and other related disorders. Unlike in developing countries, more research work has been conducted in the developed world where advanced support services and use of standardized screening and diagnostic instruments are the norm. Thus, disparities exist in the prevalence rates as high figures are reported from developed countries while the rates from developing countries are low. Furthermore, wide therapeutic options are available for children with ASD in the developed world. In developing countries, treatment interventions are largely unavailable coupled with dearth of the requisite health care professionals. To close the huge gaps in epidemiologic data and management of ASD between the developed and developing nations, there is need for international bodies such as 'Autism speaks' to increasingly drive the global advocacy action for children with ASD. It is also recommended that the governments of these developing nations should prioritize the funding of autism research, undertake massive public enlightenment and build the capacity of health professionals in synergy with international advocacy groups.

Keywords: Autism spectrum disorder; Children; Developed countries; Developing countries; Epidemiologic gaps; Management gaps; Advocacy

Introduction

Autism is one of the pervasive developmental disorders (PDD) or autism spectrum disorders (ASDs) which are characterized by developmental delays in socialization and communication [1]. There are three typical behaviors that indicate autism: autistic children have difficulties with social interaction, problems with verbal and non-verbal communication, and exhibit repetitive behaviors or narrow obsessive interests. These behaviors can range in impact from mild to disabling [2].

The Diagnostic and Statistical Manual of mental disorders, Fifth edition (DSM-V) defines a patient with autism spectrum disorders as having persistent deficits in social communication and social interaction which encompass deficits in social-emotional reciprocity, deficits in non-verbal communicative behaviors used for social interaction, and deficits in developing and understanding relationships [3,4]. DSM-V does not differentiate between the specific disorders that constitute the autism spectrum disorders. Thus, the term 'autism spectrum disorder' is now used as the nomenclature to identify children with autism and other related disorders; the age of onset of its manifestation is usually before 36 months.

Although ASD occurs worldwide, previous studies on children with the disorder have largely been conducted in affluent English-speaking developed countries which have extensive professional support

services, and utilize standardized screening and diagnostic instruments [5]. For instance, most of the prevalence studies reviewed by some authors were conducted in developed countries [6-8]. On the other hand, there is scanty information on childhood ASD in developing countries where services for children with any form of special needs are less advanced [5]. Whereas the prevalence of ASD is rising in the developed world, it is much lower in the developing world [9]. Reasons given for this disparity include more awareness and better detection seen in developed countries, as well as cultural differences between the two regions; clinical features associated with ASD may be considered as normal behavior in some cultural settings in developing countries [9].

This review therefore aims to appraise the disparities in the prevalence and management of childhood ASD in developed and developing countries, and to discuss the strategies that will possibly close the gaps.

Literature search was conducted on Google and PubMed database using relevant search terms. Research and review articles on childhood ASD were retrieved with preference for those relevant to the review objective.

Global Prevalence Rates: The Disparities in Figures and Diagnosis

Few prevalence studies on autism have been conducted in developing countries probably because of the problem of stigma, lack of awareness about mental health and limited health infrastructure. Estimation of prevalence rates is usually the initial step toward setting

in motion government and nonprofit mental health services in these countries, and can also lead to scientific deductions on the genetic, environmental and cultural basis of autism. Recently, a pilot study from Brazil reported the prevalence of pervasive developmental disorder (PDD) as 27.2 /10,000 [10]. The investigators used a case definition based on a combination of standardized instruments and clinical evaluations. In Oman (Middle East), an overall prevalence of ASD was documented as 1.4/10,000 for children aged 0-14 years [11]. Although diagnosis was made using DSM-IV-TR criteria supplemented with information from Childhood Autism Rating Scale (CARS) questionnaire, the low prevalence was attributed to under-reporting and under-diagnosis [11].

Measurement of incidence and prevalent rates for rare conditions using Health Interview Surveys is difficult. For conditions such as ASD the sample size required may reach the total population size. It is thus not surprising to note the disparity in the figures. For example in Europe, there is no central documentation of ASD cases in any European Union Member State, and there are very few epidemiological studies on ASD on which to make appropriate predictions [2]. The problems are attributable to three main causes: first, diagnostic difficulties because of the variety of Diagnostic criteria such as Kanner, ICD-10 and DSM-IV and professional differences in their application; second, use of diagnostic terms in different ways; and third, variation in case- finding methods such that higher prevalence figures are obtained in prospective studies than with retrospective ones [2]. Consequently, it remains very difficult to make comparisons among studies conducted by different investigators. Thus, the earliest epidemiological studies which used the very narrow Kanner's criteria reported prevalence rates between 4.5 to 5/10,000 children, while later studies which employed wider diagnostic criteria documented prevalence figures beyond 60/10,000. Knowledge about prevalence is nevertheless important if effective services are to be planned and provided at the appropriate points in the lives of the subjects.

A look at the picture in the Western world shows that the median prevalence rate of ASD in Europe is 61.9/10,000 while the estimated rate in the United States is 65.5/10,000 [4]. In these regions, it is the conventional practice for a pediatrician to refer children who exhibit developmental problems. The preliminary screening instruments include the Modified Checklist for Autism in Toddlers (M-CHAT), Social Communication Questionnaire (SCQ), and Autism Spectrum Screening Questionnaire (ASSQ) [12]. The evaluations for autism spectrum are typically conducted by professionals who specialize in developmental disorders, such as psychologists, psychiatrists, or neurologists [12]. The diagnostic instruments consist of the Autism Diagnostic Interview-Revised, Autism Diagnostic Observation Schedule (ADOS), and Childhood Autism Rating Scale (CARS), as well as clinical judgment using criteria from the Diagnostic and Statistical Manual of mental disorders [13].

About twenty decades ago, investigators had disputed whether autism was a universal phenomenon. Some scientists erroneously believed that autism was a disorder confined to the Western world; however, there is current evidence of increased prevalence of and knowledge about ASD cross-culturally and internationally [14]. Although autism has a biological basis with clear criteria for its diagnosis, there are still cross-cultural differences in symptoms. These disparities may extend to the perceptions of autism in different cultures and perceptions of the most effective treatment options [15]. Recently, autism rights or neurodiversity advocates believe that ASD is genetic and therefore should be accepted as a natural expression of the

human genome. This perspective is distinct from two other distinct mainstream perspectives which maintain that ASD is a genetic defect and should be addressed by targeting the autism gene(s); and that ASD is caused by environmental factors such as vaccines and pollution and thus could be cured by addressing environmental causes [16]. However, the causal link to vaccines has been disputed as it lacks convincing scientific evidence [17].

Other reports from South America also reveal low prevalence figures. For instance, in Venezuela, the prevalence of autism is estimated at 1.1/10,000 people, while the prevalence of ASD is estimated at 1.7/10,000 people [18]. The figures may represent an underestimation due to study methodology; rates were provided only for identified cases of autism and unidentified cases of autism not documented were not estimated [19].

The outlook in Africa is dismally poor where autism research has been infrequent and unrepresentative of all African countries, making the prevalence of autism in the continent difficult to estimate [20]. Nevertheless, one author has observed that more than 50% of reported ASD cases described children who were nonverbal, or lacked expressive language [21]. Nonverbal rates of as high as 71% in children with autism have been reported in Africa, while the rate in the United States is 25% nonverbal [21]. This suggests that prevalence may be underestimated because reported cases are skewed towards more severe and thus more recognizable cases of autism. In Africa, diagnosis of autism frequently occurs at the same time with epilepsy or intellectual disability [14].

In Asia, autism appears more common than previously thought. For instance in China, the estimated prevalence of autism is 11.8/10,000 people while that of autism spectrum conditions is 26.6/10,000 people [22]. Recent estimates in Japan are as high as 13/10,000 people [23]. The frequently used diagnostic instruments in China include Childhood Autism Rating Scale (CARS), Clancy Autism Behavior Scale (CABS), Autism Behavior Checklist (ABC), and Checklist for Autism in Toddlers (CHAT) [22]. In India, awareness of autism and its symptoms has increased in the past two decades, although a significant gap between initial recognition of symptoms and seeking a diagnosis exists [24]. Initial symptoms of autism recognized by parents were social difficulties and withdrawal, speech delays, and developmental difficulties. After symptom recognition, there is a delay of an average of 7.15 months before medical consult because of perceptions that the symptoms are not problematic and that the children will outgrow symptoms such as language impairments; moreover, misdiagnosis of autism as "mental retardation" is common [24].

Nevertheless, the observed differences in prevalence between the developing nations of Africa and English-speaking developed countries could be real and may arise from differing prenatal or postnatal environments related to culture and/or geography. For instance, the risk of ASD is associated with several prenatal factors including advanced parental age, maternal diabetes during gestation, and pre-gestation obesity and underweight, as well as the use of psychiatric drugs in the mother during gestation [25,26]. Postnatal factors include 'catch-up growth' in the children born to underweight mothers, and the link with neighborhoods of high socio-economic status: a common environment in developed nations [27].

Management Modalities of ASD: The Global Disparities

In the Western world, behavioral intervention and medications is the mainstay of managing the symptoms of autism. Early intervention

programs can potentially improve cognitive and language skills in children with ASD [12]. The behavioral interventions comprise the following: Applied Behavioral Analysis, Developmental, Individual Difference, Relationship-based (DIR)/Floor-time Model, and Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) [12]. Applied Behavioral Analysis is a widely used intervention that uses operant conditioning to reward and increase pro-social behaviors and diminish behaviors that negatively impact learning [28]. The DIR/Floor-time Model allows for individualization of treatment in children. Its focus is on the mastery of social, emotional, and intellectual capacities rather than focusing on skills and specific behaviors [29]. TEACCH also uses a behavioral approach and teaches children skills for self-care and to manage inappropriate behavior [30].

There are no approved medications for the treatment of ASD, but some medications may be prescribed off-label to treat its symptoms [12]. Antipsychotic medications may be used to reduce irritability and aggressive behavior in children with autism while stimulant medications are used for the treatment of hyperactivity and short attention span. In addition, antidepressants are occasionally prescribed to ameliorate the restricted and repetitive behaviors associated with autism [12]. These drugs, such as selective serotonin uptake inhibitors (SSRIs) reduce obsessive behavior, and thus improve social interaction and self-control. When used in conjunction with psychosocial therapies, these medications can substantially decrease the difficulties of social interaction for subjects on the autism spectrum, although further research is needed to validate their safety profile and therapeutic efficacy [31]. More recent research has however thrown more light on the use of SSRIs in ASD. In a systematic review by some authors which aimed, among other objectives, to determine if treatment with SSRIs (fluoxetine, fluvoxamine, fenfluramine and citalopram) improves the core features of autism (social interaction, communication and behavioral problems) and whether they cause harm, they documented no evidence of effect in children as well as emerging evidence of harm [32]. Secondly, other authors also documented that for the treatment of repetitive behaviors, SSRIs show less efficacy and are more poorly tolerated in children with ASD compared to adults [33]. They however noted that antipsychotics are the most efficacious drugs for treating irritability in children with ASD and pervasive developmental disorders. In another major review, it was observed that throughout the mid-2000s, several large-scale controlled clinical trials were published leading to the approval of two medications (aripiprazole and risperidole) for the treatment of irritability in ASD [34]. The authors further noted that the past five years have yielded no further approved medications with ASD as the primary indication [34]. They summarized the important new research findings as long-term safety and efficacy data regarding treatment with aripiprazole for irritability, as well as consensus regarding potential harm from SSRIs for the treatment of repetitive behaviors in children/adolescents with ASD.

In Africa, educational and behavioral interventions for childhood autism are largely unavailable with dearth of mental health-care facilities and trained personnel commensurate with the estimated number of autism cases [35]. Specifically, health care workers were observed to have low to average knowledge and awareness of ASD, with psychiatric health care workers recognizing symptoms of ASD better than pediatric health care workers [35]. In Nigeria, for instance, there are insufficient facilities for the care of children with autism [14,36,37]; hence family caregivers carry almost all the burden of care [38]. Within the cultural settings of most African societies, the

perception of psychiatric disorders as spiritual also applies to the perceived causes of autism. Obviously, this will influence the treatment-seeking behavior of families with autistic children. Interestingly, some workers in Nigeria have reported that the number and type of impairments found in children with autism affect the psychological health and social burden of their mothers [39]. In another survey of pediatric or psychiatric nurses in Nigeria, a substantial percentage of them cited supernatural causes of autism such as 'ancestral spirits' or the 'action of the devil' [21]. Such perceptions of autism can sway the attitude of people toward the patronage of spiritualists and traditional healers as the first option of treatment. In developing countries of Asia, the scant information on treatment options for autistic children suggests the fewness of such options. For example in India, there are a few special programs for autistic children, but most affected children attend the same educational programs as children diagnosed with mental retardation [24].

Furthermore, another category of treatment which may be culturally more acceptable than medications or behavioral treatment—especially in developing settings like Africa—is the use of ketogenic diet (KD). KD has been used in developed settings for several years. In a pilot prospective follow-up study of its role on children with ASD, 60% adhered to the diet showed improvement in several parameters and in accordance with the Childhood Autism Rating Scale [40]. The researchers concluded that some evidence exist for the use of KD as an additional or alternative therapy in autistic behavior. Another group of investigators corroborated this observation in a study of a cohort of 187 Greek patients with ASD when they reported that KD resulted in mild to significant clinical improvement in autistic features [41].

More recently, the KD has been successfully used to manage children with epilepsy in Africa. For instance in South Africa, the Keilah Foundation was formed in 2013 to enable all children with epilepsy have access to KD as a viable and scientifically-valid treatment (or additional therapeutic treatment) for infant, child and adult epilepsy [42]. The diet has also been successfully implemented in a Ugandan setting in east Africa where locally-available food stuffs were utilized [42].

Closing the Gaps: The Way Forward

To close the huge gaps in epidemiologic data and management of ASD between the developed and developing nations, there is need for international bodies such as 'Autism speaks' to increasingly drive the global advocacy action for children with ASD. Fortunately, 'Autism Speaks' is an advocacy organization with multi-national partnerships in over 40 countries, though it originated in the United States [43]. The 'Autism Speaks' website offers a resource guide in which families of individuals with autism can find support including adult programs, financial resources, community-support organizations, health services, and interventions for toddlers, children, and adults [44]. Secondly, increasing public awareness of autism in the developing countries cannot be over-emphasized in addition to increasing the funding of autism research, as well as capacity building for health care professionals. These measures will increase the capability of recognizing autism. Unfortunately, autism awareness is low, especially in sub-Saharan Africa. It has therefore been suggested that educating the public and health care workers is crucial for early diagnosis of ASD so that early intervention can be effective [14]. Currently, organizations like the International Child Neurology Association raise awareness about autism in Africa [45]. Finally, the issue of stigmatization should

also be addressed so as to improve case detection; this will ensure a more correct estimation of prevalence values which is obtainable in the Western world. Better still, support from friends, families, and professionals is critical to enhance the psychological well-being of caregivers experiencing stigmatization [46].

Conclusions

Obtaining reliable data about autism from developing countries is challenging as autism awareness differs from country to country; available services for individuals with autism and their families differ. In addition, the behavior of subjects with autism may differ cross-culturally, and the capacity to carry out research on autism can be impeded because of these differences. The limited availability of screening and diagnostic instruments in the developing countries has resulted in dearth of reliable epidemiologic data such as prevalence rates. Consequently, low prevalence rates (unrepresentative of the true picture in these regions) remain the usual outlook. Similarly, very few management options and wrong cultural perceptions mitigate the access to a wide range of standard treatments unlike in the developed Western world.

It is recommended that the governments of developing nations should prioritize the funding of autism research, undertake massive public enlightenment and build the capacity of health professionals in synergy with international advocacy groups.

Definition of Some Terms

Developed nations/countries or Western world refer to North American countries like United States and Canada, United Kingdom and Western Europe, as well as Australia and New Zealand (which are largely English-speaking).

Developing nations/countries refer to countries in Africa, Asia, Middle-east, South America and the Caribbean.

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