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SCIENTIFIC FORUM: COMMENTARY

The status of early identification and early intervention in autism spectrum disorders in lower- and middle-income countries

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Abstract

There is limited information on autism spectrum disorders from lower- and middle-income countries (LMIC). This paper reviews the status of early identification and early intervention for autism spectrum disorders in response to the article by Camarata (2014). The PubMed database was searched to identify relevant epidemiological studies from LMIC. Seven studies from five countries were identified: Colombia, India, Jamaica, Jordan, and Mexico. The mean age of parental concern, at 21–24 months, and mean age of diagnosis, at 45–57 months, were similar in LMIC, but later than in high-income countries. Both country groups reported language disorder to be the symptom of initial concern. Similarities in biological aspects of the disorders were noted across LMIC and high-income countries. Comparable ages of identification and diagnosis across vastly different LMIC suggest limited resources to be the underlying contributory factor. Recommendations for improving early identification and intervention made by researchers in the LMIC are reported.

Keywords: *Autism spectrum disorders, early identification, lower and middle income countries.*

Background

The autism spectrum disorders (ASD) are neuro-developmental disabilities typically identified in childhood, in which affected individuals display core symptoms of impairment in reciprocal social communication and social interaction; restrictive, repetitive, patterns of behaviour interests or activities; and in whom symptoms were present from early childhood and limit or impair everyday functioning (American Psychiatric Association, 2013). The prevalence of one affected child in every 88 births established in the US in 2012 (Centres for Disease Control and Prevention, 2012), the presence of intellectual disability, the severity of symptoms in many affected persons, and the lifelong nature of the condition render these disorders a significant concern for countries throughout the world and a focus for research.

Research has been conducted in two main areas. Research addressing aetiology is intended to reduce the incidence of the condition, while research on interventions aims to improve the outcome of affected children and adults. Intervention studies have been focussed on improving developmental, educational, or behavioural status. Warren, McPheeters, Sathe, Foss-Feig, Glasser, and Veenstra-VanderWeele (2011), after reviewing a number of intervention studies,

reported the efficacy of early intensive behavioural and developmental intervention for some children, using either the University of California, Los Angeles/Lovaas approach or a comprehensive approach utilizing the principles of applied behaviour analysis (e.g., the Early Start Denver Model) for young children (Warren et al., 2011). Warren et al. found that these interventions must be prolonged, at least 1–2 years, and also found individual variation in treatment response that was not well understood. The need for well-designed intervention studies to address research gaps and guidelines on the conduct of high quality intervention studies were documented (Warren et al., 2011).

Camarata (2014), in the lead article in this journal issue has suggested that the weak evidence for early intervention studies may be a result of evolutionary changes in diagnosis and identification of ASD. The article reports the conflict between the lower diagnostic accuracy prior to 2 years of age and missed opportunities for intensive early intervention when interventions are commenced later. Camarata's article also comments on the face validity of early identification and intervention, while acknowledging the limited well-designed studies and supporting the guidelines for designing intervention studies, as documented by Warren et al. (2011).

The lower- and middle-income countries (LMIC) with the greatest population of children are likely to have the greatest population of children with ASD. A recent global survey did not support geographical variation in prevalence, but acknowledged limited prevalence studies from lower-middle-income countries (Elsabbagh, Divan, Koh, Kim, Kauchali, Marcin, et al., 2012). There have been limited epidemiological studies of ASD in lower-middle-income countries, although there have been individual country papers (Bakare & Munir, 2011; Daley, 2002). This paper reviews the status of early identification and intervention in LMIC. The information obtained is expected to contribute to the international body of evidence in this area.

Method

A review of published epidemiological studies on early identification and intervention for ASD conducted in LMIC was undertaken. The World Bank (2013) classification of countries was utilized, in which economies are divided according to 2012 Gross National Income per capita, calculated using the World Bank Atlas method. The resulting groups are: low-income, US\$1035 or less; lower-middle-income, US\$1036–\$4085; upper-middle-income, US\$4086–\$12,615; and high-income, US\$12,616 or more. This paper was confined to the lower- and middle-income countries (World Bank, 2013). A search of papers in the PubMed database was conducted using the keywords autistic disorder, autism spectrum disorder, and pervasive developmental disorder for each LMIC. References of identified publications were also reviewed to identify any additional publications, and these, as well as any other relevant publications of which the author was aware were included.

Results

Search results

Publications were located for six of 36 (16.7%) low-income countries (income less than or equal to \$1035): Bangladesh, Somalia, Tanzania, Togo, Uganda, and Zimbabwe. The majority consisted of reviews of immigrant populations in high-income countries, but there was also a case series, case reports, and reports of ASD as a co-morbidity in other medical conditions. None of the studies was epidemiological in nature, aimed at studying populations of children with ASD. Publications were also identified for 11 of 48 (22.9%) lower-middle-income countries (income between \$1036–\$4085), and 23 of 55 (41.8%) upper-middle-income countries (income between \$4086–\$12,615). Of the lower-middle-income countries, India ($n = 65$) and Egypt ($n = 15$) had the greatest number of publications. For the

upper-middle income countries, those with the greatest number of publications were China ($n = 118$), Brazil ($n = 64$), Iran ($n = 26$), Thailand ($n = 18$), Turkey ($n = 11$) and Argentina ($n = 11$).

Criteria for inclusion were a sample size of a minimum of 40 cases, documentation of diagnostic tools utilized, types of pervasive developmental disorders included, and summary data of age of parental concern and/or diagnosis. Few papers of those indicated above were epidemiological in nature and/or contained information on early identification and intervention. Seven papers from five LMIC (Colombia, India, Jamaica, Jordan, Mexico) were identified (Table I).

Early identification of children with ASD

Age of parental concern. The age of parental concern can be considered an important indicator of early identification of children with ASD. Table I shows the mean/median age of parental concern for the LMIC included in this study.

Three studies, the Jamaican study and two from India, analysed risk factors for age of parental concern (Daley, 2004; Jain, Juneja, & Sairam, 2013; Samms-Vaughan & Franklyn-Banton, 2008). In Jamaica, there was a significant difference in age of parental concern by gender, with the mean age of parental concern for male children and parents of higher educational status being earlier than girls and parents of lower educational status ($p < 0.05$). Parental educational status is often used as a proxy for socio-economic status in Jamaica. In India, factors associated with an early age of parental concern were physician's recognition of the condition and a history of early neonatal admission (Jain et al., 2013), and co-existing medical problems such as seizures (Daley, 2004).

Symptoms causing parental concern. Data about symptoms causing parental concern were available for four of five countries, with two studies from India. Jordan, India (Chakrabarti, 2009; Daley, 2004), Mexico, and Jamaica reported language development concerns to be the first and most common parental concern identified, occurring in 48.8%, 83.0%, 44.9%, 62.5%, and 85.5% of cases, respectively. In most of these studies, the next most common symptom was behavioural problems, including co-morbid behaviours of hyperactivity and aggression and behaviours commonly associated with the pervasive developmental disorders, such as stereotyped and repetitive behaviours. Social impairment was least frequently reported as an initial concern. One study from India (Daley, 2004) reported social problems to be the second most common identified concern, at 44.5%, just below language development at 44.9%. In this study, 9.5% of parents had no concerns, but were advised by health professionals, educators, family, or friends.

Table I. Age of parental concern and age of diagnosis of autism spectrum disorder by lower- and middle-income country.

Country (reference)	Publication year	Study years	No. of cases	Recruitment	Cases included	Diagnostic tests	Mean age at concern (months)	Mean age at diagnosis (months)
Colombia (Talero-Gutiérrez et al., 2011)	2011	2003–2009	138	Developmental clinic	All PDD	DSM-IV, CARS	20.6	45.5
India (Chakrabarti, 2009)	2009	NS	141	Special schools/clinics	ASD	DSM-IV	23.4 ± 11.3	55.2 ± 25.6
India (Daley, 2004)	2004	NS	95/81 ⁺	Special schools	ASD	Professional***	25.7 ± 12.8	57
India (Jain et al., 2013)	2013	NS	47	Developmental clinic	ASD	Professional***	24**	42**
Jamaica (Samms-Vaughan & Franklyn-Banton, 2008)	2008	1999–2004	117	Developmental clinic	AD	DSM-IV, CARS	21.3 ± 10.9	47.2 ± 26.7
Jordan (Masri et al., 2013)	2013	2001–2009	84	Developmental clinic	AD	DSM-IV-TR	15*	45.6
Mexico (Brava Oro et al., 2012)	2012	1968–2009	393	Developmental clinic	All PDD	DSM-III, DSM-IV, CARS, ICCAN	–	52.8

ASD, Autism Spectrum Disorder; AD, Autistic Disorder; PDD, Pervasive Developmental Disorder; PDD-NOS, Pervasive Developmental Disorder-Not Otherwise Specified; NS, Not Stated; DSM, Diagnostic and Statistical Manual of Mental Disorders; CARS, Childhood Autism Rating Scale; ICCAN, GENNA Inventory of characteristics of autistic children.

*Sub-group with regression only.

**Median.

***Diagnoses made by trained professionals using variety of tools.

⁺Only sample of 81 children diagnosed in India included in aspects of research on diagnosis.

Age of diagnosis and treatment. Table I indicates that the mean age of diagnosis across the LMIC ranged from 45–57 months. Three studies, in Jamaica and India, investigated factors associated with delayed diagnosis and treatment. The Jamaican study identified lower maternal education as a significant risk factor for delayed diagnosis (Samms-Vaughan & Franklyn-Banton, 2008). While females and children living in rural areas in Jamaica were diagnosed later than their urban peers, these differences were not statistically significant. Physician's recognition of ASD, and medical risk factors, such as institutional delivery and history of neonatal admission were significantly associated with early age of diagnosis and referral for services in one study from India (Jain et al., 2013). In another study in India, co-morbid medical problems were associated with later diagnosis, as physicians focused their diagnosis and treatment on associated health-related problems (Daley, 2004). Jain et al. (2013) also enquired of parents' perceptions of reasons for delay in receiving treatment. Physician factors (reassurance of parents (46.7%); non-referral because of ineffectiveness of any intervention (16.7%)) accounted for 63.4% of responses, and family factors (reassurance (26.7%); family problems (3.3%); being unaware of interventions (3.3%)) accounted for 33.3% of responses. Distance from facilities accounted for only 3.3% of responses, despite the majority of patients living greater than 10 kilometres away from the referral centre. In India, children saw an average of 3.5 doctors prior to diagnosis, with the maximum number seen being eight (Daley, 2004). In Jamaica, 76.8% of children saw two or more doctors and 33.7% saw three or more, with the maximum number seen being five (Samms-Vaughan & Franklyn-Banton, 2008).

LMIC researchers, informed by scientific data when available and by their own knowledge of local culture and available service provision when data were not available, identified a number of potential contributors to diagnostic delay in their published papers. These included limited physician knowledge resulting in inaccurate diagnosis or failure to diagnose ASD (Daley, 2004; Jain et al., 2013; Samms-Vaughan & Franklyn-Banton, 2008; Talero-Gutiérrez, Rodríguez, De La Rosa, Morales, & Vélez-Van-Meerbeke, 2011), inadequate knowledge of preschool teachers preventing early identification of symptoms (Samms-Vaughan & Franklyn-Banton, 2008), incorrect beliefs by physicians about efficacy of therapy (Jain et al., 2013), reluctance to refer very young children and those with milder symptoms (Jain et al., 2013), inadequate access to specialized medical services and long waiting lists (Daley, 2004; Jain et al., 2013; Talero-Gutiérrez et al., 2011), lack of co-ordination among early intervention agencies (Jain et al., 2013), parental low socioeconomic or educational status impacting help-seeking behaviour (Daley, 2004; Samms-Vaughan & Franklyn-Banton,

2008), and parental perceptions and anxieties (Daley, 2004; Jain et al., 2013).

Among the reported parental perceptions that delayed help-seeking behaviour and therefore diagnosis in India, were children being considered as mature because they socialized with adults, cultural acceptance of delayed language development in boys, a family history of delayed language development, and the belief that children's symptoms were transient and would resolve with time (Daley, 2004).

The recommendations to reduce diagnostic delay included increasing public awareness (Masri, Al Suluh, & Nasir, 2013; Samms-Vaughan & Franklyn-Banton, 2008), the establishment of primary care based screening and surveillance systems or other early detection mechanisms (Brava Oro, Vázquez Briseño, Cuello García, Calderón Sepúlveda, Hernández Villalobos, & Esmer Sánchez, 2012; Samms-Vaughan & Franklyn-Banton, 2008; Talero-Gutiérrez et al., 2011), training in early detection of ASD for general health professionals (Brava Oro et al., 2012; Masri et al., 2013; Samms-Vaughan & Franklyn-Banton, 2008), and pre-school educators (Samms-Vaughan & Franklyn-Banton, 2008), trained and specialized professionals (Brava Oro et al., 2012), and adequate infrastructure (Brava Oro et al., 2012). Further research in LMIC, particularly national and longitudinal studies to define incidence and prevalence, aetiology (including genetic studies), and risk factors (Brava Oro et al., 2012; Talero-Gutiérrez et al., 2011), and informed national policy to improve the lives of children with ASD was also recommended.

Early intervention

A published review of interventions for children with pervasive developmental disorders in LMIC identified only four studies (Hastings, Robertson, & Yasamy, 2012). However, study limitations impacting study quality did not allow any practice implications to be identified.

Discussion

There is limited research being conducted on ASD in LMIC. Limited research in prevalence and early intervention studies in LMIC has been previously reported (Elsabbagh et al., 2012; Hastings et al., 2012). Limited research on early identification has now been confirmed by this study. The limited research is of concern because of the high prevalence of the disorder and the fact that the majority of children with ASD live in LMIC. As research is the basis for guiding evidence-based and effective policy and program development, this suggests that large numbers of children in these countries are not being diagnosed and are failing to receive appropriate care and services.

LMIC represent an heterogeneous group of countries, of vastly different geography and cultures, classified on the basis of income. Despite these differences, and differences in study methodology, the mean age of parental concern, at 21–24 months of age; the mean age of diagnosis ranging from 45–57 months, and the initial symptom of parental concern (i.e., language delay) were similar among LMIC for which data was available. This suggests that the factors impacting age of parental concern and age of diagnosis are more associated with resources than individual country factors.

High income countries report a mean age of parental concern of 19.6 months and mean age of diagnosis of 3.1 years (Mandell, Novak, & Zubritsky, 2005; Rosenberg, Landa, Kiely Law, Stuart, & Law, 2011). While the mean age of parental concern has been consistent across high income countries and has remained stable over a number of years (DeGiacomo & Fombonne, 1998), the mean age of diagnosis has decreased with time. Of the limited factors impacting age of parental concern and age of diagnosis evaluated by the LMIC, there was agreement on an earlier age of parental concern in the presence of medical problems (Mandell et al., 2005), and the symptom of initial concern being language problems. The similarity of biologically-based factors, first symptom identified and reduced age of parental concern in the presence of medical conditions, suggests that ASD may be comparable in LMIC and high-income countries. Differences in age of parental concern and age of diagnosis by country income categories suggest that physical and human resource factors limit the ability to identify, diagnose, and provide intervention.

Researchers in LMIC are aware of the country-level interventions that need to occur. For example, the identified contributors and the recommendations for improvement in early identification and intervention documented in this paper are similar to those proposed by Khan, Gallo, Arghir, Budisteanu, Budisteanu, Dobrescu, et al. (2012). These include establishment of public awareness and screening and surveillance programs, training in identification for first line professionals working with young children, specialist professional training for diagnosis, adequate infrastructure, and further research.

Improvement of services to children in LMIC are most likely to be achieved by developing culturally-relevant, low cost programs, developing partnerships for capacity building and technical support with experienced professionals and organizations and conducting research. For example, in the area of early identification and intervention, this would include development of culturally relevant local screening and diagnostic tools and parent mediated interventions. High quality intervention studies conducted in LMIC are particularly important, as limited resources must be efficiently and effectively utilized.

The existence of local professionals with experience in autistic spectrum disorders in LMIC has been

demonstrated by this paper; by the reports of current epidemiological studies in Mexico, India, Vietnam, Taiwan, South Africa, and Uganda (Elsabbagh et al., 2012); by reports on the outcome of global autism public health initiatives (GAPH) in association with Autism Speaks in Albania and Bangladesh (Wallace, Fein, Rosanoff, Dawson, Hossain, Brennan, et al., 2012), and by completion of an epidemiological study in Jamaica with a number of published findings, including the identification of older maternal and paternal age as risk factors (Rahbar, Samms-Vaughan, Ardjomand-Hessabi, Loveland, Dickerson, Chen, et al., 2012; Rahbar, Samms-Vaughan, Loveland, Ardjomand-Hessabi, Chen, Bressler, et al., 2013; Rahbar, Samms-Vaughan, Loveland, Pearson, Bressler, Chen, et al., 2012). Engagement of these professionals will be integral to ensuring interventions of relevance and the improvement of outcomes for children with autistic spectrum disorders in LMIC.

Study limitations

The study had some methodological limitations. A more extensive search of educational and psychological databases, as well as regional databases, might have identified additional epidemiological publications. However, in Brazil, while the number of papers identified by a more extensive database search almost doubled (from 50 to 93) compared with those identified in the PubMed database alone, the total number of epidemiological studies identified was still limited to three (Texeira, Meca, Velloso, Bravo, Ribeiro, Mercadante, et al., 2010). None of these studies addressed early identification or intervention. The data from all the epidemiological studies analysed were obtained from referral centres, rather than population studies. The information obtained is, therefore, biased towards that select group of children who had access to services, and may not be representative of total populations.

Conclusion

This paper has confirmed limited research on early identification of ASD in LMIC. Where data were available, important indicators of early identification, the age of parental concern, and the age of diagnosis were similar across vastly different LMIC, but were delayed in comparison to high-income countries. This suggests that limited human and physical resources are a major contributor to delayed diagnosis and likely delayed intervention. In order to improve the outcome of children with ASD in LMIC, greater attention needs to be focused on research, capacity building, and culturally relevant and cost-effective interventions.

Declaration of interest: The author reports no conflicts of interest. The author alone is responsible for the content and writing of the paper.

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