Autism: A Global Perspective

Eva-Maria Hahler · Mayada Elsabbagh

Abstract Epidemiological data estimates the presence of 52 million cases of autism worldwide, affecting around 1 %-2 % of children across the globe. There has been a recent increase in interest regarding similarities and differences in the manifestations and the impact of the condition in different world regions. Despite this interest, however, evidence remains limited in low- and middle-income countries (LMICs), and it has been difficult to draw public and policy-maker attention to autism in particular and neurological and mental health conditions more generally in these countries. We adopt a global life-span perspective by reviewing the current state of the science of autism. We include prevalence and global burden of the condition with models for identification and intervention in community based settings from early childhood to adulthood in both high-income countries and LMICs. We conclude with a summary of relevant recent research priorities for improving quality of life for people affected by the condition around the globe.

Keywords Autism · Global · High-income countries · Low-income countries · Life-span · Prevalence · Early identification · Early intervention · Comorbidities · Adulthood · Research priorities

E.-M. Hahler (✉) · M. Elsabbagh
Department of Psychiatry, Faculty of Medicine, McGill University, 4018 St Catherine St West, Montreal H3Z 1P2, QC, Canada
e-mail: eva.hahler@gmail.com

M. Elsabbagh
e-mail: mayada.elsabbagh@mcgill.ca

Introduction

Autism is a life-long neurodevelopmental condition, typically identified in early childhood, which interferes with the person's ability to communicate and relate to others. In the last decade, a substantial increase in public awareness of autism has occurred around the globe. There is also increasing interest in similarities and differences in the manifestations and the impact of the condition in different world regions. "That first time when we were told autism, we had taken it carelessly. We had never heard about it", said a parent of a child with autism in India recounting his experience of first being introduced to the term autism [1, p 620]. A general practitioner in India shared: "I won't say the diagnosis because I don't claim to be right. Autism is something that cannot be measured in easy terms. It requires a detailed analysis. So I tell the parents that at least you seek a senior opinion." [2, p 196]. In the UK, a parent of an adolescent boy with autism expressed: "One of the biggest issues is that you get the diagnosis and as a parent, you are just left to deal with it" [3•, p 10], and a professional offered: "We must try to understand how the autistic person thinks/processes the world around them, so we are able to better understand and support them" [3•, p 10]. These first-person perspectives of parents affected by autism and professionals supporting them highlight the similarities in experiences that a diagnosis of autism can entail around the world. Parents share a sense of uncertainty and helplessness as a result of a diagnosis. Professionals recognize the complexity of the condition and continue to strive to better understand it, in order to provide the most adequate services and supports possible in their context.

Despite these similarities, it has been difficult to draw public and policy-maker attention to autism in particular, and neurological and mental health conditions more generally, in many low-income and middle-income countries (LMICs), due to competing priorities in survival and physical health [4]. However, the marked decline in mortality among children

under 5-years-old in LMICs (e.g., [5]) means that more than 200 million children have developmental delays or disabilities within this increasing survivor group [6]. Therefore, there is a need for the focus on reduction of morbidity to go hand in hand with parallel improvements in identification and adequate support for developmental disabilities.

In response, recent global efforts have focused on scaling up access to evidence-based mental health services in LMICs [7]. In 2008, the mental health Gap Action Programme (mhGAP) was launched. The WHO identified child and adolescent mental disorders as one of the priority conditions and developmental disorders (DDs) as one of the priority areas for intervention among child and adolescent disorders. Similarly, the Grand Challenges in Global Mental Health Initiative has identified research priorities for the next ten years [8], aiming to reduce the burden associated with mental and neurological conditions. The Comprehensive Mental Health Action Plan 2013–2020, developed by the WHO and adopted by the World Health Assembly in May 2013, has announced the need to reinforce efforts to increase treatment for these conditions and has accordingly outlined strategies and targets for action [9•].

Building on these general efforts focused on mental health, specific initiatives have drawn more focus to autism. In 2013, the WHO headed a consultation on Autism Spectrum Disorders (ASDs) and other developmental disorders, which identified research needs and current challenges in providing comprehensive care packages for people with ASDs and other DDs, and moved to create a collaborative commitment to strengthening capacities in different countries [9•].

In the current manuscript, we adopt a global life-span perspective, reviewing the current state of the science of autism, including prevalence and global burden of the condition, and models for identification and intervention in community based settings from early childhood to adulthood. We conclude with a summary of relevant recent research priorities identified as pertinent for improving quality of life for people affected by the condition around the globe.

Epidemiology and Global Burden of ASD

In 2010, epidemiological data estimated the presence of 52 million cases of autism worldwide [10]. In 2012, the global prevalence of some form of autism was estimated to be 1 %-2 % [11•]. While there is substantial variation in current estimates, there is no evidence that this variability can be accounted for by geographic, ethnic, cultural, or socioeconomic factors [11•]. In contrast, these factors appear to be strongly associated with delays in diagnosis and barriers to accessing and utilizing services [11•, 12].

Epidemiological studies conducted over the last half-century suggest that the prevalence in ASDs is increasing around the world and that this increase is most likely due to improved awareness and reporting, expansion of diagnostic criteria, and enhancement of diagnostic tools [11•]. Additional explanations encompass changes in diagnostic practices, including expansion of developmental screening, increased diagnosis, and diagnostic substitution [9•].

A recent systematic review found that among all mental disorders, ASDs were the leading cause of disability in children under the age of 5 years [10]. In those older than 5 years, ASDs ranked among the 20 leading causes of disability considered in the 2010 Global Burden of Disease. The latter measured the overall burden of 291 conditions in terms of disability-adjusted life years (DALYs) [13]. Compared to other childhood-onset mental disorders, the total burden of ASDs (DALYs=7.7 million) was found to be greater than that of conduct disorder and attention-deficit/hyperactivity disorder (ADHD) combined (DALYs=6.2 million) [14]. As Baxter et al. (2014) pointed out, contrary to conditions like ADHD, there is little clinical or epidemiological evidence of remission in ASDs, which may result in a life-long burden, beginning in infancy and persisting across the life-span.

On the whole, epidemiological evidence is, however, very limited to date, particularly in LMICs. While the majority of people with autism live in LMICs, research knowledge about the condition is largely generated in high-income countries (HICs) [9•]. Barriers to research include financial inaccessibility, and the need to validate and adapt diagnostic tools across a variety of contexts. There is unavailability of services or lack of the development thereof and a shortage of experienced health professionals. In addition, there is both a lack of awareness of ASD in these professionals and the public in general with a lack of knowledge about epidemiological research [11•].

Early Identification of ASD

There is overwhelming evidence from biomedical and clinical research that delivering support early on in childhood can result in improvements in the developmental processes and quality of life for people with autism across the life-span. Therefore, in many communities early intervention is increasingly viewed as an effective way to reduce burden and costs to society in the long run. Moreover, availability and effectiveness of early intervention are directly motivated by the ability of children with autism to exercise their human rights to inclusion, education, and play. Nevertheless, early detection of ASD continues to constitute a global challenge, both in HICs and LMICs [9•]. The majority of tools for screening and diagnosis have been developed in HICs, and they have variable utility outside high-resource settings and/or research contexts. This creates not only challenges in the utilization of these instruments in LMICs due to barriers related to financial cost and the need for cultural adaptation and validation, but also in low-resource settings in HICs, which often lack highly trained health care professionals.

From diverse cultural and socio-economic perspectives, some practice guidelines for the identification of autism therefore have limited utility, especially in LMICs [15]. Researchers and clinicians around the globe have expressed the need for improved exchange of information and continuous dialogue around the availability of diagnostic instruments and their adaptation [9•].

The integration of screening and core packages of services into routine primary health care was identified amongst the top five challenges ranked by disease-burden reduction, impact on equity, immediacy of impact and feasibility in the Grand Challenges in Global Mental Health Initiative [8]. Primary health care services are indeed important players in developmental monitoring for the detection of ASD as they often constitute the initial point of contact with caregivers and can be the gateway to other community services for both the primary condition and co-morbid disorders. Nevertheless, the current reality is that lack of adequate knowledge in professionals about mental health in general tends to be a barrier [9•], both in LMICs and HICs. For example, in a recent UK qualitative study on experiences within the pre-diagnostic period, parents of children with autism reported that they were told that "there was nothing to worry about and their children would grow out of it" [16, p 380]. One father, who spoke about the long journeys and financial burden of multiple consultations in India, shared that he was given sleeping tablets for his child, because professionals thought that his child's autism would improve if he slept better [2]. This raises the additional issue of the extent to which health care professionals appropriately include families in the screening process to ensure improved uptake of recommendations for diagnosis and treatment [17].

Facilitators to early identification in community-based settings have been identified in a US sample. These include the presence of medical problems, particularly severe language disorders [18]. Children, who were seen by four or more primary care physicians before being diagnosed and those living in a rural versus urban area, received a diagnosis about half a year later than other children, underlining the importance of continuous pediatric care and speciality referrals [18]. Other studies suggest that while early signs of ASD are increasingly recognized, socio-economic barriers continue to play a role [12, 19]. Children with less severe ASD symptoms and with higher intelligence quotient (IQ) were also diagnosed at later ages in HICs [19] and are likely to be overseen in service points in LMICs that tend to see only the most severe cases. A number of additional challenges reported particularly in LMICs include a general lack of public awareness in the community, as well as prevalent stigma and discrimination, which prevent the engagement of families in advocacy efforts [9•].

Recommendations for improving early identification 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 [15]. Bearing these recommendations in mind, an important concern commonly raised by researchers and professionals around the world relates to the importance of offering relevant information and services, including the appropriate referrals, for those identified through screening, in both HICs and LMICs. In several HICs, children face long waitlists and have often outgrown adequate intervention programs, while there may frequently be a lack of follow-up services in LMICs. Thus, even when families are actively engaged in the process and are aware of the need for early intervention, access to adequate treatment may not readily be available, especially for families from underserved and low-resource settings [20]. The mismatch between awareness-raising initiatives and the services, therefore, poses an important ethical concern [9•].

Early Intervention in ASD

Early intervention is a very broad concept often concerned with delivery of structured and evidence-based support in a contextually appropriate manner for the child, their family, and their community as a whole. As such, early intervention needs to focus primarily on needs and priorities that are agreed on with the family and/or other caregivers in the community. Currently, the availability of early intervention for autism, and the extent to which models that are implemented are evidence-based, is variable in different communities [15]. First-line interventions used to address the core deficits in communication, social interaction, and restricted, repetitive patterns of behaviour in ASD include psycho-educational, developmental, and behavioural interventions, which have proven to be efficacious; however, these are also resource- and labour-intensive [9•], introducing the same barriers to those identified above for identification in community-based settings. In addition, there is a scarcity of published research on care provision for ASD in LMICs [21].

Despite progress in research, common to most world communities are significant delays and barriers in access to care including delayed diagnosis, challenges in navigating systems, and the lack of services and qualified professionals. In LMICs, unmet needs are even greater [22]. In both HICs and LMICs, the scarcity and unequal distribution of mental health and child health specialists in general, as well as the lack of sufficient knowledge and skills in these professionals to manage ASDs, represent some of the biggest barriers to improving access to care [9•]. While services may be more readily available in HICs, the often long diagnostic process (e.g., [23]) may prevent care from being delivered at a time that it is most crucially needed.

It is important to note that any autism intervention model constitutes only one component of a more comprehensive care plan that evaluates and addresses the child's overall health and well-being. These broader plans often include medical needs, comorbidities, and social and educational support. Families are viewed as an essential partner in formulating and implementing such care plans and, as such, they can become facilitators for their child's care. In some world regions, this approach is known as a "chronic care model", whereas it is known as a "community-based health model" in LMICs. In the latter, emphasis is given to delivery of care by non-specialists, especially in areas where specialized services do not exist (Elsabbagh et al., in press).

Recent studies (e.g., [24, 25, 26•]) suggest that the provision of services by non-specialist providers in school and community settings may constitute an effective alternative, including behaviour modification approaches and parent-mediated interventions. In contrast, other interventions designed for autism continue to require high levels of professional training and have not been found to be efficacious when implemented by parents of children younger than two-years-old compared with general community-based practices [27, 28].

Current research, therefore, calls for a shift in focus in ASD intervention development towards a better understanding of the effective elements of interventions that may lead to the development of models, which can facilitate translation into the community to build capacity in service delivery for all (e.g., [20]). These include, amongst others, methods that focus on making changes to the person's environment, including schools, instead of targeting a change in the person's abilities [9•]. The need to build human capacity, especially in LMICs, was raised as a priority issue at the 2013 WHO consultation on ASDs [9•].

To date, more and more projects are being implemented in LMICs that aim to build capacity in communities and to share lessons learnt on principles that may find application in different regions [9•]. Facing the task of serving millions of people affected in many low-resource settings, specialized professionals are increasingly advised to shift tasks where specialist health teams act as trainers, supervisors, and mentors of non-specialist providers [9•, 29]. In addition, a number of training packages was made available as open-access resources for care providers working in the field of ASD, including training material with emphasis on stigma reduction, sensitization on human rights, child development monitoring, and community-based rehabilitation [9•].

Emergence of Disability and Its Impact

Common comorbidities associated with autism include physical symptoms such as insomnia, eating and digestive difficulties, along with intellectual disability and psychiatric symptoms of anxiety, inattention, irritability, and behaviour difficulties [30]. One or a combination of these symptoms may significantly increase disability for the person affected.

Current estimates of associated intellectual disability (ID) vary. For example, recent estimates from two large-scale, records-based surveillance studies conducted in the US [31, 32] suggest that ID occurs in about 50 % of children classified as having ASD, whereas other samples around the world have identified ID as the most common comorbidity ranging from 24 % to 95 % in South East Asia [11•], suggesting that association of autism and disability is likely sample-dependent.

Core impairments of autism and associated deficits in adaptive social, communication, and daily living skills, may emerge with equal severity in a person who is cognitively impaired and a person with above-average IQ [21]. The frequent observation that the level of adaptive functioning is typically significantly lower than would be expected based on cognitive ability in ASD (e.g., [33]) is corroborated by evidence that normal or near-normal IQ, while necessary, may not be sufficient for better outcomes [34, 35].

Recent conceptualization of autism (e.g., [36]), alongside a significant amount of research, has confirmed that autism as a developmental disorder does not necessarily lead to disability. While some affected by the condition lead independent and fulfilling lives, others suffer serious disabling consequences as a result of having autism [35, 37]. It is possible that, at least in some cases, secondary disabilities may emerge as a result of inadequate care, stigma, and isolation that those affected may experience, both in LMICs (e.g., [2, 38, 39]) and HICs (e.g., [3•, 40]).

Core impairments in autism when combined with associated comorbidities can have a significant impact on the quality of life not only of the person with autism, but also on the quality of life of their family members. Parents of children with autism report high levels of psychological distress and are found to be at increased risk for stress and mental health problems, even when compared to parents of children with other disabilities [41].

The Grand Challenges in Global Mental Health Initiative similarly recognized that suffering extends beyond the affected individual to the entire family [8]. In a recent research priority setting exercise, providing support to the parents and families of children and people with developmental disabilities, including those with ASD, came out as a specifically strong theme, encompassing questions related to the most efficient ways of supporting and empowering these parents/families [42].

Caregiver level of stress and well-being, including adequate coping skills, can ultimately constitute a barrier both to identification and intervention in ASD, as both may require a high level of advocacy and engagement. Facilitators for identification and intervention are, thus, linked not only to sociodemographic but also to psychosocial factors. Recent

research conducted in Jordan, for example, suggests that parents with higher incomes, who use diverse problem-solving strategies and exhibit less escape-avoidance and more responsibility-acceptance behaviour, tend to experience lower parental distress and higher quality of life [43]. The same held true for being an older parent, having more time since the child's diagnosis, and using more distancing coping strategies [43], including Mindfulness-Based Stress Reduction (MBSR) [44].

Emergence of Mental Health Comorbidities and Transition into Adulthood

As they transition to adolescence and adulthood, people with ASD begin to exhibit a range of mental health comorbidities. In a UK sample of 10 to 14-year-olds with ASD, 70 % had at least one other psychiatric diagnosis and 41 % had two or more [45]. The most commonly identified problems were anxiety disorders (42 %), attention disorder (28 %) and oppositional disorder (30 %) [45]. Other studies corroborated the prevalence of co-occurring anxiety disorders alone as being about 40 % in children and adolescents with ASD [46] compared to typically developing peers with a prevalence of about 5–32 % [47, 48].

These findings highlight the many facets of autism and the need for continued screening and intervention adapted to the processes that may emerge during the unfolding life-long condition. There is a high risk for youth with ASD to develop an associated mental health problem and, thus, a need for screening to identify and address comorbid issues early on. Treatment of these additional conditions will not only lead to an improved quality of life, but also increase learning at school and add to adjustment in the community [49].

While it has become very clear that mental health comorbidities in persons with ASD constitute another barrier to adequate care, the limited capacity of persons with ASD to communicate their feelings of anxiety or distress, combined with the lack of knowledge in professionals, entails a whole new set of barriers pertaining to the diagnosis of these comorbidities [50]. Hence, there is also a barrier to the improvement of their quality of life. These additional challenges have just begun to receive attention in research conducted in HICs and might involve even greater stigmas in countries where common mental health issues, such as anxiety and depression, are less recognized.

Where community-based data is available, findings suggest that only one fifth (21.1 %) of youth with ASD receives services to help them transition from the pediatric health care system to the adult health care system in a large North American sample [51]. Indeed, recent research continues to identify the care for those on the spectrum who are growing older as yet another priority that has received little attention over the last decades of research. In a research priority setting exercise

in the UK, one researcher in particular commented that "as far as research is concerned, it pretends that kids on the spectrum don't exist after the age of 7" [3•, p 5].

Research into prognosis, outcomes, or effective interventions for adults with ASD is much more limited, even in HICs. The findings indicate that, as adults, many people with ASD, including those with typical IQ, face significant disadvantages regarding employment, social relationships, physical and mental health, and quality of life [52]. Reported outcomes in adulthood vary greatly across studies. Whereas social functioning, cognitive ability, and language skills were found to remain relatively stable in some studies, others indicated a decrease in these skills over time, with adaptive functioning generally improving in the majority of studies [37]. Diagnosis of ASD generally appears to be stable with severity of autism-related symptoms often improving. Childhood IQ and early language ability continue to be the strongest predictors of later outcome, although few studies examined other early variables associated with adult functioning [37].

There is generally a lack of support to facilitate integration of adults with autism into the larger community, as well as a scarcity of research on the development of intervention programs for this population [52]. Recent efforts in this direction include the WHO Executive Board resolution EB133/4, entitled *Comprehensive and coordinated efforts for the management of autism spectrum disorders* [53], which emphasizes the importance of shifting focus away from long stay health facilities towards community-based nonresidential services, while addressing disparities in access to care.

While the majority of outcome research has been conducted on people in their 20s and 30s, much less is known about outcomes for people with ASD in mid-late adulthood [52]. More longitudinal data from childhood through adulthood is, thus, required to further our understanding of trajectories of development over the life-span and to continue to identify elements that may impact prognosis in one way or another.

Conclusion

Taken together, the findings reviewed highlight the sparse knowledge about autism from a global perspective. In contrast, there is no doubt that the challenges introduced by the condition in diverse community-based settings are increasingly understood, and innovative approaches are being developed to meet these challenges. Partnerships bringing together different stakeholders including researchers, practitioners, and policy makers are critical in moving forward [54]. In recent years, WHO has expanded their efforts in the area of autism through developing partnerships at the global level with key international stakeholders [42]. Similarly, the Grand Challenges in Global Mental Health Initiative has highlighted the

need for the development of a global research agenda to create shared access to data, expertise, and capacity-building opportunities [8]. Together, these will help bridge both knowledge and treatment gaps to lead to improvements in the lives of those affected and their families.

While there is currently a need for more evidence-based research in LMICs, from prevalence studies to intervention trials, there is also a need for more translational and implementation research to determine the extent to which the present knowledge base from HICs has relevance for LMICs [9•]. Continuous dialogue and coordinated efforts by governments, experts, United Nations agencies, and civil society, including nongovernmental organizations, are crucial for the identification of sustainable strategies for provision of comprehensive and integrated support services [9•].

Further priorities for research include the need for increasingly effective approaches to intervention at all life stages, empowerment of families supporting a person with autism, and training of nonspecialist health workers [42, 55]. Increasing efforts need to be made to facilitate the production of policy-relevant evidence and its uptake by policy-makers and advocates. Finally, it is important to ensure that research is locally relevant, engaging both local communities as well as including people with ASDs and their families [9•].

Compliance with Ethics Guidelines

Conflict of Interest Eva-Maria Hahler and Mayada Elsabbagh declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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