

Researching autism in the Global South (MENA region): To what extent is Western autism research inclusive towards the Global South?

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Imene Zoulikha Kassous 

Dear Editors,

The reason behind the higher prevalence of diagnosed autism in biological males rather than biological females is not known and is subject to considerable debate. One of the theories associated with this issue is the Extreme Male Brain theory, which argues that what characterizes autistic individuals is that they have high ‘systemizing’ abilities and weak ‘empathizing’ abilities and that these are characteristics of male brains.¹ Another suggestion is that autistic females are skilful at ‘camouflaging’ (i.e. covering up the signs and symptoms of their autism); therefore, the diagnostic tools that are used with boys may be less effective with girls. Indeed, according to Halsall et al.,²

Autistic girls use a variety of strategies to negotiate the expectations and demands of school life. One of these strategies is known as camouflaging. This involves ‘hiding’ autism-based behaviours and developing ways to manage social situations, with the aim of fitting in with others.

Another possibility is related to inappropriate diagnostic tools, as the majority of autism diagnosis protocols are adapted to males’ features and characteristics. From this perspective, females struggle to get autism diagnoses and many of them receive late diagnosis because of this lack of both appropriate instruments and awareness. According to Kopp and Gillberg, ‘[t]here are a number of screening instruments for ASD available for research and clinical practice (Campbell, 2005). Most of these appear to have been modelled around the phenotypes first delineated by Kanner (1943) and Asperger (1944)’.³ Consequently, autism that manifests differently will not be diagnosed. A number of studies have proposed modifications of autism screening and diagnostic instruments to rectify this problem.^{3,4}

Research in the Global South, especially in the Middle East and North Africa (MENA), focuses mostly on diagnostic statistics when it comes to estimating the prevalence of autism in that country. Although there have been

notable advances in some countries, such as the UAE and Lebanon, there is a need for higher quality research into prevalence rates in this region. While there are papers originating from the MENA region evaluating different interventions used with autistic people, parents’ experiences and education for autistic children, there has not been a specific research focus on autism in relation to females’ experiences. This omission is not unique to the MENA region, as interest in this topic is also in its early stages in Western countries, despite the recent upsurge in use of participatory research paradigms.

In the Global South, autism is viewed differently. Awareness has taken time to spread among parents due to certain beliefs and practices. On the one hand, some people believe in the ‘evil eye’ so they have tended to seek help from sources other than medical. For example, there was a recent trend in Algeria where a group of people claimed that they could ‘heal’ autistic children using ‘Earthen Clay’. On the other hand, some people are more interested in the medical model and different interventions that would help autistic children fit in better in their schools and societies. As an example, the Algerian autism social media has been encountering continuous arguments between people who tolerate autistic behaviours and those who search for different medical and non-medical tools to ‘heal’ their autistic children.

Several studies have revealed that autistic girls tend to camouflage more, which makes it difficult to notice the signs of autism.^{5,6} With all this in mind, autistic girls in the Global South encounter more difficulties due to their gender. Indeed, discrimination against women in the whole

School of Education, University of Glasgow, Glasgow, UK

Corresponding author:

Imene Zoulikha Kassous, School of Education, University of Glasgow, Glasgow, UK.

Email: i.kassous.1@research.gla.ac.uk



world and particularly in some Global South countries is unacceptable. In a culture where women are expected to be eloquent, follow society's rules, get married, educate their children and never speak loudly of their rights, imagine what life is like for autistic girls. Within a culture that expects so much of women's behaviour, it will be very challenging to identify autism in girls due to their camouflaging ability. If your behaviour as a woman is socially accepted, you are considered to be well educated. This is mainly driven by religion and culture which essentialize certain behaviours such as kindness and manners. According to Amina Abdullah Abu Shehab, '[t]he teachings of the holy texts require men to assume full virility and women to assume full femininity'.⁷

There is currently a wide gap between the amount and quality of research about autistic females in the Global North versus Global South. Is this because of lack of awareness, funding or interest?

In an attempt to contribute to filling this research gap, I am currently conducting a study about the experiences of mothers of autistic girls in Algeria. This research is sponsored by the International Society for Autism Research (INSAR) and with the assistance of my two doctoral supervisors: Dr Ines Alves and Dr David R. Simmons from the University of Glasgow and my mentor Prof. William Mandy from the University College London (UCL). Although the original goal was to interview both autistic girls and their mothers, it has proven difficult to combine the twin demands of the ethical considerations which are standard in the Global North with the logistical constraints of field research in Algeria.

Algeria as a context is different in many ways. In addition to the cultural factors involved, multilingualism and its post-colonial status present a number of complex challenges when it comes to performing autism research. Algerian people have two national/official languages in addition to French and English being first and second foreign languages, respectively. The postcolonial and Islamic aspects of Algerian society add a different complexity in autism research especially when dealing with diagnosis and experiences.

Algeria is considered as a post-colonial context due to its previous colonial relationship with France. When it comes to research, Algeria still has many continuous collaborations with different French institutions such as the doctoral programme: 'Le programme algéro-français de bourses doctorales PROFAS B+' which allows Algerians to join French laboratories. This indicates the influence of French research on Algeria in different areas including autism research. Furthermore, one of the key constituents of Algerian culture is religion. Bouherar and Ghafsi⁸ explained that '[e]thical judgments of what is right and wrong are standardised by the degree to which the religious concepts of ethics are rooted in Algeria's daily practice' (p. 12). One example of how Islamic religion can be influential is a study conducted by Jegatheesan et al.⁹

Through an ethnographic method, the researchers found that Muslim parents of autistic children believed that they should raise their children just as any other child, by ensuring their child's participation in 'social, linguistic, and religious practices at home and in the community'.⁹

Emphasizing research with autistic females is crucial when looking at recent studies showing how many females have been left undiagnosed because of unadapted diagnostic tools. In order to highlight this in Algeria and other Global South countries, research is warranted to amend the existing diagnostic tools for Algerian (Global South) females. This can be achieved by attempting to answer the following questions:

- How can the current diagnostic tools be improved to meet the needs of other contexts including Algeria?
- How can exploring the experiences of Algerian (Global South/MENA) females improve the development of diagnostic tools?
- How can funding be more accessible to researchers from the Global South doing research in their regions?
- What should be done to be more inclusive and considerate of regional differences?

One solution to overcoming these barriers when it comes to research is by widening access. One of the initial steps is making research papers open access to researchers from the Global South, as many institutions cannot pay for access, as is the case in many Western countries. Having to pay to read a paper does not make knowledge accessible. Another thing is that, rather than giving funds to Western Institutions to do research in the Global South as if it is an object of study, more opportunities should be open to researchers from the Global South who mostly struggle to conduct studies due to lack of financial support. It is true that the voice of Western autistic females can be heard through their writing and being part of research, but they do not represent all regions or experiences. If research about autistic females' experiences in the Global South is funded, we will have all voices included. Most importantly, it should not be assumed that the insight already produced about autistic females' experiences is the Global North applies in other parts of the world. Instead, new knowledge should be produced, which takes account of context, culture and different living experiences.

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Consent for publication

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ORCID iD

Imene Zoulikha Kassous  <https://orcid.org/0000-0002-2904-8185>

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