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Biomedical research on autism in low- and middle-income countries: Considerations from the South African context

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition characterized by social/communicative difficulties and perseverative behaviours. While research on autism has flourished recently, few studies have been conducted on the disorder in non-Western contexts. In low- and middle-income countries (LMICs), biomedical research on autism is required to better understand the needs of the population and to develop contextually appropriate interventions. However, autistic individuals are a vulnerable study population and LMICs present with various considerations. While the presentation of autism is heterogeneous, stigma is a common social consequence affecting research. Drawing specifically on the South African context, the ethical intersections of these issues are discussed, along with the limitations of the current informed consent process. Community engagement is recommended as an adjunct to informed consent to ensure that biomedical research is conducted in a more inclusive way. Practical pointers are provided for implementing systematic support for conducting community engagement alongside biomedical research.

KEYWORDS
autism, community engagement, LMICs, research ethics, South Africa

1 | INTRODUCTION

1.1 | Introduction to autism

Autism Spectrum Disorder (ASD, hereafter referred to as autism) is a neurodevelopmental condition characterized by communication and relationship challenges as well as repetitive behaviors or restricted interests.[1,2] Autistic individuals do not develop along the same trajectory as their neurotypical counterparts, which often translates into a decreased ability to function in society independent of a caregiver. Autistic individuals are known to experience social challenges as a result of the stigmatization of the condition and the impact that communication deficits have on relationship formation. In order to improve the quality of life of autistic individuals, we need to understand more about the condition and investigate interventions that may be helpful in reducing sensory overload, improving motor skills and assisting in development of communication strategies.

The development of autism is poorly understood globally, and our understanding of intervention strategies is therefore limited. The sparse pharmacotherapies available are only able to treat overt symptoms without addressing the underlying neurobiological

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[1] The autism-specific language used in this article has followed the recommendations of Monk et al., and follows an identity-first format as per recommendations to reduce disorder-focused language and subsequent stigmatization. See Monk, R., Whitehouse, A. J. O., & Waddington, H. (2022). The use of language in autism research. Trends in Neurosciences. 45(11), 791–793.

[2] American Psychiatric Association, DSM-5 Task Force. (2013). Diagnostic and statistical manual of mental disorders: DSM-5™ (5th ed.). American Psychiatric Publishing, Inc.

causes.[3] The lack of understanding of a physico-medical cause of autism may also contribute to the social stigma surrounding the disorder,[4] with parents often blamed for their child's behaviour or children labelled as "naughty".[5] Importantly, while there are many physical and behavioural interventions available for improving adaptive functioning in autistic individuals, the most effective treatment strategies are often multi-dimensional and require a holistic approach that takes into account how the surrounding environment is affecting the individual.[6,7] Many interventions are also lacking a strong evidence base,[8] and research needs to be contextually situated to provide appropriate guidance to autistic individuals, their caregivers and treating practitioners.[9] It is also important to note that, as a low/middle-income country (LMIC), interventions discussed in the global arena are not necessarily available to the South African population.

Biomedical research is the wide field of science that explores ways to prevent and treat diseases causing illness and death by investigating the body's functions related to health differences and disorder. It also studies how well treatments work to improve symptoms or change the body's functions. While this may include direct pharmacological interventions, non-pharmacological interventions such as exercise interventions or other therapy modalities (e.g. music therapy, equine therapy) are also often targets of biomedical research. Thus, biomedical research on autism presents the possibility of understanding the underlying causes and impacts of treatments as well as finding new ways to improve the lives of autistic individuals and their families.

However, the autistic population is vulnerable to exploitation in the biomedical research context due to the impact that autism can have on cognition and communication, as well as the desperation that some families may have for information about or interventions for the condition. These factors may impede understanding of the procedures consented to during research projects, and may also induce participants to accept greater levels of risk out of desperation for treatment or answers. Ethical considerations around this type of research are therefore strict.

While ethical protection is certainly necessary and relevant, in this paper we argue that some of the practical aspects of research conduct in LMICs as stipulated by Research Ethics Committees (RECs) are out of date and in need of revision. More specifically, the methods of conducting the informed consent process as they currently stand are limited, and could be improved upon by the adjunct of a community engagement process that functions to inform communities about research projects. Conversely, it is insufficient to recommend community engagement processes without the implementation of additional support for researchers to ensure that ethical research can actually occur. Biomedical researchers working in the field of autism require the support of multi-disciplinary teams right from the conception and design of research projects to ensure that they are ethically implemented with community needs in mind.

1.2 | Introduction to the South African context

Up until the 1990s, South Africa was governed by a system of institutionalized racial segregation known as "apartheid", wherein society was sharply racially divided with regards to geographical location and access to resources. Despite changes in the country's legislation since the end of apartheid, the legacy of the apartheid regime is still very present in the country today, with a huge disparity between race and class groups, and Black families largely occupying the lowest socioeconomic standing. Black and other non-white families are therefore less likely to have access to even basic medical, psychological and educational services.

Families of a lower socioeconomic status are less likely to have the resources to support individuals with autism (who may require special education, extra carers, therapy of various types and perhaps eventually housing in specialized facilities) and thus will be more reliant on state resources. Families of a lower socioeconomic status are also at increased risk of exploitation, especially in a biomedical research setting, as they may see participation in research as an opportunity to access treatment options that they could not otherwise afford. In South Africa there is a system of public healthcare available to people of lower socioeconomic status, however the treatment options available through this system are limited and the system is also over-burdened with patients as compared to the resources available. More effective and timeous treatment in a greater range of options is available to patients who can pay for this privilege at private healthcare institutions. This means that a large proportion of the South African population only have access to a limited range of healthcare services. Moreover, some studies have suggested that lower socioeconomic status is associated with delayed autism diagnosis and treatment, as well as decreased access to support,[10,11,12] which may translate to poorer overall outcomes for autistic individuals. While there are no studies assessing the relationship between socioeconomic status and autism prognosis in South Africa yet, in reviewing studies looking at the phenotype of autism in Africa more generally, Franz et al.[13] concluded

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[3] Ji, N. Y., & Findling, R. L. (2015). An update on pharmacotherapy for autism spectrum disorder in children and adolescents. Current Opinion in Psychiatry. 28(2), 91–101.

[4] Franz, L., Chambers, N., von Isenburg, M., & de Vries, P. J. (2017). Autism spectrum disorder in sub-saharan africa: A comprehensive scoping review. Autism Research. 10(5), 723–749.

[5] Guler, J., de Vries, P. J., Seris, N., Shabalala. N., & Franz. L. (2018). The importance of context in early autism intervention: A qualitative South African study. Autism. 22(8), 1005–1017.

[6] Lai, M. C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: maximising potential, minimising barriers, and optimising the person–environment fit. Lancet. Neurology. 19(5), 434–451.

[7] Trembath, D., Waddington, H., Sulek, R., Varcin, K., Bent, C., Ashburner, J., Eapen, V., Goodall, E., Hudry, K., Silove, N., & Whitehouse, A. (2021). An evidence-based framework for determining the optimal amount of intervention for autistic children. Lancet. Child and Adolescent Health. 5(12), 896–904.

[8] Lai, et al., op. cit. note 6.

[9] Trembath, et al., op. cit note 7.

[10] King, M. D., & Bearman, P. S. (2011). Socioeconomic Status and the Increased Prevalence of Autism in California. American Sociological Review. 76(2), 320–346.

[11] Rai, D., Lewis, G., Lundberg, M., Araya, R., Svensson, A., Dalman, C., Carpenter, P., & Magnusson, C. (2012). Parental Socioeconomic Status and Risk of Offspring Autism Spectrum Disorders in a Swedish Population-Based Study. Journal of the American Academy of Child and Adolescent Psychiatry. 51(5), 467–476.

[12] Thomas, P., Zahorodny, W., Peng, B., Kim, S., Jani, N., Halperin, W., & Brimacombe, M. (2012). The association of autism diagnosis with socioeconomic status. Autism. 16(2), 201–213.

[13] Franz, et al., op. cit. note 4.

that the samples for such studies are biased towards a higher socioeconomic status. This bias may be due to a lack of awareness of autism as well as decreased access to diagnosis opportunities for families of a lower socioeconomic status, and indicates a gap in the research as regards autistics of lower socioeconomic status in Africa. Our own observations during biomedical research projects suggest that families of lower socioeconomic status may not have the time, energy or educational resources to engage with the information surrounding research projects in a meaningful way.

In addition to the impacts of sharp socioeconomic differentials are the considerations of cultural context on the conceptualisation of autism itself. As a disorder that presents socially and behaviourally, the question arises as to whether research findings in European and American contexts are applicable to other contexts, especially LMICs where intervention availability may differ. The question of whether autism presents differently in LMIC cultures and sub-cultures therefore arises, as well as whether the various difficulties in symptom management and societal integration experienced in these contexts therefore result in different support needs. Further research on autistic populations in LMICs is required to answer these questions and to ensure adequate provision of appropriate resources to individuals and communities affected by the condition. South Africa specifically is a conglomerate of cultures, comprising communities of Chinese, Taiwanese, Indian and Middle-Eastern origin, as well as the descendents of European settlers and the Bantu peoples, to name a few. This includes multiple spoken languages, and the language spoken by participants may present barriers to understanding the nature of research projects on autism. Further, the diversity of cultural worldviews present in South Africa means that there are also many different possible ways of conceptualizing the condition, and using only the Western framework in research projects is likely to result in the exclusion of participants from differing backgrounds.

While South Africa is considered an upper-middle income country, the massive disparity between socioeconomic classes in the country means that many parts of the country are faced with the same challenges as other LMICs. General challenges in the African context include impoverished and refugee populations with low access to healthcare, as well as barriers to communication and understanding such as low literacy levels, language barriers and cultural differences.[14] Furthermore, many of the debates on medical and research ethics have historically been dominated by scholars from the Western world and it is only since the 1990s that African voices have been internationally heard and published in this arena.[15] Jecker & Atuire[16] discuss the exclusion of consideration of African traditional medicine from the academic discipline of bioethics, and warn that to simply use Western bioethical ideas and processes as they currently stand risks further entrenching Western hegemony.

Critically, although the rate of health research in Africa has increased in the past few decades, it has seemingly been without concomitant improvements in the oversight of such research by RECs.[17] Oversight is a crucial duty of RECs, whereby they monitor the progress and activities of approved research projects in order to ensure that they abide by ethical stipulations and are working in accordance with the approved protocol. However, RECs in Africa often lack the resources and capacity to conduct sufficient oversight.[18] While active and on-going monitoring processes (such as site visits) are deemed a necessary part of ethics oversight, particularly for any studies involving vulnerable participants, it is not always possible for this to be carried out.[19]

While research on autism in LMICs is required in order to meet the needs of affected communities and individuals, such research presents a number of ethical challenges. As noted, autistic individuals and their families are already a vulnerable population group. In South Africa, the vulnerability of autistic individuals and their families is exacerbated in the case of people historically socioeconomically disadvantaged by the apartheid system. The multicultural nature of South Africa also presents with language barriers and different worldview frameworks, which need to be taken into consideration when recruiting participants for research projects. South Africa is also a resource-scarce nation, and this impacts the resources available for the conduct of research. These challenges call for a revision of the standard procedures for recruitment and informed consent in biomedical research, to allow for a more flexible approach that incorporates communities in a more inclusive way.

2 | ETHICAL CHALLENGES IN BIOMEDICAL RESEARCH ON AUTISM

In general, biomedical research on autism presents with a host of ethical challenges. Firstly, individuals with autism and their families are considered a vulnerable group in research due to the effects of the condition socially and their need for greater levels of educational and therapeutic support. Since vulnerable groups (such as prisoners, the elderly, minors, and people with mental disabilities) are easier to exploit in research, stricter rules are applied to research within these groups. One of the critical requirements for research in established ethical guidelines is that of informed and voluntary consent.[20] For truly informed consent, participants need to understand and decide whether to accept the risks involved in participating. Thus, biomedical research

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[14] Kruger, M., Ndebele, P., & Horn, L. (Eds.). (2014). Research ethics in Africa: a resource for research ethics committees. Stellenbosch, SA: Sun Press/African Sun Media.

[15] Ibid.

[16] Jecker, N. S., & Atuire, C. (2021). Bioethics in Africa: A contextually enlightened analysis of three cases. Developing World Bioethics. 22(2), 112–122.

[17] Benatar, S. R. (2002). Reflections and recommendations on research ethics in developing countries. Social Science and Medicine. 54(7), 1131–1141.

[18] Silaigwana, B., & Wassenaar, D. (2015). Biomedical Research Ethics Committees in Sub-Saharan Africa: A Collective Review of Their Structure, Functioning, and Outcomes. Journal of Empirical Research on Human Research Ethics. 10(2), 169–184.

[19] Kruger, et al., op. cit. note 14.

[20] World Medical Association. (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA. 310(20), 2191–2194.

on autism has to consider the potential vulnerabilities of the population as research participants, and to ensure that participants are able to give genuine informed consent. The issue of informed consent is especially relevant to research on anyone who is not considered competent to consent, such as children or people with mental disabilities.

2.1 | Ethical issues in research on minors

Much of autism research is conducted in minors, as there is no other way to assess the efficacy of early-life interventions. Minors are considered a vulnerable group, as they are still in a process of cognitive development and are often not considered competent to assess potential risks and benefits and make the best choice for themselves. Most ethical guidelines call for the consent of a caregiver in the case of any person who is not considered competent to consent for themselves. However, caregivers may also not always be the best judges of what is in their charge's best interest.[21] In some cases, the risks of participating fall on the participant, while the benefits apply to the person consenting,[22] such as where a caregiver stands to benefit from having their ward improve clinically. For example, the Applied Behaviour Analysis (ABA) treatment approach has been surrounded by controversy, as while it is associated with evidence for clinical improvements, the methods it entails have been described as abusive, particularly by those who have been subjected to it.[23] While caregivers may experience improved behaviour in their child, it is the child who experiences the intervention along with any risks of personal harm. An important consideration within the African context is that some cultures have higher expectations of children's subservience to their elders.[24] The consideration of cultural expectation is particularly pertinent to assessment of the sincerity of a child's assent.

2.2 | Communication difficulties and the impact on informed consent

Not all autism research is conducted in minors, but some of the difficulties around informed consent remain applicable. There is a wide spectrum of impairment associated with autism, and while some autistic individuals are fully cognitively capable, some are not. In individuals with mental disabilities more generally, there exists a wide range of competencies, with different faculties affected in different individuals,[25] and this is the case in autism as well. Autistic individuals with cognitive impairment may struggle to understand the purpose of the research or what procedures they are consenting to. Some individuals may have higher capacity than others to understand and weigh up risks. However, in autistic individuals the abilities to understand information and rationalize a decision do not necessarily co-occur with the ability to communicate their choice, and vice versa. These communication challenges may make it particularly difficult to assess an autistic individual's true level of understanding of the information provided. Many autistic individuals may be unable to communicate despite understanding the information they have received. Furthermore, it is important to bear in mind that those individuals with cognitive impairment may still wish to be treated as autonomous members of the community, and to be meaningfully involved in the process of obtaining informed consent or assent.[26]

For individuals who are not considered competent to consent for themselves, an assent process is recommended, whereby a legal guardian consents but the participant is still informed about the process and given opportunities to ask questions and express dissent. In our experience, the heterogeneity of autism means that no single format for obtaining consent or assent will be helpful across all participants in a given study. Importantly, in South Africa, many of the lower socioeconomic populations do not have access to communication-support devices which could otherwise assist in this regard. A personalized assent process that responds to the needs of the individual and that is continuous throughout the duration of the study, as opposed to a once-off activity, has been suggested.[27] In addition, it has been suggested that assent processes should be designed and piloted before use in a study, and that quizzes should be used to assess understanding of what participants are assenting to.[28] While these are valuable ethical practices, they have the potential to place an even bigger hurdle in front of the researcher, especially in resource-scarce settings. Lack of resources available for research means that there may be insufficient funding for research assistants and time restrictions on the completion of research projects. The additional time and energy requirements on researchers to complete tailored informed consent processes for every individual can therefore create a barrier to the completion of research projects, if researchers are not better supported in these endeavours.

2.3 | Stigma in autism

Another ethical factor specific to autism is that of stigma. Autistic individuals experience stigma in the form of social exclusion and lack

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[21] Worku, E. B., Davis, A. M., & Morrow, B. M. (2016). A critical review of health research ethical guidelines regarding caregiver consent for HIV research involving minors in South Africa: Ethical and legal issues. South African Journal of Bioethics and Law. 9(2), 78–83.

[22] Glass, K. C., & Speyer-Ofenberg, M. (1996). Incompetent Persons as Research Subjects and the Ethics of Minimal Risk. Cambridge Quarterly of Healthcare Ethics. 5(3), 362–72.

[23] Kirkham, P. (2017). 'The line between intervention and abuse' – autism and applied behaviour analysis. History of the Human Sciences. 30(2), 107–126.

[24] Kruger, et al., op. cit. note 14.

[25] Fisher, C. B. (2003). Goodness-of-fit ethic for informed consent to research involving adults with mental retardation and developmental disabilities. Mental Retardation and Developmental Disabilities Research Reviews. 9(1), 27–31.

[26] Ibid.

[27] Giesbertz, N. A. A., Bredenoord, A. L., & van Delden, J. J. M. (2014). Clarifying assent in pediatric research. European Journal of Human Genetics. 22(2), 266–269.

[28] Crane, S., & Broome, M. E. (2017). Understanding Ethical Issues of Research Participation From the Perspective of Participating Children and Adolescents: A Systematic Review. Worldviews on Evidence-Based Nursing. 14(3), 200–209.

of understanding for the challenges they face.[29] Stigma occurs as a result of stereotyped assumptions regarding the competence of autistic individuals in social roles and the causes and characteristics of autism. The flourishing of research on autism in recent decades, with progress specifically in the fields of genetics and neuroscience, has led to excitement about the development of a possible "cure" for autism. However, some advocates for the autism community have expressed concerns that the idea that autism requires a cure contributes to the stigma surrounding autism.[30] Autistic advocates challenge the ideas that autism needs to be cured or prevented, as these ideas reinforce the stigma that autism is something undesirable that requires correction.[31] The lack of understanding of autism has even led to the use of inhumane treatment programmes, in which autistics are dangerously restrained or physically and emotionally punished in order to "correct" undesirable behaviours.[32] Importantly, the question has been raised of what is and is not "normal" and that a broader conception of neurodiversity could be more helpful. Many autistics consider their condition to be an integral part of their identity and not something that they would want to change about themselves.

In South Africa, evidence for social stigma against autism has been documented.[33,34] The effects of stigma on parents of autistic children in the South African context have been described as blame towards parents for the child's behaviour; caregiver isolation, secrecy and shame; and labelling of the autistic child as "naughty".[35] Additionally, community stigma may lead to an aversion to accessing support services for an autistic child.[36] When approaching biomedical research in autism, stigma is a particularly pertinent consideration since biomedical research often frames autism as something that requires prevention or a cure. In light of the difficulties experienced by autistic people, it is easy to see how biomedical scientists may come to view autism as a problem that needs solving. However, the cause of the difficulties experienced by autistics may lie less in the condition itself and more in the ways in which society treats autistic individuals. In the current global capitalist framework, people are treated as dispensable if they cannot easily form part of the productive workforce driving the economy. Researchers investigating autism need to be aware of the social implications of their work and how the questions they ask or the answers they produce will influence the way autistic individuals are viewed and therefore treated by society.

2.4 | Challenges with the current informed consent process

In our experience, outdated frameworks around the informed consent process present a major barrier to recruitment and retention of research participants. A key point in the Declaration of Helsinki[37] is the stipulation that groups that are underrepresented in medical research should be provided with appropriate access to participation. During the conduct of the first author's PhD (a biomedical study drawing on autistic children in South Africa), the medical REC's requirements for what needed to be included in the information sheets resulted in a complex three-page document. While we were aware of families of very low socioeconomic status in the schools from which the sample was drawn, none of the children from these families were successfully recruited into the research project.[38] Critically in South Africa, low education levels in impoverished and previously disadvantaged communities, along with language and cultural barriers, complicate the acquisition of genuine informed consent or assent. How much detail does a participant need? The process of obtaining informed consent in research can pose a significant challenge to individuals who may be under-resourced in terms of time, educational background, and capacity. In particular, individuals facing these issues may find it difficult to fully comprehend and engage with the information presented during the consent process. In contexts where time is scarce, individuals may feel rushed or pressured, hindering their ability to carefully consider the details of the research study. Similarly, those with limited educational backgrounds might encounter challenges in understanding complex scientific or medical terminology, potentially leading to confusion or incomplete comprehension of the study's objectives or potential risks. These factors may therefore create a participation bias that falls along socioeconomic lines and keeps under-resourced populations from being represented in research. Parents of autistic children already have resource constraints due to the special care needs that autistic children often have, and this is compounded in cases of lower socioeconomic status. Consequently, there is a potential bias to inclusion in research, and considering the factors at play, we can expect that such a bias would inadvertently skew the proportion of African families of colour included in a given research project. The fact that studies on autism in Africa generally have shown a bias towards participants of a higher soecioeconomic status,[39] as well as our own observations of difficulties in recruiting participants of lower socioeconomic status lends credence to this theory. Further research on participation rates and demographics in South Africa would be useful in assessing the extent to which participation may be biased by language, cultural background and level of education.

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[29] Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., Daou, N., & Smith, D. S. (2015). Changing college students' conceptions of autism: An online training to increase knowledge and decrease stigma. Journal of Autism and Developmental Disorders. 45(8), 2553–2566.

[30] Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: moving toward an ethically informed approach to autism research. Autism Research. 4(4), 271–282.

[31] Ibid.

[32] Neumeier, S. M., & Brown, L. X. Z. (2020). Torture in the Name of Treatment: The Mission to Stop the Shocks in the Age of Deinstitutionalization. In S. K. Kapp (Ed.), Autistic Community and the Neurodiversity Movement (pp. 195–210). Palgrave Macmillan, Singapore.

[33] Guler, et al., op. cit. note 5.

[34] Fewster, D. L., & Gurayah, T. (2015). First port of call: facing the parents of autism spectrum disorder. South African Family Practice. 57(1), 31–34.

[35] Guler, et al., op. cit. note 5.

[36] Ibid.

[37] World Medical Association. (2013). WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects. Retrieved February 2, 2024, from https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/

[38] de Lange, S., Muller, D., & Dafkin, C. (2024). Relationships between autistic traits, motor skills and socioeconomic status. Research in Autism Spectrum Disorders. 110, 102296.

[39] Franz, et al., op. cit. note 4.

In addition to the issues inherent in medical research on autism are considerations of the cultural context in which research takes place. Autism is diagnosed by observed communicative and social behaviours, which means it will be conceptualized differently in different cultures. The sociocultural lens shapes how local communities view autism as well as their understandings of, and receptiveness to, research investigating the condition. It is therefore important for the researcher to interrogate their own potential idealogical biases when entering into a community in order to perform research projects, as their worldview may differ to that of potential participants in ways that could skew research results. Scientific research is situated within a reductionist, materialist framework with predominantly Western origins. Researchers often take this worldview for granted as fact, while the reality is that such a perspective may differ significantly from the worldviews of their research subjects. African participants' beliefs about disease causation may differ to those of the researcher,[40] which affects their understanding and comprehension of information provided for informed consent. For example, while Western medicine focuses on the structures and functions of bodily organs, traditional African medicine views disease as caused by socio-religious factors.[41] For a genuine informed consent process to occur, true levels of understanding of the information provided needs to be determined, and the vast differences in worldview in some instances make this very difficult.[42] Thus, it is important for researchers not to adopt a dismissive attitude towards the community's frameworks for understanding the world and lived experience. In such a culturally diverse context as South Africa, researchers need to be mindful regarding assumptions that traditions or beliefs observed in one community will be relevant or applicable to another community.

Given these concerns, African RECs may need to re-evaluate their requirements around the informed consent process. The way consent and assent are usually collected is also based on an individualist conception of selfhood, in which an individual consents for him/herself only, or consent is given by a caretaker on behalf of a minor or adult of limited capacity. Western cultures utilise a more individualist construction of personhood than that of many African communities.[43] For example, many African cultures have a more communitarian view of personhood and this influences decision-making processes and, potentially therefore, the process of obtaining informed consent. The communitarian systems require consensus among elders, who summarize the prevailing opinions of the group as a whole.[44] Therefore, the standard Western process of collecting consent, whereby a person (or caretaker, in the case of a non-competent subject) is approached in their individual capacity and makes an autonomous decision about participation, may not always apply appropriately to an African cultural setting. Importantly, however, South African culture (like other African cultures) is not a monolith[45] and the variations within and between cultural groupings means that the construction of a specific, rigid framework to conduct informed consent processes would equally be inappropriate.

3 | COMMUNITY ENGAGEMENT

3.1 | Argument for community engagement as an adjunct to the informed consent process

In light of the challenges presented above, we suggest that the process of obtaining informed consent in autism research needs to be re-evaluated. However, ethics committees have requirements on what needs to be included in information sheets in order to protect participants and prevent coercion. Providing sufficient information about a research project is aimed at ensuring participant autonomy. Doing away with written information sheets is therefore not an ethical solution to the conundrum presented here, but alternative ways to ensure the protection and autonomy of participants engaged in research projects need to be explored and implemented. Importantly, the dearth of non-Western dialogue in the academic sphere of bioethics[46] creates a barrier to the construction of specific theoretical frameworks that could be applied in LMIC contexts. It may be more appropriate to aim for a more flexible approach in which continuous dialogues are maintained with the communities participating in research. A conference on medical ethics in Kenya in 2005 produced useful discussions on the limitations of the existing system in the African context,[47] highlighting the need to move away from a top-down approach to a more egalitarian approach in which a greater relevance is accorded to fieldworkers and other liaison-personnel.

Given the communitarian nature of many African cultures, a contextually appropriate alternative to consider is that of community engagement. This process should involve the community members in an oversight capacity in the research process at every stage, but particularly in the earlier stages of problem identification and question construction. Such processes have the potential to provide choice and autonomy to community members in a more profound way than simply agreeing or disagreeing to participate. To this point, Kruger et al.[48] suggest questions to consider when analysing the ethical position of a research project, the most pertinent to this topic centering on addressing community needs, involving the community in identifying problems, priorities and protocols for research and finally establishing whether research findings have made a difference

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[40] Tangwa, G. B. (2000). The Traditional African Perception of a Person: Some Implications for Bioethics. Hastings Center Report. 30(5), 39–43.

[41] Onuoha, C. (2007). Bioethics Across Borders: An African Perspective. Uppsala Studies in Social Ethics. 34.

[42] Kruger, et al., op. cit. note 14.

[43] Eaton, L., & Louw, J. (2000). Culture and Self in South Africa: Individualism-Collectivism Predictions. Journal of Social Psychology. 140(2), 210–217.

[44] Tindana, P. O., Kass, N., & Akweongo, P. (2006). The Informed Consent Process in a Rural African Setting: IRB. 28(3), 1–6.

[45] Frimpong-Mansoh, A. (2008). Culture and Voluntary Informed Consent in African Health Care Systems. Developing World Bioethics. 8(2), 104–114.

[46] Chattopadhyay, S., & De Vries, R. (2008). Bioethical concerns are global, bioethics is Western. Eubios Journal of Asian and International Bioethics. 18(4), 106-109.

[47] Molyneux, S., & Geissler, P. W. (2008). Ethics and the ethnography of medical research in Africa. Social Science and Medicine. 67(5), 685–695.

[48] Kruger, et al., op. cit. note 14.

to the affected community. In autism research these questions are critical, and ethically-minded scientists and research groups are urged to consider engagement with their research population as an essential component of their vocation.[49] Importantly, this process should not be a once-off interaction, but rather should involve the development and maintenance of on-going relationships between key members within the community of interest and trusted liaisons from the academic community.

For researchers to effectively help communities and produce relevant, applicable research, finding out what the affected community actually needs from the research is important. For example, the beliefs of parents of autistic children have been found to differ significantly from the beliefs of autism researchers as regards the causes of autism and priorities for future research.[50] While some parents may want autism to be "fixed", many other parents may just want to know that their children will be taken care of if they are no longer able to fulfill that role. A fair analysis of the impact of research on the affected communities requires engagement with real-world situations and culturally-situated narratives. In case studies from India, the importance of confidentiality in autism research has been observed as a core community concern, since lay beliefs about the disorder may negatively impact the marriageability of female relatives.[51] In South Africa, there is evidence for similar social stigma surrounding autism.[52,53] Researchers investigating autism in LMICs therefore need to interrogate what social harm may come to the individual or their family if they are publicly identified as autistic. Community engagement processes may help researchers to assess levels of stigma within a given community, so that research protocols may be adjusted accordingly, in order to minimize the risk of stigmatization of research participants. Moreover, within a community engagement setting, members of the community have the opportunity to learn more about autism as a condition, and inappropriate or judgmental ideas about the condition can be addressed. Community engagement practices therefore have the potential to reduce overall social stigmatization of autism. Furthermore, community engagement processes present the opportunity to educate the community about interventions available in their respective contexts and the relative pros and cons of each. This has the potential to empower individuals with autism and their families to make safe choices about treatment options.

Finally, community engagement as an adjunct to informed consent may allow for greater flexibility in the process of informing the community about research and helping researchers to adapt to the various research contexts. Importantly in South Africa, the high diversity of cultural communities implies that what is discovered and enacted in one community may not be applicable to another community.

Additionally, in contrast to the scientific focus on academic information, another aspect of community engagement may be the incorporation of "experience-based expertise" into the design and conduct of research projects.[54] As has been suggested previously,[55] the inclusion of the autistic community in these processes is invaluable for informing useful and ethical research. Additionally, occupational therapists who treat children with autism may have experiential insight into the disorder that can be of benefit to biomedical researchers. Another group of experts who may contribute meaningfully to understanding autism in South Africa are traditional healers, historically sidelined in medical practice. In South Africa, traditional healers are fairly commonly sought out for mental health disorders, and traditional healing approaches are reported to have a positive influence on individual and community mental health.[56] Traditional healers operate within culturally appropriate explanatory models, which has been shown to have a positive impact on treatment adherence. It has been suggested previously that Western medical institutions collaborate with traditional healers in order to increase quality of care, access to care and adherence to treatment protocols.[57] These positive effects may translate to biomedical research as well. Traditional healers may also have historical knowledge of mental health disorders within African communities. Historical knowledge would help to evaluate prevalence and potential changes in prevalence over time. It would also assist researchers in understanding and communicating with a cultural construction of autism. Traditional healers may also help to mediate communication between researchers and the participant population in a way that facilitates greater participant understanding of the purposes and procedures involved in a given research project. Jecker & Atuire[58] discuss the importance of partnerships between biomedically trained practitioners and traditional healers in the African setting, wherein the work that traditional healers have already been doing for their communities is affirmed and diverse parties work together towards the common goal of helping people in need.

3.2 | The community engagement process

Community engagement in research, however, is a complicated process. Community engagement entails establishing a trust relationship and facilitating communication between researchers and the community.[59] Thus community engagement requires an awareness of

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[49] Pellicano & Stears, op. cit. note 30.

[50] Fischbach, R. L., Harris, M. J., Ballan, M. S., Fischbach, G. D., & Link, B. G. (2016). Is there concordance in attitudes and beliefs between parents and scientists about autism spectrum disorder? Autism. 20(3), 353–363.

[51] Daley, T. C., Singhal, N., & Krishnamurthy, V. (2013). Ethical Considerations in Conducting Research on Autism Spectrum Disorders in Low and Middle Income Countries. Journal of Autism and Developmental Disorders. 43(9), 2002–2014.

[52] Guler, et al., op. cit. note 5.

[53] Fewster & Gurayah, op. cit. note 34.

[54] Pellicano & Stears, op. cit. note 30.

[55] Ibid.

[56] Campbell-Hall, V., Petersen, I., Bhana, A., Mjadu, S., Hosegood, V., & Flisher, A. J., MHaPP Research Programme Consortium. (2010). Collaboration Between Traditional Practitioners and Primary Health Care Staff in South Africa: Developing a Workable Partnership for Community Mental Health Services. Transcultural Psychiatry. 47(4), 610–628.

[57] Ibid.

[58] Jecker & Atuire, op. cit. note 16.

[59] Kruger, et al., op. cit note 14.

underlying hierarchical structures and power dynamics, which are relevant in how they manifest between the community, the researchers and recognized community leaders. In South Africa, the diversity of communities and cultures means that this process will have to be especially flexible and adaptable. Unforeseen dangers to participants may arise when applying a framework successful in one context, to another context. It is therefore important to bear in mind that structures of conduct should be flexible to growth and change as issues arise and are documented. Pellicano & Stears [60] make the point that disagreement is inevitable in these processes, and that consensus is not always the ultimate goal of engagement, but rather raising awareness of the concerns and uncertainties of the affected parties. Importantly, autistic individuals and their families have more at stake than researchers do, as it will have a greater impact on their lives, and their input should be weighted accordingly. Community-based discussions of research and consent may be especially appropriate in the tribally-oriented rural communities of South Africa. Creating a community-based approach to research may benefit participants who may have difficulty in understanding typed consent forms, by providing them with the opportunity to learn about a project in a more accessible way.

An existing system of community engagement is that of community-based participatory research, wherein local communities participate with researchers through dialogic development to select and design research topics.[61] The Early Autism Project in the Kwa-Zulu Natal region of South Africa provides a good example of how community engagement via interviews and focus groups with appropriate stakeholders helped to develop a culturally sensitive *modus operandi* for conducting the research project in question.[62] The Early Autism Project was aimed at improving early detection of autism and other developmental disorders, and elicited community input in order to adapt screening tools to be more appropriate to the cultural context. Another well-characterised tool that could be implemented as part of community engagement is democratic deliberation, which has already been used to inform research in various formats.[63] Democratic deliberation typically consists of providing a group of community members with information on a specific topic, allowing them time to interact with one another and with experts on the topic, and then collecting the opinions they form following this process.[64] While community engagement processes already occur in some humanities and public health research spaces, the implementation of increased community engagement alongside biomedical research would be invaluable. Community engagement has been suggested as an important adjunct to autism research before[65] and some researchers have started to put this into practice.[66,67] However, there is still very little structural support for community engagement in biomedical research spaces in South Africa.

3.3 | Practical recommendations for the implementation of community engagement in biomedical research spaces

While community engagement as an ethical research imperative has been given some attention in the literature recently, particularly as a recommendation in autism research, in our experience there is an implementation gap in the biomedical research sphere. Support in the activity of community engagement is something that biomedical researchers have to seek out, rather than it being par for the course. Here we encounter a conundrum: how do we as researchers treat our subjects in the most ethical and humane way, while also producing useful and beneficial research? The answer lies not in requiring individual researchers to navigate a maze of ethical requirements, but rather in a system of collaboration between researchers and subjects to find a way forward that is best suited to the specific community being researched. Thus, a gap exists between what is discussed in the literature and what occurs in the biomedical research spaces of LMICs. The real-world implementation of this recommendation requires pointers for practical application.

It is important to note that in the LMIC context, researchers already experience barriers to research conduct in the forms of low resources, decreased access to financial capital, and logistical hurdles, to name a few. In making community engagement a requirement for biomedical researchers we should not be adding to the administrative burden that already falls onto the shoulders of individual researchers. Rather, implementation of community engagement processes requires some structural and institutional support. While the question has been raised about alterations to legislation in order to support this initiative, we argue that implementation can already begin at an institutional and departmental level. Biomedical schools and faculties can begin to build community engagement support blocs drawing on the experiences of current research staff. There is a historic divide between research in humanities and research in the biomedical sciences, and in our experience ethical training of biomedical scientists is limited and does not prepare us as scientists for the nuances and dilemmas of real-world contexts. Community engagement has been a part of humanities research for some time now (for example, focus groups and ethnographic analysis), and their sociocultural expertise may help to build community engagement capacity within the departments that focus more exclusively on biomedical research. Addressing the

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[60] Pellicano & Stears, op. cit. note 30.

[61] Minkler, M., & Wallerstein, N. (Eds.). (2004). Part One: Introduction to community-based participatory research. Participatory Research for Health: From Process to Outcomes (pp. 5-24). San Francisco, CA: Jossey-Bass.

[62] Grinker, R. R., Chambers, N., Njongwe, N., Lagman, A. E., Guthrie, W., Stronach, S., Richard, B. O., Kauchali, S., Killian, B., Chhagan, M., Yucel, F., Kudumu, M., Barker-Cummings, C., Grether, J., & Wetherby, A. M. (2012). "Communities" in Community Engagement: Lessons Learned From Autism Research in South Korea and South Africa. Autism Research. 5(3), 201–210.

[63] De Vries, R., Stanczyk, A., Wall, I. F., Uhlmann, R., Damschroder, L. J., & Kim, S. Y. (2010). Assessing the quality of democratic deliberation: A case study of public deliberation on the ethics of surrogate consent for research. Social Science and Medicine. 70(12), 1896–1903.

[64] Ibid.

[65] Pellicano & Stears, op. cit. note 30.

[66] Grinker, et al., op. cit. note 62.

[67] Kim, Y. S., Leventhal, B. L., Koh, Y.-J., Fombonne, E., Laska, E., Lim, E.-C., Cheon, K.-A., Kim, S.-J., Kim, Y.-K., Lee, H., Song, D.-H., & Grinker, R. R. (2011). Prevalence of Autism Spectrum Disorders in a Total Population Sample. American Journal of Psychiatry. 168(9), 904–912.

complexities of autism research requires multi-disciplinary teams in which sociocultural experts can lend their support to biomedical scientists right from the conception and design of research projects to ensure that research is conducted in an ethical way.

While obviously important for autism research, community engagement as a process adjunct to biomedical research in general should be made a routine part of research activity. To apply community engagement as something necessary only in autism research, or even only in mental health research spaces, would impede its occurring at all. Wider implementation of community engagement practices would decrease the energy investment required for an individual research project. Having the structures already set up in a systematic way decreases the burden on individual researchers who may feel it is an ethical imperative in their own biomedical research projects. It may be important within biomedical research departments to have one or two staff members who are dedicated to the project of increasing community engagement alongside research. With decreased workload in other areas of their academic responsibilities, such staff members can research the appropriate methods for approaching the community within the locale of the institution, focusing on the types of research conducted within their specific department. Having staff dedicated to community engagement support would help to reduce the administrative burden of enacting community engagement that would then fall onto specialist researchers.

4 | CONCLUSION

More biomedical research on autism is needed in the South African context in order to understand and thereby provide for the needs of communities affected by the condition. However, consideration of the ethical concerns that intersect around biomedical research on a social and cognitive condition in the culturally diverse setting of South Africa complicates the conduct of such research. The informed consent process as it stands is designed to protect the vulnerable participants, but may lead to the inadvertent exclusion of previously disadvantaged and under-represented groups in current and continuing research. The current informed consent process may therefore not be applicable to the culturally diverse environment of South Africa. Community engagement provides a theoretical framework for the revision of the informed consent process, but requires concrete action to become a routine part of biomedical research that is supported by academic institutions.

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