

# Ethical issues arising in research with people with mental health conditions

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## Case study

### Genetic attribution and mental illness: implications for moral agency and moral responsibility from the perspective of an African philosophy

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#### Brief description of the research project

Through the H3Africa ELSI project titled, *Stigma in African Genomics research on schizophrenia and rheumatic heart disease in Africa*<sup>1, 2</sup>, colleagues and I explored the impact of a genetic explanation for schizophrenia on internalised stigma experiences of South African Xhosa people with this condition<sup>3</sup>. We used a qualitative approach, which included six focus group discussions held with 36 Xhosa people who have schizophrenia. In our study, genetics was understood by our participants as something 'passed down' in their blood. Participants held this explanation based on previous exposure to a genetic explanation of schizophrenia through their involvement in multiple genomics projects. Despite that exposure, most participants held a complex multitude of causal explanations for their condition, which included psychological, social, environmental, and cultural/supernatural factors. Importantly, we found that historical and contemporary contextual realities of living in low-income, poverty-stricken environments, served as an overarching frame for how our participants understood the cause of their disease. In our work, internalised stigma was defined as a person experiencing shame and expecting discrimination when others know about their condition<sup>4, 5</sup>. Based on this understanding of genetics and internalised stigma, we found no straight-forward relation between a genetic attribution and internalised stigma.

Expanding on that work and based on an examination of African philosophical literature, I propose two reasons why the relation between genetic attribution and mental illness is unlikely to impact on questions of moral agency and moral responsibility for some African populations. First, I propose that this is unlikely because some African cultures conceptualise mental illness differently from the dominant Western perspective. In many traditional cultures in sub-Saharan Africa, including South Africa, mental illness may be attributed to the influence of ancestors or bewitchment factors. In our own research, supernatural and cultural explanations such as these were commonly cited by participants as important explanations for understanding the cause of mental conditions such as schizophrenia<sup>3</sup>. This is supported by research conducted by other scholars on Xhosa people with mental illness<sup>6, 7</sup>, and among other African cultural groups<sup>8, 9</sup>.

Second, I propose that this is unlikely because of how moral agency and moral responsibility are understood in some African accounts of personhood. Specifically, the source of personhood in most Western societies is considered in relation to the dominant individualistic view of the human body, with an emphasis on its intrinsic traits. Since genetics – or biology – is a fundamental constituent of the body, this naturally gives rise to questions about how biology influences human behaviour. Yet, in at least some accounts of African personhood, a human body is a necessary but not sufficient condition for personhood. For instance, a moralised account of personhood is defined – to some extent – in relation to the virtues one engages in that benefit the communal good. Furthermore, in some African cultures, personhood tends to have a spiritual component in addition to a physical component. Notably, this view is not held by all African scholars and other African philosophers may highlight other notions of personhood. Given that it is a dominant account in African philosophy, I will focus on it for this presentation. Additionally, based on African philosophy, an individual's agency is considered to be influenced by spiritual, social, and individual elements. In at least some African traditions, the implication is that moral agency and responsibility

questions are explained more by external constituents than intrinsic factors, including genetics and biology. Understood as such, the relation between genetics and human actions may be less pertinent, and questions about their relations may not be as relevant to the agenda for genomics and mental illness research in Africa. Taken together, given that in some African cultures mental illness is first and for most understood in relation to external factors, it is critical for African bioethics scholars to seriously consider this view when setting the agenda for mental health research. This is important to highlight because often the research agendas set are guided by questions stemming from and relevant to the global north.

## **Background**

Over the years, a range of international stakeholders – largely from the global north – have highlighted the possibility that genomic research may impact stigma, blame and responsibility associated with psychiatric disorders. Limited research has been conducted in Africa to investigate this relation. There is an ongoing lively debate in the Western ethical, legal, and philosophical literature on the relevance of genetic data to questions of individual moral responsibility<sup>10</sup>. Yet, even amidst the rise in genomic research studies, this ethical issue has hardly attracted any attention in the African context and in this presentation, I attempt to consider possible reasons why.

### ***Ethical issues with commentary on each issue***

#### *Different conceptualisations of mental illness*

An ethical issue to take seriously from our research and this presentation is the extent to which African people with a mental illness – such as the Xhosa people in our study – conceptualise mental illness through a multifactorial model which, includes psychological, social, environmental, and cultural/supernatural factors. This conceptualisation of mental illness differs from, for instance the biopsychosocial framework which is often used in mental illness research in the US, other Western countries and in African contexts, which only emphasises genetics, biological, psychological, environmental, and social factors with limited consideration of cultural and spiritual domains. It is possible that using that framework in the African context and perhaps in other LMIC countries may not resonate with the ways in which mental illness is conceptualised by those people. As suggested by Kong and colleagues, a suggestion to address this disconnect is to create constructive points of contact and dialogues between African and Western scholars in order to advance dominant models or develop new models into a framework that resonates with most African people<sup>11</sup>.

#### *Stigma in mental illness research*

I believe that it is an ethical imperative that researchers assess and address mental health stigma through their research while ensuring that the research does not exacerbate the pre-existing stigma. In our study for instance, we first sought to assess the internalised and associative stigma experienced by Xhosa people with schizophrenia, prior to exploring how that stigma may be impacted by genomics research. One notable way we found to be useful for addressing mental illness stigma is through using different bi-directional strategies of community engagement to engage with African people and share accurate mental health information and then measuring the impact of those strategies<sup>12</sup>. This, we found, empowers individuals to be able to articulate their beliefs and experiences in a way that is meaningful for themselves and for others around them, thus addressing some of their own internalised stigma and stigma they may face in their family and/or communities.

### ***Conclusions and two recommendations for how to improve the ethics of, and ethical approaches to mental health research***

In conclusion, mental health research conducted in Africa requires a critical examination of how dominant African conceptualisations may be important for understanding the relevance of its research questions. Without a deep appreciation of cultural belief systems and African perspectives, researchers' risk, 1) investigating questions which are less relevant for different cultural groups and 2) drawing misguided conclusions about that research. One way of mitigating that would be to empower African researchers from the same cultural groups who

are conscious of the socio-cultural understandings of mental illness and are trained in the biomedical sciences, to lead mental health research in their countries. This would promote structural and cultural competence, which have been identified as a key step in guarding against stigma arising as a consequence of health research<sup>13, 14</sup>. Another recommendation would be to explore innovative ways to include African people with mental illness's views in the co-creation of the research agenda.

## References

1. Faure, M.C., et al., *Does genetics matter for disease-related stigma? The impact of genetic attribution on stigma associated with rheumatic heart disease in the Western Cape, South Africa*. *Social Science & Medicine*, 2019: p. 112619.
2. Matshabane, O.P., et al., *The role of causal knowledge in stigma considerations in African genomics research: Views of South African Xhosa people*. *Social Science Medicine*, 2021. **277**: p. 113902.
3. Matshabane, O.P., et al., *Exploring how a genetic attribution to disease relates to stigma experiences of Xhosa patients with schizophrenia in South Africa*. *Social Psychiatry and Psychiatric Epidemiology*, 2020.
4. Gray, D.E., *'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism*. *Sociology of Health and Illness*, 2002. **24**(6): p. 734-749.
5. Corrigan, P.W. and A.C. Watson, *Understanding the impact of stigma on people with mental illness*. *World psychiatry*, 2002. **1**(1): p. 16.
6. Campbell, M., et al., *The content of delusions in a sample of South African Xhosa people with schizophrenia*. *BMC Psychiatry*, 2017. **17**(1): p. 41.
7. Mbang, N., et al., *Attitudes towards and beliefs about schizophrenia in Xhosa families with affected probands*. *Curationis*, 2002. **25**(1): p. 69-73.
8. Sorsdahl, K.R., et al., *Explanatory models of mental disorders and treatment practices among traditional healers in Mpumalanga, South Africa*. *African Journal of Psychiatry*, 2010. **13**(4).
9. Naanyu, V., *Social Context and Mental Illness Stigma in South Africa: Ghost*. 2010: VDM Publishing.
10. Tabb, K., M.S. Lebowitz, and P.S. Appelbaum, *Behavioral genetics and attributions of moral responsibility*. *J Behavior genetics*, 2019. **49**(2): p. 128-135.
11. Kong, C., et al., *The hermeneutics of recovery: Facilitating dialogue between African and Western mental health frameworks*. *Transcultural Psychiatry*, 2020: p. 13634615211000549.
12. Campbell, M., et al., *Evaluating Community Engagement Strategies to Manage Stigma in Two African Genomics Studies Involving People Living with Schizophrenia or Rheumatic Heart Disease*. *J Global Health, Epidemiology and Genomics*, 2021. **2021**.
13. de Vries, J., G. Landouré, and A. Wonkam, *Stigma in African genomics research: gendered blame, polygamy, ancestry and African epistemology impact on the risk of harm*. *Social Science & Medicine*, 2020: p. 113091.
14. Claw, K.G., et al., *A framework for enhancing ethical genomic research with Indigenous communities*. *J Nature Communications*, 2018. **9**(1): p. 1-7.

This case study was prepared for GFBR 2021, which took place virtually. Further details are available at [www.gfbr.global](http://www.gfbr.global).