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Stigma in African genomics research: Gendered blame, polygamy, ancestry and disease causal beliefs impact on the risk of harm

Jantina de Vries[a,*], **Guida Landouré**[b,c], **Ambroise Wonkam**[a,d,e]

[a]Department of Medicine, Faculty of Health Sciences, University of Cape Town, South Africa

[b]Faculté de Médecine et d'Odontostomatologie, USTTB, Bamako, Mali

[c]Service de Neurologie, CHU du Point "G", Bamako, Mali

[d]Institute of Infectious Diseases and Molecular Medicine, Faculty of Health Sciences, University of Cape Town, South Africa

[e]Department of Pathology, Faculty of Health Sciences, University of Cape Town, South Africa

Abstract

A recurring concern in genomics research is the possibility that it could lead to stigma for participants, their families and the population groups they belong to. Little evidence exists to explain how and when this ought to be a concern in genomics research in Africa whilst there is growing international evidence drawing into question the direct link between stigma and genetics. In this paper, we interrogate practical instances from African genomics research where stigma was identified as a concern in an attempt to nuance and refine accounts of when stigma should be considered as an ethical issue. The paper describes examples involving gendered blame, polygamy, beliefs in supernatural disease causation and sensitive information about group lineage. We propose that the concern may not be about stigma so much as broader research-related harm, including for instance reputational harm to population groups. Furthermore, we propose to shift the analytical gaze from establishing causal relationships to exploring the intersection of genomics with pre-existing stigma. Finally, we emphasize the importance of ensuring genomics researchers are culturally competent, meaning able to recognise when cultural factors impact on the possibility that genomics research could cause harm.

Keywords

Africa; Stigma; Genomics; Genetic attribution; Polygamy; Ancestry; Gendered blame

1. Introduction

A recurring concern in African genomics research is the possibility that it could lead to or increase stigma associated with diseases or population groups (Ramsay et al., 2014). This

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*Corresponding author: jantina.devries@uct.ac.za (J. de Vries).

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concern is not unique to the African research context and is related partly to the eugenics history (Duster, 2006). For quite a few years, researchers have attempted to investigate the link between genetic attribution and stigma, exploring under what circumstances genetic knowledge could give cause to, aggravate or alleviate stigma. This work has resulted in some evidence suggesting that information about a genetic predisposition to illness could reduce personal blame and internalised stigma (Sankar et al., 2006); that it could increase stigma for healthy biological relatives (Tekola et al., 2009); and that the systematic association of population groups with 'bad genes' could be stigmatising (de Vries et al., 2012; McGregor, 2010).

Yet the overwhelming conclusion of several decades' worth of work in this field is that at a minimum, the relation between genetic attribution and stigma is not straightforward and that this ethical concern may have been overplayed (Parens and Appelbaum, 2019). Furthermore, whilst there is evidence suggesting that lay people may use genomic information to affirm pre-existing beliefs (Condit, 2019), genomic information in itself may not cause or entrench such beliefs. Such findings resonate with emerging insights from empirical research on the African continent, which has emphasized the importance of recognising pre-existing disease stigma (Marsh et al., 2011; Tekola et al., 2009), stigmatising features of alternative (non-genetic) disease causal beliefs (Faure et al., 2019; Matshabane et al., 2020) and whether the population groups involved are already marginalised (de Vries et al., 2012).

To date, none of this work has demonstrated that genomics research or genomic information causes stigma simply because of the genetic attribution of traits – which logically should provide a counterweight to ethical concerns linking the two. Yet overwhelmingly, concerns about stigma continue to take a prominent position in African genomics research – most recently in relation to the return of genome summary results (Tiffin, 2019). When it is described as a risk in African genomics research, it is typically treated as a black box with no consideration of the types of stigma (Brewis and Wutich, 2019; Major et al., 2017) or the social and political processes that give rise to, entrench and perpetuate it (Link and Phelan, 2001; Tyler and Slater, 2018). Furthermore, genomics research is also treated as a black box, with no regard for how different types of genomics research and different stages of the research process may interact with those different types of stigma and the processes that uphold it. Finally, 'Africa' and its people are also treated as a black box, without appreciation for how historical, cultural, social and political dynamics impact on the possibility that individuals or groups could become stigmatised (Metzl and Roberts, 2014).

In an attempt to unpack these black boxes, we set out to interrogate practical instances we encountered in African genomics research where stigma was identified as a concern, but which were not published. The purpose in doing so was to attempt to nuance and refine accounts of when stigma should be considered as being of ethical concern in the conduct of African genomics research. Through the examples we hope to demonstrate that the relation between stigma and genetic knowledge on the African continent is nuanced, context-specific and often related to mundane aspects of everyday life. We also hope to demonstrate that the question is not about genomics research *causing* stigma – as many of the commentators would like to have it – but rather more about whether and how the genomics research process and the ability of genomic knowledge to reveal information

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that is considered private, relate to existing social and cultural dynamics that are already stigmatising or discriminatory. We present these examples in two categories below.

2. Examples where the *design and conduct* of genomics research intersect with stigma

Our first set of examples involves instances in which the design and conduct of genomics research intersected with pre-existing stigma. As such, they are examples where what is called 'stigma' is probably more a concern about research harms (Millum et al., 2019). Where genomics research intersects with pre-existing stigma, the onus is on researchers to recognise this to be the case, to not aggravate existing stigma and possibly to work to address it. We found three instances in which pre-existing stigma mattered in the conduct of genomics research, namely gendered blame, polygamy and supernatural explanations for disease.

2.1. Stigma and gendered blame

Gendered blame (Berns, 2001) occurs when women are systematically blamed for social and economic misfortunes and is a form of public stigma (Brewis and Wutich, 2019). When children are born with congenital abnormalities or illnesses, it is common for women in traditional African settings to be held responsible for their condition, usually because of things the woman is alleged to have done during pregnancy. In those cases, the focus is often on behaviour that is considered taboo or socially undesirable, such as for instance alleged promiscuity. Gendered blame is recorded for many different conditions including for instance Sickle Cell Disease (Marsh et al., 2011) and Down's Syndrome (Mbazima, 2016).

We encountered gendered blame in different instances of which we describe two here. The first involved a genomic study in South Africa focusing on neurodevelopmental conditions (de Menil et al., 2019). Neurodevelopmental conditions are associated with cognitive delays and behavioural challenges and can be difficult to recognise for lay people. This can result in accusations of bad parenting that tend to be directed towards mothers. The clinical team involved in the study had identified gendered blame as a particular issue of concern. In the case we were involved with, we were interested in seeing if the genomic study could also be used to counter narratives of gendered blame. Yet in fostering discussions around genomics for complex traits, what we found to be challenging is that the study area has a very high incidence of children born with Foetal Alcohol Syndrome (FASD) (Watt et al., 2014). This disorder shares symptoms with neurodevelopmental conditions and is caused by excessive maternal alcohol consumption during pregnancy.

Previous work on the African continent has illustrated that genomic information could be a tool to reduce gendered blame by fostering dialogue about the role of biology and inheritance in disease causation (Marsh et al., 2011). Community-based interventions may be successful in countering such narratives (Tora et al., 2016). Yet what our experience demonstrated is that it is not straightforward to use genomic explanations of illness to foster discussions about gendered blame in an environment where there is apparent factual evidence to support it. This was true in the case of the FASD example we described. It

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is similarly true for illnesses that are carried on the X-Chromosome, such as Fragile X Syndrome and Haemophilia. More work needs to be directed to understanding how genetic narratives about disease elaborated in genomics research, intersect with existing gendered blame particularly for conditions that travel through the female line.

2.2. Polygamy

Building on this example, one way in which gendered blame may manifest is in relation to polygamy. Although in decline and no longer customary in more urbanised parts of the continent, polygyny remains relatively common (Fenske, 2015) and is legal in many African states. One important feature of polygamous households is that they tend to be hierarchical and economic and reputational benefits accrue to the higher-ranked women in the household (Munro et al., 2011). Rank can be dependent on when the marriage took place, the individual's productivity, how many children a woman gave birth to and the health of those children (Rossi, 2016). Rank is important because it determines the individual's share of and access to household resources, with lower-ranking household members at greater risk of poverty and food insecurity (Nanama and Frongillo, 2012).

Yet despite it being relatively common in some parts of Africa, polygamy has hardly received any attention in African research ethics, probably partly because the practice itself is made invisible in professional discourse (Ekechi, 1976). We encountered polygamy to matter for stigma in cases where only one or few of the children in a household are affected by conditions that have a (partial) genetic origin. This challenge is compounded by a tradition in polygamous African societies where the first wife is preferably a relative of the husband; therefore more prone to give birth to children with autosomal recessive conditions. In cases where the first wife is recurrently having children with congenital anomalies, the husband is often stimulated by his family to take a second wife, often of his choice and from outside the family, who may be less likely to be a carrier of the same condition and to have children with genetic disorders.

In one medical genetic study focusing on neurodegenerative diseases in West Africa, doctors enrolled a paediatric patient from a polygamous household. The patients' mother had ten children with his father with three children affected by the disease. His father had six children with his other two wives; none of them had the condition. The study found both parents to be carriers. The mother was stigmatised in the family and community because of her children's illness - the father was not. Whilst there was a theoretical possibility that the stigma experienced by the mother could have been alleviated through a discussion about homozygosity and inheritance, the research team was unable to impact on the stigma experienced by the wife, because the husband controlled the flow of information and did not engage in discussions about inheritance. What this case demonstrates is that even when genomic knowledge could impact on gendered blame, its effect is subject to existing power dynamics within families and communities that research alone is unlikely to change.

2.3. Stigma and supernatural or spiritual disease attribution

Stigma has also frequently arisen as a concern in African genomics research in cases where the disease under investigation is attributed to spiritual or supernatural causes. One

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important component of African ontology is the continuity between those who lived in the past, those who are alive today, and those who will live in the future (Adjei, 2019). In this worldview, relations with those that have gone before – the ancestors – are tangible and the belief may be that people are born or fall ill with diseases because the ancestors are upset and need to be appeased (Mbazima, 2016). Equally important is attribution of illness to supernatural causes such as God/Allah, the withdrawing of nature spirits or human supernatural agents (Kahissay et al., 2017). Spirit mediumship, divination and witchcraft are important components of African health epistemology (Thabede, 2014) and (partial) supernatural attribution of disease is common.

There is evidence that suggests that diseases that have strong supernatural connotations are also stigmatised. This is the case for instance for cleft lip palate, which attracts a range of explanations such as 'Devil's child' in some parts of Africa (Adeyemo et al., 2016). In those cases, social pressure and fear of ostracization can lead to infanticide (Denham et al., 2010; Moseson et al., 2019). Furthermore, for those children who do survive, stigma can affect health-seeking behaviour and may cause social isolation (Shirol, 2018). Finally, notions may emerge that the body parts of people suffering from these conditions are good luck charms or possess magical powers as is the case for albinism. As a result there have been hundreds of albino murders in the past decade (Cruz-Inigo et al., 2011).

When genomics research is conducted on these conditions, it is imperative that attention be paid to understanding how the conduct of genomics research intersects with the stigma experienced by patients and their family members. At one level, there are questions about how experienced and public stigma (Brewis and Wutich, 2019) impact on recruitment processes. But perhaps more importantly, there are questions about whether conducting genomics research on these conditions may enforce or counter stigmatising narratives that need to be taken seriously in the conduct of genomics research and in research investigating stigma and genetic attribution.

3. Examples of where genomic *information* intersects with stigma and discrimination

A second way in which stigma manifests in African genetic or genomics research relates to the information that the research may reveal, particularly where it reveals information that is considered private and sensitive.

4. Where genomic knowledge informs on ancestry

Internationally some of the clearest evidence of genomics impacting on feelings of marginalisation or stigmatisation is where genomic knowledge has informed on people's ancestry, particularly where this information is in conflict with people's knowledge or beliefs. This seems to have been the case for the Havasupai as well as for many of the population groups that were targeted for the Human Genome Diversity Project (Reardon, 2005).

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In one example we encountered, researchers in a malaria genomic study were interested in ensuring that they captured participants' 'true' ethnicity, by which they meant their genetic ancestry. Participants were recruited from an area in Africa with a history of inter-tribal kidnapping and slavery. Although now equal before the law, the study found that descendants of these two groups are genetically distinct (Lulli et al., 2009). Slave descendants continue to have lower social and economic status and their origin is normally not openly discussed or acknowledged. When asked, all participants initially indicated belonging to the more powerful group. In order to access this private information, the research team used an informant from the powerful group to confirm and 're-assign' the ethnicity of participants to fit the parameters of the scientific study. In this case, what is problematic is the flattening of complex questions around identity and belonging to mere questions of an individual's 'true' genetic ancestry.

A second example of genomics research informing on ancestry of population groups relates to the involvement of the San in international genomics research. The San population is a nomadic, hunter-gatherer population from South-West Africa and is considered the oldest human ancestral population. It is also subjected to historical and contemporary marginalisation. In 2009, four elderly San people were enrolled in an international genomics research project in a manner that the San communities across South Africa, Namibia and Botswana found to be inappropriate and offensive (Chennells and Steenkamp, 2018). Specifically, the scientific publications emanating out of this study included "numerous conclusions and details that the San regarded as private, pejorative, discriminatory and inappropriate" (Chennells and Steenkamp, 2018: 15), including information about historical admixture between the San and other populations. Not unlike other examples where outsiders are using genomic information to make normative claims about population groups (Lea and Chambers, 2007), also in this case the complete isolation of researchers from the participant's culture meant they were not able to anticipate, understand or appreciate concerns about how genomic information – or their interpretation – could cause offense.

5. Where genomics informs on group customs or lineage

Beyond ancestry, it is also possible for genomic information to inform on group lineage. One compelling example involved a genomic study proposing to investigate an inherited X-linked neurodegenerative condition highly prevalent in a rural town in West Africa. Through research, it became obvious that the founding Chief of the village had suffered from this condition. The Chief had many wives and transferred his condition to his offspring. The condition worsens with every generation. People in the village make sense of the large number of descendants affected through a narrative of a curse affecting the Chieftaincy and have turned to traditional healing practices to contain or lift the curse. Genomics research provides a counter-narrative to this explanation. The question is what the interrelation of the royal blood-line with a genetic condition would do to the royal families' power, their social status and the political stability of the community.

Taken together, these examples shed light on the possibility that genomic information may reveal customs, practices, history or information that would normally be considered private

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and which (groups of) people may not normally choose to reveal or speak about. This happens almost accidentally and so is often not explicitly described or discussed.

6. Discussion

Against the rapidly growing number of African laboratories using genomics research methods to elucidate disease, the ethical concern that genomic knowledge could increase stigma needs to be taken seriously. Yet the tendency of ethicists and commentators to black box stigma and to cast it as a universal threat pertinent to all African genomics research and all people is problematic – not in the least because it does not equip us to distinguish cases in which stigma should really be considered a threat, from cases in which it should not.

In this Commentary, we first observed that there is very little evidence of instances where genomics research caused or aggravated stigma in African genomics, with two exceptions (Chennells and Steenkamp, 2018; Tekola et al., 2009). There have also been few studies examining the relation between genomics and stigma in Africa – and the few that have been conducted, have either failed to provide compelling evidence that genomics research could cause or aggravate existing stigma (Faure et al., 2019; Matshabane et al., 2020), or shown the opposite effect (Marsh et al., 2011; Shibre et al., 2001).

Based on this literature, one would be forgiven for concluding that the concern that genomics research or genomic information could impact on stigma has been overplayed – as some have recently proposed (Parens and Appelbaum, 2019). Yet in this paper, we described several instances in which concerns about stigma were raised – by researchers, ethicists or community members. In this Commentary, we took a closer look at those cases to see what they would teach us about the possibility that genomics research could cause stigma.

Taken together, there are some important lessons to be drawn about the risk of stigma in African genomics research. The first and perhaps most important of these, is that what may be called ‘stigma’, is most often a more general concern about research-related harm (Millum et al., 2019). Using examples of general harm to illustrate the potential of genomics to cause stigma is inappropriate – not only because it obscures the complex processes by which stigma arises and is perpetuated (Brewis and Wutich, 2018; Link and Phelan, 2001; Tyler and Slater, 2018), but also because it obscures from view the much more nuanced way in which genomics research and stigma intersect. As a result, fundamental questions are left uninterrogated and researchers are left to navigate these issues without guidance or evidence.

The second important insight from our analysis is that where the design or conduct of genomics research intersects with stigma, the stigma tends to be pre-existing: it is not caused by genomics research. Furthermore, the types of stigma encountered cut across different categories (Brewis and Wutich, 2019). *Public stigma* could play a role when participants are worried that research enrolment could be seen as confirmation that they suffer from a stigmatised trait; it may also be a factor in understanding gendered blame, for instance when women are cast as ‘bad parents’ when they have children with neurodevelopmental conditions. *Self-stigma* is an issue when involving participants with mental health conditions

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in genomics research for instance (Matshabane et al., 2020). *Experienced stigma* is very important when enrolling participants suffering from conditions where stigma is so severe that patients' lives are under threat. This is the case for conditions that attract strong supernatural or superstitious beliefs, such as for instance albinism and cleft palate. In these cases, experienced stigma may prevent or obstruct enrolment. Going forward, research investigating the relationship between genomics and stigma needs to consider these different kinds of stigma and how genomics research and information intersect with the complex social and political processes that give rise to and perpetuate stigma.

A third important insight is that in order to recognise the particular instances in which genomics research or information may intersect with stigma, researchers need to be culturally competent (Metzl and Hansen, 2014; Metzl and Roberts, 2014), meaning able to recognise when particular cultural factors impact on the possibility that genomics research could cause harm. This means researchers need to be knowledgeable of the history, culture and customs of the persons involved in the research. With increasing geographic, ontological and epistemological distance between the persons conducting research and those who are researched, the cultural competence of researchers seems to diminish. In our experience, this is most pronounced when researchers are from high-income, non-African countries. In those cases what seems to be at play is structural stigma relating to how Africa is perceived and treated – namely as something that is exotic and in need of interpretation and explanation, where non-Africans are entitled to hypothesise, scrutinise and comment on the lives of others without a thorough understanding of how the probing may impact on existing stigma.

Overall, our analysis carries several implications. First, we propose that in most cases, the ethical focus should shift from concerns about stigma to broader concerns about (reputational) harm and the revealing of sensitive information about group history that should be considered private. Where there are concerns about stigma, the focus should be on how genomics research intersects with pre-existing stigma, with greater focus on understanding the different types of stigma and the social and political processes that uphold it. Attention should also be paid to better understand the relation between certain cultural practices such as polygamy, patterns of stigmatisation such as gendered blame, and disease causal beliefs such as superstition. Furthermore, our analysis suggests that detailed knowledge of participants' causal belief systems, local customs, taboos and beliefs is essential to recognise where genomic knowledge may negatively or positively impact on stigma associated with conditions or groups. This means that, as a minimum, the meaningful involvement of knowledgeable African stakeholders – including for instance patient or community representatives and African researchers – in the design and conduct of genomics research on the continent is required to detect early the possibility that genomics research could impact on existing stigma.

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