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# Prioritising African Perspectives in Psychiatric Genomics Research: Issues of Translation and Informed Consent

## Abstract

Psychiatric genomics research with African populations comes with a range of practical challenges around translation of psychiatric genomics research concepts, procedures, and nosology. These challenges raise deep ethical issues particularly around legitimacy of informed consent, a core foundation of research ethics. Through a consideration of the constitutive function of language, the paper problematises like-for-like, designative translations which often involve the ‘indigenization’ of English terms or use of metaphors which misrepresent the risks and benefits of research. This paper argues that effective translation of psychiatric genomics research terminology in African contexts demands substantive engagement with African conceptual schemas and values. In developing attenuated forms of translational thinking, researchers may recognise the deeper motivational reasons behind participation in research, highlighting the possibility that such reasons may depart from the original meaning implied within informed consent forms. These translational issues might be ameliorated with a critical re-examination of how researchers develop and present protocols to institutional ethics review boards.

**Key words:** African perspectives, psychiatric genomics research, translation, informed consent

## *Introduction*

The language used in psychiatric genomics research tools currently draws mainly from Western conceptualisations of psychiatric constructs and explanatory tools developed by and for English-speaking European populations. The valuable contribution that African populations can make in advancing the science of psychiatric genomics has resulted in widespread interest in sampling from the African continent.<sup>1</sup> With this comes a range of practical challenges around the development of scientific discourses about psychiatric genomics in local African languages, such as the absence of linguistically equivalent vocabulary for

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<sup>1</sup> Campbell MC, Tishkoff SA. (2008) African genetic diversity: implications for human demographic history, modern human origins, and complex disease mapping. *Annual Review of Genomics and Human Genetics*. 2008(9), 403-33.

psychiatric terminology (e.g.: schizophrenia)<sup>2</sup> as well as genomic concepts (e.g.: genes, DNA) and associated research practices<sup>3</sup>, forcing researchers in these contexts to develop innovative discourses to support the explanation of these terms. One potential advantage of this process is that it encourages broader engagement with African participants in the refinement of these scientific discourses.

Yet these practical challenges reveal deeper issues at stake around the linguistic and conceptual translation of genomics discourse in the African context. This paper focusses on the central question of how practical and ethical issues of translation may be addressed to accurately and meaningfully facilitate participants towards informed consent, the most basic ethical principle on which all other principles are founded. An important ethical concern is that translated descriptions can be broad and vague, potentially open to misinterpretation – not only misrepresenting the risks and benefits of participating in this type of research study, but also reflecting superficial or poor engagement with the value frameworks and perspectives which are deeply embedded within different African cultures.

The tendency to overlook African value and conceptual frameworks is especially problematic given the fact that biogenetic explanations of psychiatric conditions are often only one of the explanatory illness models used by African participants.<sup>4</sup> Indeed, others include religious and traditional spiritual explanations (see for example how these religious and traditional spiritual explanations influence the content of psychotic delusions in Southern African samples.<sup>5</sup> These explanatory models may lead to participants' resistance to provide

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<sup>2</sup> Campbell, M. M., Susser, E., de Vries, J., Baldinger, A., Sibeko, G., Mndini, M. M., ... & Stein, D. J. (2015). Exploring researchers' experiences of working with a researcher-driven, population-specific community advisory board in a South African schizophrenia genomics study. *BMC medical ethics*, 16(1), 45.

<sup>3</sup> De Vries, J., Bull, S. J., Doumbo, O., Ibrahim, M., Mercereau-Puijalon, O., Kwiatkowski, D., & Parker, M. (2011). Ethical issues in human genomics research in developing countries. *BMC medical ethics*, 12(1), 5.

<sup>4</sup> Kong, Camillia. (2019). Cultural Translation, Human Meaning, and Genes: Why Interpretation Matters in Psychiatric Genomics'. In Y. A. Frimpong-Mansoh and C. A. Atuire, *Bioethics in Africa: Theories and Praxis* (Eds.) 95-112. Wilmington: Vernon Press.

<sup>5</sup> Campbell, M. M., Sibeko, G., Mall, S., Baldinger, A., Nagdee, M., Susser, E., & Stein, D. J. (2017). The content of delusions in a sample of South African Xhosa people with schizophrenia. *BMC psychiatry*, 17(1), 41;

their blood and saliva samples – the principal mode of sample collection in genomics research – particularly in instances where the use of these biological samples is not clearly defined.

This paper argues that efforts to translate concepts around psychiatric genomics for research purposes in African contexts demand substantive engagement with African conceptual schemas and values. The absence of linguistic equivalents around genetic scientific terminology, descriptions of scientific procedures used in genomics studies, and psychiatric nosology present significant challenges. Whilst the temptation may be to deploy ‘like-for-like’ translation of terms, such an approach ignores the deeper constitutive function of language, in as much as language expresses the interpretative reality, substantive practices, and conceptual schemas of a people.<sup>6</sup> Issues of translation are by no means isolated to psychiatric genomics studies, however, the content and foci of such studies uniquely rely on presuppositions around the fundamental ontology of human minds and behaviour – the latter of which are frequently substantively and culturally laden concepts. Thus, the interpenetration between language and cultural worldview are all the more explicit and acute, making attempts to translate or indeed, construct relevant genomic terms without deep understanding of the constitutive worldview of African cultures not only impractical, but ethically questionable for obtaining proper consent. Yet, psychiatric genomics studies continue to be driven by an approach focused on linguistic equivalence despite efforts in other domains of clinical and indeed, psychiatric interventions, which have integrated

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Connell A, Koen L, Niehaus D, Cloete KJ, Jordaan E, Botha U. Religious Delusions in a Xhosa Schizophrenia Population. *Journal of Religion and Health*. 2015; 54(5):1555-62.

Patel V. Explanatory models of mental illness in sub-Saharan Africa. *Soc Sci Med*. 1995; 40(9):1291–8.

<sup>6</sup> Hill, Jane H. & Mannheim, Bruce. (2003). Language and World View. *Annual Review of Anthropology*. 21. 381-404. 10.1146/annurev.an.21.100192.002121; See also: Taylor, Charles. (2016). *The Language Animal*. Cambridge, Mass.: Harvard University Press.

community-driven efforts to ensure that the translation of tools are appropriately attuned to the conceptual schemas of communities.<sup>7</sup>

This narrow focus, however, does not limit the potential applicability of our analysis to other clinical studies, but distils an already largely recognised point about the significance of successful communication as necessary for informed consent, even by the lights of Western bioethical theories.<sup>8</sup> Indeed, the ethical issues raised by the translational pitfalls encountered in psychiatric genomics studies is a pressing issue for Western scientific researchers, translators, and bioethicists, precisely because it in fact illustrates clearly a broad, cross-cultural consensus how miscommunication remains a major obstacle to obtaining informed consent.<sup>9</sup> The challenge of translation therefore raises, not just practical consequences for psychiatric genomics studies, but also deeper ethical issues in clinical studies more generally. Most notable here are the incumbent responsibilities and obligations of scientific and clinical researchers to ensure translational efforts engage meaningfully with the conceptual schemas implied in the vocabulary – or absence of vocabulary – of clinical study concepts. We cannot explore this generality in any depth, however gesture towards it so as to highlight the significance of our narrow focus on psychiatric genomics research.<sup>10</sup>

Section I outlines the constitutive rather than designative function of language, which explains the need for translators of psychiatric genomics studies, to engage substantively with the normative practices and conceptual framework of the community to which translation is made. Section II then provides a broad overview of salient features of African belief, thought

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<sup>7</sup> For example, the highly successful work of The Friendship Bench in Zimbabwe: see <https://www.friendshipbenchzimbabwe.org>.

<sup>8</sup> Faden, Ruth R. and Tom L. Beauchamp. (1985). *A History and Theory of Informed Consent*. Oxford: Oxford University Press, 1986; also Bromwich, Danielle and Joseph Millum. Disclosure and consent to medical participation, *Journal of Moral Philosophy*. 12:2 (2015): 195-219 and Bromwich, Danielle and Joseph R. Millum. Informed consent to HIV cure research. *Journal of Medical Ethics* 43:2 (2017): 108-113.

<sup>9</sup> Our thanks to an anonymous reviewer for pushing this point.

<sup>10</sup> We also set aside the competency requirements of informed consent as this detracts from the main focus of the paper. For more on the problematisation of these requirements within psychiatric genomics studies, see Kong, Camillia, Mehret Efrem, and Megan Campbell. (In Press). Education vs Screening: The Use of Capacity to Consent Tools in Psychiatric Genomics. *Journal of Medical Ethics*.

and practices which impact on African notions of mental health treatment and research. It is against this background that practical and ethical challenges of translation in psychiatric genomics research are discussed in Sections III and IV.

### *I. Language as constitutive*

Often, psychiatric genomics studies treat translational issues as a simple matter of finding the equivalent indigenous terms to describe putatively neutral ideas or phenomena. Approaches of adapting North American and European psychiatric assessment tools for different language and cultural contexts using forward and back-translation designs that focus exclusively on linguistic equivalence are examples here. Materials are first translated into the target language by one translator then back-translated into the original language of the tool by another translator and the original and back-translated versions compared for consistency. However, this implies the questionable presumption that language has a purely designative rather than constitutive function. In designative accounts of language, words and linguistic idioms are reduced to the designation of things – the usage of words or utterances to correlate to or describe features of our surroundings or behaviours.<sup>11</sup> As such, language is thought of as ‘an assemblage of separable instruments, which lie as it were transparently to hand, and which can be used to marshal ideas, this use being something we can fully control and oversee’<sup>12</sup>. According to such a designative account, the absence of relevant genomic terms in African cultures would be a relatively minor issue, redressed by the construction of signs that can be used instrumentally to convey scientific ideas like DNA.

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<sup>11</sup> Taylor, Charles. (2016). *The Language Animal*. Cambridge, Mass.: Harvard University Press. Also Taylor, Charles. (1995). *The Importance of Herder*. In *Philosophical Arguments* (79-99) Cambridge, Mass.: Harvard University Press.

<sup>12</sup> Taylor, Charles. (1995). *The Importance of Herder*. In *Philosophical Arguments* (96) Cambridge, Mass.: Harvard University Press

However, the challenges consistently reported in translation studies of psychiatric instruments from English into African languages suggest language has a markedly different, more constitutive function, particularly in interpreting and shaping peoples' experiences of illness<sup>13</sup>. For example while the English language supports a wide range of emotional experiences illustrated by the many emotive adjectives within the language, isiXhosa, an Nguni language prevalent in South Africa, has far fewer emotive adjectives and more easily accommodates somatic descriptions of distress.<sup>14</sup> It stands to reason then that there is a difference in symptom presentation and the way in which psychological distress is described between these two language groups. Language as such cannot be treated as an instrument to convey or describe neutral datum, but rather, is the intersubjectively constituted framework which allows individuals to interpret, understand, and express the meaning of their experiences and social bonds.<sup>15</sup> Words only make sense in relation to the whole semantic field that expresses a web of values, social practices, and conceptual framework that constitute the worldview of different people. In other words, language is vital in facilitating the interpretative reality, understanding, and expression of individuals *through* and *within* their social relations. This means that 'we can never in principle have a clear oversight of the implications of what we say at any moment'.<sup>16</sup>

Importantly, this view of language does not mean new terminology within a culture is automatically invalid or inherently problematic. But it does suggest that unique issues arise specific to the process of cross-cultural translation. For example, English, like any language, is dynamic and consistently evolving. The terminology of genomics is likewise relatively

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<sup>13</sup> Swartz, Leslie. (1998). *Culture and mental health: A Southern African view*. Oxford: Oxford University Press, Southern Africa.

<sup>14</sup> Campbell, M. M., & Young, C. (2016). A Xhosa language translation of the CORE-OM using South African university student samples. *Transcultural psychiatry*, 53(5), 654-673.

<sup>15</sup> There is a great deal to be explored here around the designative vs constitutive traditions of language, but this would detract from the primary focus of our paper. For a rich account of the philosophical background of these two traditions, see Taylor, Charles. 2016. *The Language Animal*, Cambridge, Mass.: Harvard University Press.

<sup>16</sup> Taylor, Charles. (1985). *Human Agency and Language: Philosophical Papers I*. Charles Taylor, Cambridge: Cambridge University Press, 231.

recent, with terms like DNA and gene coming from the scientific lab and gradually incorporated into common linguistic usage. This process of what we might call ‘culturally internal’ incorporation is distinct from that of cross-cultural translation for the following reason. First, whilst genomic terms were new to English at some point, the semantic field and its constitutive values were not: the epistemological and ontological commitments embedded within genomics study were not wholly alien to the Western context but a reflecting a long tradition of a particular mode of scientific investigation. By contrast, such genomics study, its constitutive presumptions and substantive meanings, are all relatively new and indeed, alien to different African contexts, representing a new reality in effect.<sup>17</sup>

Attention to the constitutive nature of language is also important to illustrate precisely how translational issues within psychiatric genomics studies cannot be viewed simply as a straightforwardly linguistic issue, where there is an absence of appropriate linguistic terms. Language has a constitutive relation to cultural values, meaning that the absence of linguistic terms *in itself* could be indicative of culturally significant values which orient divergent ways of fundamentally understanding particular phenomena or experiences. For example, one might argue that the absence the concept of ‘biological sample’ in African languages suggests a simple linguistic puzzle – what appears to be required is simply the need to either simply introduce a new term of usage, or indeed, find a roughly equivalent term. However, the absence of ‘biological sample’ is itself an indication of how cultural value penetrates the linguistic domain: as we explore more fully below, the semantic field around the concept involves assumptions of taking blood or saliva, of the scientific rather than metaphysical meaning of these bodily fluids, of instrumentalising parts of one’s physical being. This

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<sup>17</sup> Another example might be found in many indigenous communities across East African communities whereby the word ‘school’ was also a new term that is merely indigenized to become, for example in Kikuyu, ‘*thukuru*’. But by contrast, this translation is not problematic due to its physical representation and common interpretation across East African communities. The intent of ‘school’ tracks already existing substantive cultural commitments, such as to the education of children, fostering of community, and so on.



semantic field is notably different and often alien to different African contexts. Only once the constitutive nature of language is taken as our starting point is it possible to devote critical attention to the ‘alienness’ of certain semantic fields, to the absences or presences of certain linguistic terms, in an attempt to forge the type of deeper understanding necessary for translation.

This does not mean that all translational efforts should be abandoned (as we discuss later in the paper). However, effective translation will involve recognising the intrinsic limitations of translation (i.e. that we cannot fully control the meanings that emerge) as well as of its open-ended nature (i.e. that translation is always an ongoing process). But it will also demand substantive engagement with the ways in which people view and interact with their world, revealed through the ways in which people express and interpret themselves. As Nida explains, words as ‘symbols for features of [...] cultures’ suggests that ‘the person who is engaged in translating from one language into another ought to be constantly aware of the contrast in the entire range of culture represented by the two languages’.<sup>18</sup>

## *II. Overview of common salient features of African thought and practice*

We have suggested thus far that effective translation demands a more holistic approach to language, where there is a need to interpretively engage with and understand the practices and conceptual schemas of a people. This is vital in the case of health and especially mental health within African settings, not least if translations of psychiatric and genomic terms are to avoid distortion and improve local application in future. Four particularly salient features of African thought and practice are outlined below: importantly, such is the interconnection of these features that it is difficult to discuss one without the

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<sup>18</sup> Nida, E. (1964), *Principles of Correspondence*. In: Venuti, L. (Ed.). *The Translation Studies Reader*, London: Routledge.

other. It is only for purposes of simplicity and clarity that we discuss them separately here. Moreover, in pointing out these features, nowhere are we claiming that Africa is a homogenous unit: different cultural groups across Africa have different languages, and different cultural beliefs on the causes of ill health and therefore how healing may be achieved. Therefore, every time we give an example or illustration, we cite the specific communities that we are referring to and/or provide the source of the specific information. Nevertheless, certain broad understanding and explanations of health and healing are held in common across sub-Saharan Africa. As Johnson (2010: 57) observes: ‘... in sub-Saharan black Africa the different cultures do share a consciousness of the world’.<sup>19</sup>

i) *Holistic view of illness*

First and foremost, the concept of health is firmly embedded within a holistic sense of the world and of persons. The world is not divided into distinct, isolated parts and components, such as different spheres of life (i.e. the spiritual, physical, and social) or different individual selves. Rather, these components are completely intertwined as a whole, both in a definitional and normative sense. Health refers to, not simply physical health but also the psychological, emotional, spiritual, and socio-cultural well-being of individuals, their families, and their communities.<sup>20</sup> The intersection of many factors is likewise understood to cause illness. Supernatural, natural, and social causes co-exist in common explanations<sup>21</sup>: for example, mental illness may be understood as simultaneously socially- and spiritually-caused, whereby the spiritual world inflicts illness onto an individual or group in response to

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<sup>19</sup> Johnson F.A. (2010). African Perspectives on Mental Disorder. In Mezzich J.E., Kastrup M.C., Honda Y. (Eds.), *Psychiatric Diagnosis*, 57. New York: Springer. See also: Gyekye, Kwame. (1995). *African philosophical thought: the Akan conceptual scheme*. Philadelphia: Temple University Press.

<sup>20</sup> Omonzejele PF. (2008). African Concepts of Health, Disease, and Treatment: An Ethical Inquiry. *The Journal of Science and Healing*, 4 (2): 120-126; Truter I. (2007). African traditional healers: cultural and religious beliefs intertwined in a holistic way. *SA Pharmaceutical Journal*. (2007), 56–60.

<sup>21</sup> Kahissay, M. H., Fenta, T. G., & Boon, H. (2017). Beliefs and perception of ill-health causation: a socio-cultural qualitative study in rural North-Eastern Ethiopia. *BMC Public Health*, (17), 124. Retrieved March 10, 2019, from <http://doi.org/10.1186/s12889-017-4052-y>

those perceived to be responsible for unhealthy social practices.<sup>22</sup> Or mental illness could be caused *because* of the asocial sentiments and spiritual practices of others. For example, in a sample of 200 South African Xhosa people with schizophrenia, over 70% (n=125) reported bewitchment to be the cause of their mental illness, inflicted by family members, neighbours and community members because of jealousy towards the patient.<sup>23</sup>

Moreover, the ethical priority of the social good, particularly in rural settings, has some important implications for conceptualisations of intergenerational mental illness: poor family relationships or individual/group transgressions which harm the community are seen to trigger ill mental health in individual members of the family, within the same generation, or one or many generations later.<sup>24</sup> Countering illness therefore demands understanding, not just a single cause, but attending to its connection to others, not least the social community and spirit world which is an integral part of the whole.<sup>25</sup>

## ii) *Communitarianism*

Another prominent way in which holism is expressed in African thought is in the conceptualisation of human persons as situated within the community. Contrary to the Western view of atomistic individuals who possess biological and psychological independence, African perspectives understand persons as integrated within a community, encompassing an intrinsic connection between biological, psychological, and particularly, social components. This communitarian outlook contains both definitional and normative

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<sup>22</sup> Kyei, J.J., Dueck, A., Indart, M.J. and Nyarko, N.Y. (2014). Supernatural belief systems, mental health and perceptions of mental disorders in Ghana. *International Journal of Culture and Mental Health*, 7(2), 137-151.

<sup>23</sup> Campbell, Megan M., Goodman Sibeko, Sumaya Mall, Adam Baldinger, Mohamed Nagdee, Ezra Susser, and Dan J. Stein. (2017a). The content of delusions in a sample of South African Xhosa people with schizophrenia. *BMC Psychiatry*. 17(1), 41.

<sup>24</sup> Aina, OF, and O Morakinyo. (2011). Culture-bound syndromes and the neglect of cultural factors in psychopathologies among Africans. *African Journal of Psychiatry*. (September 2011): 278-285; Aina, OF, and O Morakinyo. (2011). Culture-bound syndromes and the neglect of cultural factors in psychopathologies among Africans. *African Journal of Psychiatry*. (September 2011): 278-285.

<sup>25</sup> Amenga-Etego, Rose Mary. (2019). The Practice of Traditional Medicine and Bioethical Challenges. In Y. A. Frimpong-Mansoh and C. A. Atuire (Eds.), *Bioethics in Africa: Theories and Praxis* (77-94). Wilmington: Vernon Press.

dimensions:<sup>26</sup> it is definitional in so far as individual identity cannot be defined apart from community. Describing the ontological priority of the community in defining the self, Mbiti states: ‘I am because we are, and since we are, therefore I am’<sup>27</sup>. In other words, the existence of the individual depends on the existence of community<sup>28</sup> – a sentiment that informs the philosophical concept and practice of *Ubuntu* (Nussbaum 2003).

The normative dimension of communitarianism is also reflected in the notion that the communal good is constitutive of the individual good, whereby the social norms of one’s community guide and constrain individual motivation and agency<sup>29</sup>. The attainment of social status, conceived of as personhood, depends on the extent to which individuals have undergone rituals of incorporation, participate in social life, and fulfil requisite obligations as determined by one’s social role<sup>30</sup>. African personhood thus represents a certain normative status that is acquired, not by mere birth, but over time, through the process of socialization and the fulfilment of social expectations within one’s community. A common admonishment in rural Kenya, for example, is ‘Behave like a person and people will treat you like one’ – suggesting that the status of personhood is contingent on one’s incorporation into the social good and can also be lost through forms of asociality and relational disconnection<sup>31</sup>.

iii) *The African ethical community*

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<sup>26</sup> See: Ikuenobe, P. (2006). *Philosophical perspectives on communalism and morality in African traditions*. Lexington Books.

<sup>27</sup> Mbiti, J.S. (1969). *African Religions and Philosophy*. Nairobi: Heinemann, 141.

<sup>28</sup> Menkiti I. (2017). *Community, Communism, Communitarianism: An African Intervention*. In: Afolayan A., Falola T. (Eds.) *The Palgrave Handbook of African Philosophy*. (461-473). New York: Palgrave Macmillan.

<sup>29</sup> Gyekye, Kwame. (1997). *Tradition and Modernity: Philosophical Reflections on the African Experience*. Oxford: OUP USA.

<sup>30</sup> Menkiti I. (2017). *Community, Communism, Communitarianism: An African Intervention*. In: Afolayan A., Falola T. (Eds.) *The Palgrave Handbook of African Philosophy*. (461-473). New York: Palgrave Macmillan; Presbey, G.M. (2002). *Maasai concepts of personhood: the roles of recognition, community, and individuality*. *International Studies in Philosophy*. 34(2), 57-82.

<sup>31</sup> Cf: Gyekye, Kwame. (2011). *African Ethics*. In Edward N. Zalta (Ed.), *The Stanford Encyclopedia of Philosophy* (Fall 2011 Edition), Retrieved July 27 2018, from URL: <http://plato.stanford.edu>

Closely related to the holistic and communitarian outlook is the belief in and practice of the African ‘ethical community’. Africans believe in the co-existence of and interrelationships between the supernatural and natural worlds, whereby both constitute an ethical community with humans at its centre. Moreover, all existents in this community, including those that are supernatural, are thought to exercise real agency in the natural and human worlds<sup>32</sup>.

The supernatural world is structured hierarchically and is comprised of an omniscient being, spirits, and ancestors. The one all-powerful and all-knowing being created everything that exists, be it material or non-material, including spirits, human persons (both living and the living dead – otherwise called ancestors) animals, and all within the natural environment. Known by different names in different communities across the continent, the omniscient supernatural being is generally thought to support and maintain good health. Personal and communal practices like rituals therefore have an important function in directly appealing to this being for the maintenance of good health<sup>33</sup>. The loss of health may likewise be associated with the agency of the omniscient being, of whose intervention may heal and restore health.

Supernatural spirits function as communicative intermediaries between humans and the omniscient being<sup>34</sup>. Functioning as both good and evil forces, their agency transmits good and evil in the human world. Good spirits are responsible for the maintenance of health and restoration of health, whilst some dis(eases), including mental illness, may result from the agency of evil spirits in response to unhealthy relationships among individuals or groups of individuals within the ethical community. Appeasing the spirits through personal and communal practices like rituals help maintain or restore good health. In addition,

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<sup>32</sup> Wiredu, K. (1996). *Cultural universals and particulars: An African perspective*. Indiana: Indiana University Press.

<sup>33</sup> Omonzejele PF. (2008). African Concepts of Health, Disease, and Treatment: An Ethical Inquiry. *The Journal of Science and Healing*. 4 (2): 120-126.

<sup>34</sup> Omonzejele PF. *Op. cit.* Note 23.

ancestors who Mbiti <sup>35</sup> calls the ‘living dead’ are community members who have died but remain in the memory of the living. Like spirits, ancestors can cause good or evil, with ill health, especially mental illness resulting from ancestors being angered or offended by the thoughts, actions, or speech of an individual person or entire community.

Supernatural agency is not confined solely to spirits, ancestors, or an omniscient being, but manifests itself also through witchcraft and traditional healing. Certain community members are thought to possess mystical and innate powers which manipulate natural forces to inflict harm on individual persons or groups through witchcraft<sup>36</sup>. Where sorcerers and witches inflict mental illness on a fellow community member, a traditional healer would be deployed to counter the effect of witchcraft and bring about healing<sup>37</sup>. Depending on the diagnosis, different preventive and curative treatments may be administered, drawing upon a variety of specialists: diviners help with diagnosis, whilst witchdoctors help with prevention and treatment, using special positive powers to counteract witchcraft related to poor social relations and restore health, or to mitigate causes of foreseen ill health. Herbalists will also be consulted if diagnosis indicates a physical or social cause of ill health.

This importance of maintaining the balance and health of both supernatural and natural parts of the ethical community has led to an emphasis on cultivating healthy relationships, with humans at the centre. Human relationships, as fundamentally part of an integrated whole, can disrupt the necessary balance between various constituents of the ethical community, with healthy relationships promoting life and good health and unhealthy relationships leading to dis(ease), contrary to life. Cultivating healthy relationships demands adherence to an elaborate ethics system with prescribed and prohibited behaviours,

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<sup>35</sup> Mbiti J.S. Op cit. Note 17.

<sup>36</sup> Middleton T. and Winter E. (Eds). (1970). *Witchcraft and Sorcery in East Africa*. London: Routledge and Kegan Paul.

<sup>37</sup> Mokgobi, M.G., (2014). Understanding traditional African healing. *African Journal for Physical Health Education, Recreation, and Dance*. 20 (2), 24.

encompassing one's thoughts, speech, and actions. For example, specific African communities have taboos around speaking about negative realities like mental illness: they believe that the very act of vocalising these negative realities could lead to afflicting oneself or those closely related with the very same condition.<sup>38</sup>

iv) *Parallel Beliefs in Biomedicine and Traditional Medicine*

African thought and practice contain an important dynamism between divergent explanatory and treatment models of illness. Belief in biomedicine, particularly for certain physical illnesses (such as malaria and the common cold) exists alongside the use of traditional medicine and appeals to the intervention of supernatural forces. Biomedicine refers to the dominant medical system that is based on Western science<sup>39</sup>, whilst traditional medicine draws on the 'theories, beliefs, and experiences indigenous to different cultures' in the prevention, diagnosis, and treatment of illness<sup>40</sup>. Delving deeper, traditional medicine views life as interconnected around a concept of *bios* or life in a more profound sense – intimately bound by 'the context of life [which] takes into consideration a sophisticated cycle of systems, all of which are geared toward providing wholeness and wellbeing to a person, a people, and their environment. This is because life, which embodies wellbeing or wholeness, has both physical and spiritual dimensions, and extends beyond any physical individual or group'.<sup>41</sup> Multiple causes of ill health in complex and chronic conditions therefore demand multiple approaches to healing. Many Africans will therefore seek biomedicine *alongside* traditional medicine. For example, a study on the use of traditional medicine in the

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<sup>38</sup> By implication, reluctance to speak about mental illness in these contexts presents inherent difficulties in the informed consent process, whereby translators would struggle to engage with potential participants to explicitly describe the objectives, procedures, and risks of a study as normally expected, let alone describe their symptomatology and subjective experience of living with disorder.

<sup>39</sup> Zank S, & N Hanazaki. (2017). The coexistence of traditional medicine and biomedicine: A study with local health experts in two Brazilian regions. PLoS ONE 12(4): e0174731

<sup>40</sup> WHO. (2013). WHO Traditional medicine Strategy 2014-2023. Retrieved November 15, 2018, from <http://www.who.int/medicines/areas/traditional/definitions/en/>

<sup>41</sup> Amenga-Etego. Op cit. Note 15, p. 114.

management of HIV and AIDS in western Kenya suggested that a significant number of people used antiretroviral therapy and traditional medicine either intermittently or simultaneously.<sup>42</sup> Likewise, in the case of mental disorder, individuals will seek traditional and spiritual forms of healing alongside biomedicine, given that the root of mental illness is often attributed to spiritual malfunction while the resultant psychiatric symptoms are recognised to respond to psychiatric medications<sup>43</sup>.

### *III. Practical Challenges of Translation*

Our discussion thus far clarifies how African understandings of disease causation and recommended interventions often differ from the Western biomedical framework, largely due to certain ontological and ethical commitments embedded in African thought and practice. By implication, significant practical and ethical challenges emerge when translation is attempted without the necessary prior engagement with the interpretive reality and conceptual schemas underlying the African worldview. Although language embeds an inherent communicative function, attempts to communicate across different cultures through translation can be severely limited, not least because the worldview expressed within language can differ in substantial ways. Language thus promotes certain experiences of illness and resultant distress whilst silencing others.<sup>44</sup> These challenges play out explicitly in the translation of psychiatric genomics research concepts, procedures, and nosology from English to local African languages. Not only do translations of psychiatric genomics terms

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<sup>42</sup> Kamaara Eunice, Atwoli L., Maithya h., Shitemi N. L., Nduru, G., Braitstein P., Inui T., Ayuo, P., and Folk, W.R. (2012). Holistic Healing: The Use of Traditional Medicine and Complementary Alternative Medicine (T/CAM) in the Context of HIV/AIDS in Western Kenya. *International Journal of Professional Practice*. 3(4), 342-355.

<sup>43</sup> Kpobi, L.N., Swartz, L. and Omenyo, C.N. (2019). Traditional herbalists' methods of treating mental disorders in Ghana. *Transcultural psychiatry*, 56(1), 250-266; Salifu Yendork, J., Kpobi, L. and Sarfo, E.A. (2016). "It's only 'madness' that I know": analysis of how mental illness is conceptualised by congregants of selected Charismatic churches in Ghana. *Mental Health, Religion & Culture*. 19(9), 984-999.

<sup>44</sup> Westermeyer, J., & Janca, A. (1997). Language, culture and psychopathology: conceptual and methodological issues. *Transcultural Psychiatry*, 34(3), 291-311.



often risk incoherence to the population they seek to reach, but they also raise difficult ethical questions about the legitimacy of informed consent.

*(i) Genetic scientific terminology and research procedures*

English scientific terminology is often difficult to translate to any African language because the substantive reality that these words describe either does not exist or is viewed differently. For example, none of the indigenous African languages have a word for *science* or *technology* which references the same semantic field, with all its constitutive epistemological assumptions and commitments which render those terms comprehensible in English. Rendered in Kiswahili, *science* and *technology* is translated into *sayansi* (science) and *teknolojia* (technology). Two notable features emerge here: first, English terms have been merely ‘indigenised’, making it questionable that basic translation has even taken place. Instead, new consonants and vowels have been introduced to the English terms so that the words appear like Kiswahili. Efforts have been made to mimic the English pronunciation, suggesting a literal rendering of the original terms rather than an exploration of ways in which potential Kiswahili words may capture (however imperfectly) parts of the semantic field of *science* and *technology*. Thus, to understand *sayansi na teknolojia* in Kiswahili presupposes a prior understanding of the English terms *science and technology*, essentially negating the need for translation.

Second, the creation of simple, new ‘indigenised’ terms fails as translation because it omits the prior and entirely necessary step of substantive engagement with cultural thought and practices.<sup>45</sup> As a result, the ‘indigenisation’ of terms can ignore ways in which standard scientific practices have altogether different meaning and normative significance. For example, the translation of *biological samples* is rendered in Kiswahili as *sampuli za*

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<sup>45</sup> Kong, C. Op. Cit. Note 4.

*kibiolojia*, yet not only would the phrase mean little to someone who is unfamiliar with the English phrase, but the very practice of taking bodily substance as samples remains foreign or is imbued with deeper cultural significance (such as the use of witchcraft). Likewise, linguistically equivalent African terminology currently does not exist for explaining the scientific procedures in psychiatric genomics studies. These difficulties include very simple procedures associated with collecting DNA from saliva (including certain restrictions on eating before drawing saliva or the storage of samples), let alone complex procedures (such as cell line immortalization and its related risks and benefits). For example, the purpose of extracting DNA from saliva or blood is often explained through translation as isolating the unique identifier of one's person.<sup>46</sup> Yet such a translation risks incoherence in a cultural context where personhood and the value of one's identity is bestowed over time through social relationships within the ethical community rather than through one's biological make-up or genetic heritage.

One way to overcome the absence of linguistic equivalents is for translators to draw from indigenous concepts in order to construct ways of describing these procedures. Yet these innovative descriptions share similar challenges to the 'indigenisation' of English terms, often misrepresenting the original meanings of concepts. For instance, broad sample sharing refers to the sharing of participant DNA with other scientific communities, yet to explain the process translators may draw upon normative practices and ethical concepts in the African philosophy of Ubuntu which refer to a much more expansive sense of sharing, one which emphasises the benefit and empowerment of others more generally. This appeal to such normative practices can have a profound effect on consent rates, as seen in a South African psychiatric genomics study sampling Xhosa speaking participations from the Eastern

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<sup>46</sup> Kong, C. Op. Cit. Note 4.

and Western Cape provinces.<sup>47</sup> Comparing the divergent consent rates between the two regions, Campbell *et al* suggested that participants from the Eastern Cape, typically more rural and traditional, may have been more likely to consent to sample sharing and cell line immortalization owing to the emphasis on the psychiatric healthcare benefits for later generations of the broader Xhosa community in the consent documents. In contrast to the more urban Western Cape, participants within the Eastern Cape may have more strongly interpreted this emphasis on sharing within an *Ubuntu* framework of interconnectedness through positive regard and humane and mutual assistance. This reveals the difficulty in determining to what extent this deeper understanding of sharing influences participants' decision to consent to broad sample sharing.

The use of metaphors is another common approach in describing unknown scientific procedures in genomic studies. According to O'Keefe *et al*<sup>48</sup> a metaphor is 'understanding and experiencing one kind of thing in terms of the other'. On one hand, metaphors are useful in human communication and can enhance affective and cognitive uptake of information; on the other hand, they can also misrepresent, oversimplify, or distort relevant information. Metaphors may impede communication because to effectively appreciate and interpret a metaphor, a target audience needs to have some meta-linguistic awareness.<sup>49</sup> In this context, meta-linguistic awareness refers to an implicit awareness that language functions also as artefact, that is, a reality that often has deeper meaning beyond the symbols or signs. In other words, the general meaning of words is fundamentally refracted through a people's orientation to the world. In many African contexts, the required meta-linguistic awareness

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<sup>47</sup> Campbell, M. M., de Vries, J., Mqulwana, S. G., Mndini, M. M., Ntola, O. A., Jonker, D., ... & Stein, D. J. (2018). Predictors of consent to cell line creation and immortalisation in a South African schizophrenia genomics study. *BMC medical ethics*, 19(1), 72.

<sup>48</sup> O'Keefe, M., Perrault, S., Halpern, J., Ikemoto, L., Yarborough, M., & Sciences, U. N. B. C. for L. & H. (2015). "Editing" Genes: A Case Study about How Language Matters in Bioethics. *The American Journal of Bioethics*, 15(12), 4.

<sup>49</sup> Goddard, C. (2004). The Ethnopragmatics and Semantics of 'Active Metaphors. *Journal of Pragmatics* (36):1211–30; Knudsen Susanne. (2005). Communicating novel and conventional scientific metaphors: a study of the development of the metaphor of genetic code. *Public Understanding of Science*, SAGE Publications, 14 (4), 373-392.

around psychiatric genomics may be lacking, and the reality being presented by a metaphor does not exist or may not be conceptualized within the people's worldview.

A good example of this difficulty would be the metaphor of book for DNA: in the comic books *Genome Adventure Blast*, the authors use the metaphor 'instruction books' to clarify the meaning of genes, explaining how 'our traits are determined by special instruction books in our bodies called genes. We look different from each other because our genes are different'.<sup>50</sup> Other book metaphors include reference to DNA as 'the book of life'.<sup>51</sup> Importantly, the metaphor of 'book' to an illiterate population is unlikely to make coherent sense to the intended audience, given how their daily reality does not include books: what is a book and what does it mean? And even further, what would be the function of an instruction book, or indeed, what would the 'book of life' refer to? The normative connotations around the metaphor 'book of life' are also significant: from some Christian perspectives, this refers to God's records of human moral deeds to be referred to on the day of judgement, recorded in both the Old and the New Testament (see for example, Ez. 9:4 & Rev. 3:5). Instead of suggesting gene manipulability, this normative orientation fundamentally would deny the notion that the human beings can read, write, and edit the essence of life. Similarly, the use of the term 'blueprint' is misleading and prone to misinterpretation in the same vein. According to Zwart<sup>52</sup>, this metaphor suggests that humans are masters of their own design and through gene editing, they can determine their destiny. Although the book or blueprint metaphors are meant to clarify and elucidate the meaning of an alien concept, using the same metaphors in a different cultural context may in fact obfuscate the meaning further, given the

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<sup>50</sup> Collaborative African Genomics Network (CafGEN), Genome Adventure Comic, Book 1: Blast to the past: Kitso explores heredity and genetics. Retrieved 22 February, 2019, from [http://botswanabaylor.org/genome\\_adventures.html](http://botswanabaylor.org/genome_adventures.html).

<sup>51</sup> Yohan J. John. (2015). If the DNA molecule is the book of life, it's a very strange book indeed. Retrieved November 15, 2018, from <https://www.3quarksdaily.com/3quarksdaily/2015/04/if-the-dna-molecule-is-the-book-of-life-its-a-very-strange-book-indeed.html>

<sup>52</sup> Zwart, Hub. (2009). Genomics Metaphors and Genetic Determinism. In Martin Drenthen; Jozef Keulartz & James Proctor (Eds.), *New Visions of Nature. Complexity and Authenticity*. 155-172.

absence of the metaphorical referent or corresponding normative orientation in the audience's worldview.

Hofmann, Solbakk, and Holm<sup>53</sup> highlight another instance where a metaphor may be confusing: reference to storage of biological samples as 'bio banking' elicits transactional connotations, suggesting a profit-driven practice which may cause many potential participants to withhold consent. The connotations surrounding the metaphor are fundamentally problematic in the African context given the continent's colonial and neo-colonial histories of Western exploitation. Misunderstanding of metaphors can then impede effective, and indeed, ethical descriptions of genomic technologies and its processes.<sup>54</sup>

#### *(ii) Psychiatric nosology and classification*

Genomic technologies are not alone in lacking linguistically equivalent terms in African languages: the diagnostic classifications of Western psychiatry are also notably absent. Traditional African perspectives and concepts on mental health resist the categorisations which persist in Western psychiatric nosology. Though mental illness may be associated with many causes, indigenous African perspectives often view it primarily as the manifestation of spiritual dis(ease), that is, the possession by evils spirits<sup>55</sup>. This means that mental illness is often referred to in the singular, as reference to the loss of mental health, directly translated to English as 'insanity'. Though technically manifesting one form of dis(ease), insanity is considered to be a continuum: in the Bantu language of Gikuyu, for example, a person who exhibits mental illness through hyperactivity (in thought, emotions,

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<sup>53</sup> Hofmann, B., J. H. Solbakk, and S. Holm. (2006). Analogical reasoning in handling emerging technologies: The case of umbilical cord blood biobanking. *The American Journal of Bioethics* 6(6):49–57.

<sup>54</sup> Maben, Alex. J. 2016. CRISPR Fantasy: Flaws in Current Metaphors of Gene-Modifying Technology. *Inquiries*. 8(6), 1-2; Bono, J. J. (2001). Why metaphor? Toward a metaphoric of scientific practice. In S. Maasen and M. Winterhager (Eds.), *Science studies: Probing the dynamics of scientific knowledge* (215–34). Bielefeld, Germany: Transcript.

<sup>55</sup> For example: Patel V. (1995) Explanatory models of mental illness in sub-Saharan Africa. *Social Science and Medicine*. 40(9), 1291–8.

speech, and action) is called *muguruki* (mad). At the extreme end of insanity is one who exhibits mental impairments through nominal speech and action. Such a person is said to be *kirimu* (a fool). Notably, the same term is used to describe persons who have hearing and speech impairments. Translators therefore often use a broad description of thought and emotional problems to counter the difficulties associated with psychiatric nosology and classification. But these descriptions can mislead participants as to the disorders under investigation and the extent to which these refer to their illness experiences.

#### *IV. Ethical Challenge of Informed Consent*

When considering all these examples of translation challenges we recognise the deeper ethical issues around the validity of consent in psychiatric genomics studies within the African context. As the core foundation of research ethics, informed consent has three essential elements: information, comprehension and voluntariness.<sup>56</sup> Whether the requirements of comprehension and voluntariness are fulfilled becomes questionable when the embedded meaning of linguistic terms deviates from the intent of the researchers. Do individuals genuinely understand and ‘freely’ consent if their decision is based on a superficial grasp of the procedures and overarching objectives of psychiatric genomics research? Or if their consent is based primarily on the consent forms’ unintended – and potentially distortive – resonance with indigenous conceptual and normative frameworks? Our discussion thus far highlights deeply problematic questions as to whether alternative – potentially misrepresentative – understandings of translated terms qualify as valid consent. We propose that these sensitive issues can be addressed by cultivating *attenuated forms of*

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<sup>56</sup> National Council for Science and Technology. (2004). Guidelines for ethical conduct of biomedical research involving human subjects in Kenya. Nairobi: NCST.

*translational thinking*,<sup>57</sup> which should form the basis of any attempts at translation. Such translational thinking describes an ethos towards the interpretation and understanding of external conceptual frameworks to oneself and one's own cultural tradition. Such thinking captures the preparatory work and necessary intellectual conditions *prior* to obtaining consent. Notably, clinical researchers and IRBs recognise the ethical imperative to avoid miscommunication<sup>58</sup> but neglect the intellectual orientation and ethical commitment that is precisely needed to foster cross-cultural understanding at a deeper level. Attenuated forms of translational thinking develop through the contextual, interpretive engagement with the different African conceptual schemas that underlie various practices. Such necessary engagement must precede any efforts at linguistic translation. This demands Western scientific researchers, translators, and bioethicists to critically reflect and situate *their own* conceptual frameworks and attendant values, as well as actively cultivate an intellectual orientation of humility, openness, and reciprocity towards alternative conceptual schemas. As Kong writes:

The willingness to be challenged and risk our own perspectives, an orientation of epistemic humility and openness to the truth contained in frameworks of others – are all prerequisites to cultivating this type of translational thinking. Such efforts are required to avoid mis-describing the experiences and social reality of people within the concerns of alien conceptual schemes as well as to challenge the complacency and inertia in our own ways of thinking.<sup>59</sup>

Such an approach to translation would call into serious question the mere 'indigenisation' of English terms, or the appeal to indigenous terms in a denuded, decontextualized manner

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<sup>57</sup> Kong C. Op. cit. Note 4.

<sup>58</sup> Faden and Beauchamp (1986); Bromwich and Millum (2015) and (2017).

<sup>59</sup> Kong C. Op. cit. Note 4, 107.

which fails to properly engage with the common salient features of African thought and practice that we have broadly schematised above.

Without doubt cultivating attenuated forms of translational thinking is a challenging intellectual ethos and requires concerted commitment. It moreover touches on foundational issues which we cannot fully explore here, such as the incorporation and validation of interpretive meaning as a legitimate scientific form of understanding human behaviour and experience,<sup>60</sup> as well as the critical evaluation of how cross-cultural comparisons are undertaken within the domain of mental health.<sup>61</sup> For our purposes, however, an ethos that incorporates such attuned translational thinking will have concrete implications in terms of how informed consent procedures are developed and applied within psychiatric genomics studies in African settings in three ways. First is the need to attend to the motivational question – to understand *why* individuals consent. Second, translators and psychiatric genomics researchers must acknowledge the possibility of divergent intent, where the motives of potential participants may suggest an entirely different normative orientation to that of psychiatric genomics research. Finally, the manner of developing and presenting research protocols for institutional ethics boards requires critical re-examination.

First, informed consent procedures are frequently regarded as an epistemological exercise that revolves around the person's requisite knowledge about the research, to make a decision about her participation. But this narrow focus loses sight of the crucial motivational question, where substantive values and commitments – either not referenced to in the consent form or evoked through entirely unrelated terminology – may motivate consent or non-consent.<sup>62</sup> Translational issues reveal the intimate connection between comprehension and

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<sup>60</sup> See Gadamer, *Truth and Method*; Kong C. op cit. Note 4.

<sup>61</sup> Kong C., M. Campbell, L. Kpobi, L. Swartz, C. Atuire, 'The Hermeneutics of Recovery: Facilitating Dialogue Between African and Western Mental Health Frameworks' (under review).

<sup>62</sup> Ajei, M. and Myles, N.O. (2019). Personhood, Autonomy and Informed Consent. In Y. A. Frimpong-Mansoh and C. A. Atuire (Eds.), *Bioethics in Africa: Theories and Praxis* (77-94). Wilmington: Vernon Press.



motivation. For instance, consider the threshold for comprehending the phrase, *sampuli za kibiojia* (samples of biology): attempts to explain *biological samples* as bodily substances would elicit deeper metaphysical and normative questions, particularly bound up with the issue as to whether ‘biological’ refers to material or nonmaterial substance. As suggested above, these questions are far from trivial: African perspectives attach material, religious, and spiritual meanings to blood or saliva which means the taking of these samples would be imbued with cultural significance. In theory, scientific researchers may attempt to narrow these meanings, adopting a purely designative approach to language so as to more aptly allude to its reductivist connotations in Western settings. The reality, however, is that appeals to reductive definitions refer to a framework of meaning that is fundamentally external to the indigenous culture of African participants. The gain in simple, like-for-like translation is a loss in coherent interpretive meaning and understanding for the populations such translation seeks to reach.<sup>63</sup> As a result, failure or success in obtaining consent are misattributed or misunderstood, focusing attention on superficial epistemic knowledge and understanding of scientific terms, when the spiritual implications of taking bodily substance may be more central to the motivation to participate or not.

Second, attending to the motivational question raises the possibility of divergent intent: the inherent challenge in translating the relevant terminology in psychiatric genomics studies reveals how a people’s normative orientation towards biology, nature, and genetic identity may differ in profound ways from the overarching objectives of such scientific research. Acknowledging this possibility may help foster more nuanced approaches to the absence of linguistic equivalences. For example, the concept of *genes* is absolutely essential to genomic studies. Though the meaning of the term seems self-evident in English, African research settings often lack any equivalent word or meaning in local languages. Researchers

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<sup>63</sup> Kong C. Op. cit. Note 4.

therefore often explain the concept to people without basic literacy through reference to indigenous concepts of inheritance and ancestry.<sup>64</sup> At first glance, this would appear to be an effective strategy, given the prevailing importance of family bloodlines and community within African thought and practice. Yet the Western scientific meaning of genes and African notion of inheritance reveals a fundamentally divergent normative outlook, thus generating further confusion amongst participants: not only does the communal conception of bloodlines resist the individualistic connotations of DNA (i.e. that these are unique identifiers of one's biological self), the value-laden meaning of ancestry and bloodlines in the African context likewise departs significantly from its reductivist connotations within the scientific framework. The concept of inheritance expresses a normative ethos which prioritises the sanctity and givenness of nature whereby that which is gifted by an omniscient being ought not to be tampered with – a view strongly at odds with the permissibility of gene alteration and manipulation in the Western context.<sup>65</sup>

Third, the ways in which research proposals and informed consent procedures are developed to achieve ethics approval demands critical re-examination. We have intimated that the translational problems in psychiatric genomics studies are symptomatic of deeper issues around divergent worldviews which resist simplistic like-for-like, designative terms. But these problems are amplified by the expectations of Institutional Review Boards (IRBs) which demand cross-cultural researchers to *first* develop research proposals and informed consent forms in non-indigenous languages (English, French or Portuguese) *then* translate these original documents to the local languages. This approach assumes precisely the possibility of like-for-like translation and more worryingly, suggests that such translational strategies are ethically warranted. Yet, as we have suggested here, the ethical justification for

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<sup>64</sup> Kegley, Jacquelyn Ann K. (2004). Challenges to informed consent and new developments in biomedical research and healthcare may mark the end of the traditional concept of informed consent: View point. *Science and Society EMBO reports*. 5(9): 24; see also: Collaborative African Genomics Network (CAfGEN). *Genome Adventures Comic*. Retrieved February 22, 2019, from [http://botswanabaylor.org/genome\\_adventures.html](http://botswanabaylor.org/genome_adventures.html)

<sup>65</sup> Kong C. *Op. cit.* Note 4.

this approach is far from clear. Instead, the presumption of IRBs must be critically challenged in order to facilitate much greater nuance in translational efforts, where research protocols must be developed *first* in local languages *then* translated into the foreign languages. Such an approach aligns well with global mental health thinking around culturally-sensitive translations and adaptations of psychiatric assessment instruments and mental health interventions.<sup>66</sup> An exemplary instance of this in the treatment rather than research context is The Friendship Bench project in Zimbabwe, whereby community mental health workers utilise their status, connectedness, and intimate knowledge within local communities and apply contextually sensitive approach to patients' distress such as *kufungisisa* ('thinking too much') and 'painful heart', developing strategies that are often 'masked' to outsiders.<sup>67</sup> Adopting similar strategies in the research context, the focus would be on engaging with the target community initially, understanding how they understand psychiatric illness and genetic attribution, becoming cognisant of local idioms of distress and how these relate to illness experiences, and then developing informed consent materials that align more closely with meaning-making frameworks already in place within the community.

An example helps illustrate our point here. First, at times, researchers might consider using a paragraph, a vignette or a story to translate an English phrase. For example instead of translating the sentence 'has bipolar' into '*ako na bipolar*' one might use two or more sentences: "*Ako na ugonjwa unaoitwa kwa Kingereza, 'bipolar'. Hii ni kusema kwamba, huwa ana hisi furaha mingi na punde si punde anahisi huzuni mingi. Inakuwa hisia zake sinabadilika kutoka furaha mingi au huzuni mingi kwenda huzuni mingi au furaha mingi*" (He has the disease called 'bipolar' in English. This is to say, he can feel very happy for some

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<sup>66</sup> Lund, C., Tomlinson, M., De Silva, M., Fekadu, A., Shidhaye, R., Jordans, M., ... & Thornicroft, G. (2012). PRIME: a programme to reduce the treatment gap for mental disorders in five low-and middle-income countries. *PLoS medicine*, 9(12), e1001359.

<sup>67</sup> Abas, M., Bowers, T., Manda, E., Cooper, S., Machando, D., Verhey, R., ... & Chibanda, D. (2016). 'Opening up the mind': problem-solving therapy delivered by female lay health workers to improve access to evidence-based care for depression and other common mental disorders through the Friendship Bench Project in Zimbabwe. *International journal of mental health systems*, 10(1), 39.

time and in a short while he feels very sad. His feelings can move from a lot of happiness to a lot of sorrow).<sup>68</sup> Translation therefore ought to be based on the metaphysical and epistemological orientations as well as the intersubjective interpretations expressed by the community targeted for research. Whilst the example here illustrate that the challenges of translation would not be eliminated, such a process would necessarily integrate a significant level of prior community engagement, treating attenuated forms of translational thinking as a necessity so that psychiatric genomics researchers begin with an enriched understanding of the African worldview, mitigating the dangers of conceptual imposition and in the process, enhance validity and reliability of consent.

Finally, an ethos of attenuated translational thinking raises difficult but fundamental questions about psychiatric genomics study design and protocols. We cannot address it here fully but can only gesture towards it as warranting future bioethical exploration. One important aspect of the ethos we are describing is the critical reflexivity of one's own conceptual schema and the cultivation of intellectual reciprocity. What often prevents more nuanced translational thinking is the devaluing and non-integration of more interpretive forms of knowledge within the prior development and presentation of scientific protocols – something that we think of as remiss if effective translation is to be achieved in the consenting process. Psychiatric genomics studies purport to examine the common genetic basis of human thinking and behaviour; yet there is an unavoidable collision of moral, epistemological, and ontological visions at play within cross-cultural studies. In no way are we suggesting that such research must cease on the grounds of the divergent conceptual

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<sup>68</sup> The current requirement by some IRB/RECs to complete Informed Consent templates with word limitations would therefore demand amendment. There is further question as to whether the supernatural or spiritual explanations of good and ill health can be incorporated in informed consent procedures. This raises very important issues but ones which we cannot resolve here. On one hand, we can see how incorporating these spiritual explanations could be an instance of engaging more fully with the reality of different African contexts. On the other hand, for most scientists the prospect of epistemically legitimating these metaphysical commitments within formal research procedures would be deeply problematic (and thus, represent an ethical dilemma from the perspective of those engaged in the research). Hence, we leave aside this issue, though do believe it to be worth further investigation. Our thanks to an anonymous reviewer for raising this interesting question.

schemas at play between Western and African frameworks, nor that translation is impossible, as clearly discussed above. But often the scientific examination, with its accompanying conceptual framework, is taken as truth, without the corresponding humility towards and engagement with what African conceptual schemas can contribute to our common knowledge and understanding of the phenomena concerned. Such a stance is unsustainable within the ethos we describe above – not simply due to how informed consent procedures may be ethically compromised in the process – but because it ignores the potential gain in knowledge and understanding that might be obtained through genuine cross-cultural understanding and reciprocity.

#### *V. Conclusion*

The translation of psychiatric genomics research terminology, research procedures, and explanations of psychiatric nosology faces difficult challenges. Although international psychiatric genomics researchers are constructing innovative ways of communicating in different cultural contexts, the danger of misrepresenting, oversimplifying and confusing relevant information remains nonetheless. These challenges are particularly acute in determining the validity and reliability of informed consent, whereby failure to properly engage with specific African linguistic contexts can fundamentally compromise consent procedures and potentially mislead individuals when participating in research.

Addressing the problem of translation requires rejecting the claim that language functions purely in a designative fashion, where it is used simply as an instrument to assign indigenous terms to scientific facts or things. Language is a constitutive medium that expresses our interpretive understanding, our shared conceptual schemas, values, and way of life which help make sense of our different modes of experience. The language of mental

disorder as experience, of genetic identity and inheritance, are therefore enriched with local connotations and meanings that vary depending on one's context. From this perspective the act of translation takes on a very different significance, far deeper than like-for-like designative attempts. Although research protocols of psychiatric genomics studies demand some degree of scientific accuracy, we suggest that the problem of translation demands a critical reappraisal of what constitutes ethically appropriate and responsible translational procedures as warranting ethical approval. Indeed, rendering scientific studies and its protocols first in local languages may be an important, innovative strategy to foster deeper intellectual engagement with and better understanding of the African worldview.

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