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Psychiatric Genomics: Ethical Implications for Public Health in Lower- and Middle-Income Countries

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Kong and colleagues (Kong, Dunn, and Parker 2017) explore how a genomic medicine approach may impact on the perceptions and treatment of psychiatric conditions, and set out an interdisciplinary, clinical ethics research agenda to investigate some of the concerns they identified. Their article offers a useful contribution to evolving ethics literature around the role of genetics and genomics in health care delivery, but a number of issues deserve further consideration. In particular, we want to ask: For whom does this paper set “the ethical agenda” in psychiatric genomics? Our arguments are based in a global mental health perspective, and focus on the implications of psychiatric genomics research and translation in low- and middle-income countries (LMICs).

Mental Health Stigma is Culturally Inflected

It is striking that Kong and colleagues’ review of the literature on stigma and genomics includes almost exclusively literature originating from high-income countries, when stigma is a major barrier for mental health services access and treatment in LMICs (Andrade et al. 2014). As such, the authors’ argument that a genetic focus on mental illness and neurodevelopmental conditions is unlikely to reduce stigma for patients with these conditions deserves reanalysis, or at least, a query as to its general applicability. As a substantial literature has shown, mental health stigma is strongly culturally inflected; preexisting explanatory models of disease; cognitive, emotional, and developmental norms; religious beliefs; and social adversity of different kinds can impact on interpretations of, and responses to, the signs and symptoms associated with psychiatric and neurodevelopmental

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conditions (e.g., Thornicroft et al. 2009; Girma et al. 2013; Shibre et al. 2003; Abbo 2011; Crabb et al. 2012; Hugo et al. 2003). It is likely that the impact of genetic attributions to those signs and symptoms will be subject to similar cultural inflections. Early results from ongoing research in South Africa suggest that genomic knowledge could play a role in reducing personal blame, particularly in cases where patients with schizophrenia blame an early episode of drug abuse for their condition. Moreover, explanatory models that include genomics might be protective against gender-based stigma in communities where neurological or psychiatric symptoms, such as epilepsy and autism, are associated with maternal behavior during pregnancy or with the supernatural (Baskind and Birbeck 2005; Elafros et al. 2013).

Few working in and around mental health would support genetic essentialist assertions (as Kong and colleagues point out). Neither should we accept a globalized assumption of the stigmatizing impact of such assertions (where such assertions are made). We agree with the first priority outlined by Kong and colleagues: More research in translational settings is needed; but we want to emphasize the need for empirical and ethical analyses that offer a wider view on the way cultural and national contexts may impact on the relation between genetic attribution, stigma, and mental health experience and practice.

The Active Consumer of Genomics is Not Everyman

Kong and colleagues draw on the sociological analysis of the biological citizen as a responsible, active consumer of genomic information to raise ethical concerns about self-understanding, accountability, overuse of psychotropic solutions, and ramifications for the therapeutic alliance with patients. While this critique has valuable theoretical implications, we are concerned that it has less empirical relevance in LMIC mental health care settings. We raise two examples here: First is the assumption of overuse of pharmaceutical medications and a broken therapeutic alliance. In many LMIC contexts, even though some progress has been made to close the treatment gap, mental health conditions still go largely untreated. To scale up treatment access and delivery requires establishing resources, including primary health care facilities, health care workers trained in the recognition and treatment of mental disorders, and access to basic psychotropics. One might argue that in such contexts, genomic medicine is unlikely in any case to have an impact, and we take the point. Genomic information—and indeed, the very possibility to be a responsible biological citizen even in the performative sense—might be said to be part of the privilege of a robust health care system. There is little concern about overuse of pharmaceutical medications and a broken therapeutic alliance where basic mental health services are so sparse on the ground.

This brings us to the second example, which imagines a future in which genomic knowledge is also available in LMIC mental health settings. Because resources for and access to mental health services in such settings can be unpredictable, some promises of genomic-based mental health are welcome: earlier intervention; stratified diagnoses; more efficient and effective treatments; and a shift in emphasis from mental disorder to mental well-being across the life course. These broader systemic implications of genomic research may play a critical part in strengthening the delivery of health care for mental health patients. In LMIC contexts, interventions are likely to focus on sustainable and scalable options, particularly

the use of task-shifting interventions (van Ginneken et al. 2011). Should genomic information ultimately impact on clinical interventions, there will be a need to assess whether nonspecialized health workers can be trained to use such information.

The incorporation of genomic knowledge in clinical settings is not free of ethical risk, and certainly concerns about maternal responsabilization, family accountability, and medicalization at a presymptomatic stage all need substantive empirical investigation. However these examples also illustrate the dangers of reifying genomic information, even in theoretical ethical analyses about developments in mental health. The biological citizen model imagines a consumer who acts on the basis of a genomic readout sitting in a consulting room of a mental health clinician. However, psychiatry tends toward a multifactorial view on risk and resilience. In LMIC contexts the importance of adapting assessments and interventions to be consistent with local explanatory models is necessarily paramount. Whether the addition of genomic information will singularly affect the ethical harm–benefit calculation in actual mental health delivery contexts should be viewed as an open question.

Genomic Approaches can Create Systemic Public Health Goods in LMIC

Kong and colleagues mainly focus on the potential impacts of genetic attribution on individual health care. However, in LMICs genomics research could ultimately impact positively on public, not individual, health (Tekola-Ayele and Rotimi 2015; Folarin, Happi and Happi 2014). As is true for much health research, genomics research also has the potential to generate evidence on (the nature of) a disease burden. It does this in part through its requirement for large sample numbers, which means that data collection normally happens across multiple health care centers across countries. The mere collection of genomic samples and data gives researchers greater insight into the epidemiology and manifestation of certain conditions. For example, in our ongoing work exploring the genetic architecture of schizophrenia in the Xhosa population of South Africa, we realized during recruitment that males far outnumber females in our cohort, presumably because many more males than females with Psychiatric Genomics and Mental Health Treatment schizophrenia seek health care in the public sector. We have now started exploring why that may be the case.

Finally, while we acknowledge that Kong and colleagues specifically focus on challenges relating to the translation of genomics research into health care provision rather than on those relating to conducting such research, it is important to highlight that clinical research is one key component of building and maintaining good, cost-effective health care systems (Lansang and Dennis 2004; Thornicroft et al. 2012). Not only does research help in the identification of causes of disease and effective (and ineffective) therapies, it also trains critical health care professionals who can assist in the translation of pertinent findings into appropriate national health care policies (ASSAF 2009). Genomics research in LMICs can potentially contribute to capacity building, allowing local scientists to engage with cutting-edge science and ensuring that any developments or new insights are also pertinent to LMIC patients. This is particularly important for mental health, for which the provision of care in LMICs is generally severely underresourced (Thornicroft et al. 2012). Global psychiatric

genomics research consortia, such as the initiative headed by the Stanley Centre at the Broad Institute of Harvard and MIT (Dalvie et al. 2015), have ethical obligations to ensure that global scientific partnerships include capacity-building opportunities, such as training and knowledge exchange. Such consortia also need to ensure that accompanying policies do not undermine the ability of LMIC researchers to meaningfully use genomic resources, and as far as possible need to consider opportunities for the translation of genomic knowledge into health care practice and policy (Parker and Bull 2015; Parker et al. 2009).

If a genomic focus on mental health leads to personalized medicine, then it is vital that such knowledge is relevant to psychiatric patients across the world. We fully accept that genomics research is not the most important form of research that would lead to immediate improvements in health care provision for such patients, but its potential for informing downstream policy development, understanding treatment efficacy, and understanding disease causation means that it is potentially one valuable component of ensuring the development of appropriate contextual knowledge about the nature of mental health and illness in LMICs.

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