Published in final edited form as:

Am J Bioeth. 2017 April ; 17(4): 27–29. doi:10.1080/15265161.2017.1284925.

Psychiatric Genomics and Public Mental Health in the Young Mind

Maya Sabatello, LLB, PhD

Dr. Sabatello is Assistant Professor of Clinical Bioethics, and Co-Director, Precision Medicine: Ethics, Politics, and Culture Project, Department of Psychiatry, Columbia University College of Physicians and Surgeons

Kong and colleagues consider the ethical challenges in translating psychiatric genomic research findings into clinical and public health settings. They discuss the promise of psychiatric genomic medicine in reducing mental health crises by identifying risk susceptibility genes and offering tailored preventative and therapeutic options but highlight two caveats about its individualized/empowerment discourse. First, that the rise of genomic responsibility—that is: the expectation that patients become informed about and act upon their genomic risks as “rational consumers” to maximize their mental wellbeing—would increase pharmaceutical-based rather than psychosocial interventions and clinicians’ punitive attitude towards patients who make genomically imprudent choices. Second, that the genomic “personalization” of psychiatric disorders would undermine successful public health interventions by diverting attention from socio-cultural-economic factors that impact mental health. Here, the authors mention children to emphasize the connection between adult psychopathology and childhood experiences of abuse and socioeconomic deprivation and the inadequacy of psychiatric genomic medicine in addressing the ethical and political issues associated with such trying upbringing. However, the article does not distinguish among children of varying ages or consider how different the complexities may be for adolescents (> 13 years-old). These distinctions are important given the growth of adolescents as genomic consumers; the challenges and opportunities arising at the intersection of adolescence and the uncertain nature of psychiatric genetics; and the ethical intricacies of delivering psychiatric genomic medicine to adolescents across demographic groups. This commentary considers these issues, focusing on asymptomatic adolescents.

The rise in childhood psychiatric disorders is one of the greatest challenges facing practitioners and health systems worldwide. In the US, studies indicate that 20% of adolescents have a diagnosable mental disorder, that most of them do not seek or receive treatment, and that the social, healthcare, and monetary costs associated with childhood psychiatric disorders commonly endure into adulthood. Addressing youth mental health problems—which will likely increasingly include psychiatric genomic medicine—is thus important for adolescents, families, and society.

Clinical, research, and market-based genetic testing already encompasses adolescents as genomic consumers. Studies demonstrate that adolescents with family histories of neuropsychiatric genetic disorders (e.g., Huntington's disease) are actively considering, and if possible, increasingly undertaking genetic testing (Sparkel et al., 2008). This trend will likely extend to more common psychiatric conditions once genetic testing with sufficiently high positive predictive power is developed. Adolescents also participate in longitudinal genomic studies that offer return of results, which, in the future, may include psychiatric findings. And, although no comprehensive data exists, it seems inevitable that adolescents' use of direct-to-consumers (DTC) genetic testing companies—some of which specifically target adolescents over age 13—will increase. With exceedingly low-costs of sequencing, adolescents (and their parents) who are concerned or just curious may find psychiatric genomic testing through DTC companies (once available) particularly appealing.

Paradoxically, however, the rise of adolescents' genomic consumerism has not been accompanied by a parallel increase in measures to empower—and protect—adolescents as consumers. Although studies indicate that adolescents' medical decision-making and knowledge of genetics are comparable to adults', their legal status is indistinguishable from that of young children: they do not commonly consent to genetic testing in clinical and research settings but their parents or legal guardians do (for discussion of relevant studies see, Sabatello and Appelbaum, 2016). This creates a troubling consumerism/agency gap that the genomic discourse does not address. Although adolescents' genomic data are available and could inform relevant preventative strategies, adolescents' ability to assume responsibility over their psychiatric genomic predispositions—as they are expected to gradually do in all contexts of their lives—is significantly curtailed. This consumerism/agency gap may be particularly frustrating for adolescents whose parents cannot provide consent, hold different views about testing or withhold the genomic results from them, against the adolescent's preferences. Involving adolescents in genomic-related decisions will enable better tailoring of preventative measures to the needs of adolescents at risk of developing psychiatric conditions and further advance the goals of psychiatric genomic medicine.

Concurrently, adolescents are particularly vulnerable consumers. Although genuine consumerism entails informed choices, adolescents as a group face unique challenges in developing genomic literacy: school curriculums about genomics, including gene-environment interactions are poor, and public initiatives are, generally, not adolescent-friendly (Dougherty, 2009). Adolescents are thus at heightened risk of drawing on inaccurate media reports about psychiatric genomics and being enticed by marketing campaigns of DTC companies—which are neither in the clinical nor public health business—that offer testing for “fun” and lack appropriate genetic counseling services to ensure that adolescent-consumers are indeed informed about the clinical, legal, and social implications of findings of genetic predispositions to psychiatric conditions.

The possible harms and benefits of psychiatric genomic medicine to adolescents require further consideration. As the authors mention, such assessment is also a leading aim of current translational public health approaches. However, how adolescents and parents of asymptomatic adolescents will respond to psychiatric genomic findings is under-studied. A

study of parents with bipolar disorder found that they are actively monitoring their children's moods, although coping with and acceptance of their children's risk was associated with endorsement of genetic explanations of mental illness (Landrum Peay et al., 2014). However, the outcomes of such parental monitoring and coping strategies on adolescents' development are unknown. One concern is that such monitoring—which may become overly-controlling the more stressed parents are about managing their own condition and mitigating their children's risks—would be detrimental to the adolescent's sense of self-identity and mental wellbeing. Another concern is that providing psychiatric genomic predisposition to asymptomatic adolescents would become a self-fulfilling prophecy or trigger a psychiatric crisis on its own. Yet another concern is that parents will be increasingly expected to extend their genomic responsibility to their children and pressured to actively reduce their children's psychiatric genomic risk by pursuing pharmaceutical-based interventions, also when clinical indication is lacking. Conversely, the finding that at-risk youth who underwent predictive testing for Huntington's disease found potential benefits from this knowledge (regardless of whether the results were positive or negative) (Sparkel et al., 2008) may be reassuring for psychiatric genomic medicine. Adolescents' understanding of the uncertain nature of psychiatric genomics and the moderating effect—for better and worse—of environmental factors on genetic vulnerability for psychiatric disorders can enable them to consider their genomic results as one among other uncertainties that they experience during this age period that are yet to unfold or, better: be acted upon.

Whether adolescents will translate psychiatric genomic knowledge into positive health behavior is unclear. Adolescence is often characterized by impulsive, risk taking behavior—which may be exacerbated by psychological distresses, including over genomic predispositions—and influence of peer pressure. But adolescence is also a period for developing long-term health behaviors. Importantly, small studies of adolescents and young adults further suggest that many are willing to make changes in response to data about genetic predisposition to psychiatric conditions (Tercyak et al., 2006; Schiffman et al., 2016). However, adolescents' ability to endorse tailored mental health coping strategies is stymied by acute shortage of providers, including genetic counselors who specialize in and are comfortable communicating about mental health disorders, especially psychiatric genetics, with this age group (Monaco et al., 2010; Duncan & Young, 2013).

These challenges are further exacerbated when adolescents' socio-cultural-economic characteristics are considered. As the authors highlight, socioeconomically disadvantaged children are at increased risk of developing psychiatric conditions and are especially vulnerable to the costs of the genomic personalization of psychiatric disorders. An unmentioned fact, however, is that such children are also overwhelmingly from racial and ethnic minorities and that under existing structures, they are the least likely to enjoy the benefits of translational genomic efforts. Because existing human biorepositories comprise mostly European-ancestry samples, the likelihood of identifying clinically relevant genetic variants that affect mental health risk or predict drug response is lower—even impossible—for racial/ethnic populations (Cohn, Henderson and Appelbaum, 2016). Underrepresentation of adolescents, especially those from racial/ethnic groups in pharmacogenomics and psychological therapies clinical trials further preclude them from enjoying tailored therapeutic benefits (Midgley et al., 2016). And, despite recent

improvements in adolescents' access to mental health services, adolescents from racial/ethnic minorities are still more likely than White adolescents to be uninsured or have insufficient coverage. Socioeconomically disadvantaged adolescents from racial/ethnic minorities are thus more likely to be without access to psychiatric genomic medicine, and worse, with an increased sense of disempowerment to mitigate their psychiatric genomic risks due to structural barriers of poverty and social exclusion that are beyond their control. Measures (and political will) to address socio-economic-environmental barriers that such adolescents experience are needed for the promise of psychiatric genomic medicine to be accomplished across the board.

It may be impossible—and undesirable—to stop the progress of psychiatric genomic medicine, making Kong and colleagues' call for a concurrent development of a multifaceted and ethical approach to translational efforts particularly salient. Adolescent-friendly practices are necessary, however, to ensure that adolescents are included in psychiatric genomic conversations. Indeed, the psychiatric genomic revolution should leverage the medical and health-behavior opportunities that are available to adolescents, and if delivered correctly, it can have an impact that would last for their lifetime. Increasing adolescents' genomic consumerism without providing appropriate education, supports, and empowerment mechanisms (which may not require full decision-making power) may cause more harm than benefit, especially among adolescents from socio-economically disadvantaged groups who are already disenfranchised in present psychiatric genomic medicine and public mental health programs.

Acknowledgments

This work was supported by NHGRI grants K01HG008653 and P50HG007257, as well as by Columbia Precision Medicine Initiative.

References

- Cohn, EG., Henderson, GE., Appelbaum, PS. Distributive justice, diversity, and inclusion in precision medicine: What will success look like?; *Genetics in Medicine*. 2016 Aug. p. 1-3. Available at: <http://dx.doi.org/10.1038/gim.2016.92>
- Dougherty MJ. Closing the gap: Inverting the genetics curriculum to ensure an informed public. *American Journal of Human Genetics*. 2009; 85(1):6–12. Available at: <http://dx.doi.org/10.1016/j.ajhg.2009.05.010>. [PubMed: 19559400]
- Duncan R, Young MA. Tricky teens: Are they really tricky or do genetic health professionals simply require more training in adolescent health? *Personalized Medicine*. 2013; 10(6):589–600. Available at: <http://dx.doi.org/10.2217/PME.13.49>.
- Landrum Peay H, Rosenstein DL, Bowles Biesecker B. Parenting with bipolar disorder: Coping with risk of mood disorders to children. *Social Science and Medicine*. 2014; 104:194–200. Available at: <http://dx.doi.org/10.1016/j.socscimed.2013.10.022>. [PubMed: 24581078]
- Midgley N, et al. The experience of adolescents participating in a randomised clinical trial in the field of mental health: a qualitative study. *Trials*. 2016; 17:364. Available at: <http://dx.doi.org/10.1186/s13063-016-1474-2>. [PubMed: 27465740]
- Monaco LC, et al. Exploring genetic counselors' perceptions of and attitudes towards schizophrenia. *Public Health Genomics*. 2010; 13(1):21–26. Available at: <http://dx.doi.org/10.1159/000210096>. [PubMed: 19321939]

- Sabatello M, Appelbaum PS. Raising genomic citizens: Adolescents and the return of secondary genomic findings. *Journal of Law, Medicine, and Ethics*. 2016; 44(2016):292–308. Available at: <http://dx.doi.org/10.1177/1073110516654123>.
- Schiffman J, et al. Attitudes towards cannabis use and genetic testing for schizophrenia. *Early Intervention in Psychiatry*. 2016; 10(3):220–226. Available at: <http://dx.doi.org/10.1111/eip.12164>. [PubMed: 24957110]
- Sparbel KJH, et al. Experiences of teens living in the shadow of Huntington Disease. *Journal of Genetic Counseling*. 2008; 17(4):327–335. Available at: <http://dx.doi.org/10.1007/s10897-008-9151-6>. [PubMed: 18347962]
- Tercyak KP, et al. Interest of adolescents in genetic testing for nicotine addiction susceptibility. *Preventative Medicine*. 2006; 42(1):60–65. Available at: <http://dx.doi.org/10.1016/j.ypmed.2005.09.007>.