COMMENTARY | Genetics inMedicine

Pushing the envelope in genomics education

Bruce R. Korf, MD, PhD[1]

The lack of preparedness of health providers and the public to interpret and utilize genomic information is widely recognized as one of the major obstacles to the integration of genomics into health care. An innovative approach to genomics education, as described by Sanderson et al.,[1] is therefore to be applauded. I admit, however, that the article also left me uneasy about their approach.

Sanderson et al.[1] present the results of a set of questionnaires administered to 19 students who participated in an advanced genomics course in which they were offered the chance to have their genomes sequenced at no charge. The point of the exercise was for them to analyze their own data, unless they preferred to work with anonymized data (which none did). The students, who had previously taken an introductory genomics course, included five genetic counseling students, three medical genetics residents, a genetics fellow, and two junior faculty who use genomics in their work; hence most had some background in genetics or genomics. Genetic counseling was not automatically provided, though it was available (two indicated an interest in receiving counseling though at the time of writing had not done so).

The rationale for this approach was derived from self-determination theory, which is a theory of human motivation that can be applied to many areas, including education and health care.[2,3] The theory emphasizes the importance of autonomy as an important factor in maximizing engagement and the effectiveness of an experience, such as an educational experience. The authors also reference a paper in *JAMA*[4] that highlights the importance of achieving autonomy in residency training; that is, the goal of training is to achieve the ability to practice without supervision.

I find it easy to see how the opportunity to analyze one's own genome would be motivational and engaging, and this is indeed what the surveys of participants revealed. So why did this make me uneasy? Two issues come to mind.

First is the obvious possibility that a student may learn something he or she is not prepared for, with resultant anxiety, distress, and possibly even risk of making an unwise personal decision based on misinterpretation of the data. Sanderson et al.[1] acknowledge this risk, and measuring distress was one of the goals of the surveys. They also note that the analysis was viewed as an educational experience, not a clinical one, and emphasized that results should not be used for clinical decision making. Only one student reported significant distress, attributed to finding a variant that might be associated with Brugada syndrome upon analyzing the data after the end of the course (the data remained available to the students), though ultimately the variant was determined to be benign. If this educational approach is used on a wider scale, some students certainly will learn things that predict serious illness in the future, such as cancer or heart disease. They will surely learn much about how to empathize with a patient who might be in a similar situation in the future, but the price they pay for this educational experience might be too high for some. They could opt out of participating, assuming there is no pressure to participate, but I suspect that at least some will opt in and later regret doing so. It could be argued that they will gain more in terms of awareness regarding future health care than they will lose in terms of a sense of well-being. That might be true, assuming that the finding is associated with an action that can modify their risk or improve outcome. No mention of limiting the analysis to such variants was made in this paper. If even a very small subset of students experiences a severely adverse psychological reaction to information derived from testing in circumstances that are removed from a clinical context it will not leave a good taste. Indeed, our field has already grappled with this very question. There was a day when it was common for students to learn cytogenetics by analyzing their own karyotypes. This practice was uniformly abandoned because of cases where students were faced with unexpected karyotypic abnormalities that raised issues regarding their own health or reproductive planning or that of family members.

This concern could be construed as paternalistic, in contradiction to the principle of personal autonomy. I am not questioning here whether an individual should or should not have access to his personal genome if he wants it. The question is whether educational institutions are prepared to provide adequate support to students who experience distress while participating in an educational activity. I do not believe that disclaimers about not using the data for clinical decision making will ameliorate this risk.

My other concern arises from a different interpretation of the concept of "autonomy." Are we teaching these students to be competent to interpret genomic data without supervision? Is

[1]Department of Genetics, University of Alabama at Birmingham, Birmingham, Alabama, USA. Correspondence: Bruce R. Korf (bkorf@uab.edu)

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the intention to teach that access to counseling in the interpretation of genomic data in a health-care context is dispensable? I don't doubt that the students would have received an intense experience in the analysis of genomic data. I do doubt that the experience models an approach to analysis that would be used in a clinical situation.

I have said that the article made me uneasy, and uneasy means, well, uneasy. I'm not sure it is a good approach that should be emulated, and I'm not sure it is a bad one that should be shunned. I applaud the authors' willingness to innovate and to measure the outcomes of their efforts. Upon reflection, maybe it's okay to be left uneasy. Genomics has the potential to drive innovation, and if innovation does not leave us somewhat uneasy, maybe it isn't being pushed far enough. We should be prepared to have long-held assumptions challenged and new approaches tested. Some of these will survive and propagate, others will not. As long as those that fail do not leave serious damage in their wake, this notion should be very familiar—even comfortable—to geneticists. Moreover, such educational innovations provide a research opportunity to explore the potential harms and benefits as we seek a path through this new world of medical genomics.

DISCLOSURE

The authors declare no conflict of interest.

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