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Personalized Genomic Educational Testing: What do the Undergrads Think?

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Despite the increasing number of published papers examining the use of personalized genomic educational testing (PGET), including the target article by Callier (2012), there are no published studies surveying the views of undergraduate students towards this technology and its possible use in their classrooms. To address this lacuna in the literature, I recently completed an IRB-approved study to assess the knowledge, attitudes, and concerns of college students enrolled in an introductory majors course in biology at Providence College regarding the use of direct-to-consumer genetic testing in the college classroom (Austriaco, *submitted*). Using a survey instrument modeled after the questionnaires developed by Ormond et al. (2011) and by McGuire et al. (2009), I solicited responses from the 183 students (mean age 18.2 years, 28% male, 79% freshmen) enrolled this past fall semester in the first semester course of a yearlong introductory majors sequence in biology in my home institution. One hundred and eighteen students completed my survey (64.5% response rate).

When the University of California at Berkeley decided to ask its incoming freshman and transfer students to submit a DNA sample for personalized genetic testing as part of its annual new-student orientation program, the proposal generated a heated debate surrounding three ethical issues: obtaining informed consent without coercion, protecting student privacy, and preparing students to properly interpret the results of their genetic tests (Jabr 2011). Similar concerns could also be levied against proposals to incorporate direct-to-consumer genetic testing in the undergraduate classroom. My survey solicited responses within each of these ethical areas of concern.

First, commentators were worried that the incoming UC Berkeley students could not give proper informed consent because they lacked the knowledge that they would need to adequately assess the benefits and burdens associated with direct-to-consumer genetic testing (Sanders 2010). It is clear that the introductory biology students who participated in my study had limited knowledge about direct-to-consumer genetic testing. A large number of the college student respondents (71%) were unaware that direct-to-consumer personalized genetic tests were already available to the public. This is not surprising since surveys of the general public have revealed that a majority of respondents were similarly not aware of this technology. (Goddard et al. 2009; Kolor et al. 2009). Any proposal to incorporate direct-to-consumer genetic testing in the undergraduate classroom will have to include ways to introduce prospective student participants to this technology prior to their giving or withholding of consent. This information needs to be provided not only to students but also to their parents -- it is striking that a not insignificant number of students (34%) acknowledged that they would seek out parental guidance and permission before deciding to participate in an in-class genetic test -- either the semester before or during the summer prior

to the beginning of the course. It should include descriptions of the benefits, the risks, and the limitations associated with personalized genetic testing.

Next, commentators were also worried that the incoming students at UC Berkeley could have experienced some coercion when they were asked to participate in the direct-to-consumer orientation activity (Jabr 2011). This would have impaired their ability to give consent freely. The coercion could have been experienced in at least three ways. First, the new students could have experienced pressure to participate in the genetic testing program because they were aware that their participation would impress or influence their professors. Next, the freshmen could have experienced peer pressure to participate because they may not have wanted to be left out of any of their orientation activities. Finally, the opportunity to take a test that normally involves significant costs without payment -- the genetic tests were made available at no cost to the Berkeley students -- could have unduly pressured students to take the test despite concerns about their participation.

The results of my survey revealed that about half of the undergraduate study participants who responded to the questionnaire were not concerned about whether or not their professors (48% Strongly agree or agree) or their peers (51% Strongly agree or agree) would know about their involvement in the genetic testing. Despite this, it is clear that the remainder of the potential participants would still be worried to some degree that their professors and their peers would know if they chose to participate or to forego the genetic testing. These students could then experience some coercion that could impair their ability to give consent freely. As for financial coercion, the survey also revealed that a significant majority of the respondents (72% Strongly agree or agree) would see their participation in the personal genomic testing as an opportunity to get a service for less than its original price. This suggests that any efforts to incorporate direct-to-consumer genetic testing in the college classroom should include a nominal fee for participants to mitigate any undue pressure they may experience from financial exigencies. Though UC Berkeley offered the genetic testing to its students without a fee, Stanford University asked its medical and graduate students to pay ninety-nine dollars to have their genotypes analyzed by the personalized genomics company (Jabr 2011).

Next, several commentators were concerned that the privacy of the incoming UC Berkeley students would not be respected by the personalized genomics testing companies (Jabr 2011). Of note, a large majority (64% Strongly agree or agree) of my undergraduate survey respondents would permit a personal genome testing company to include their de-identified sample in scientific research. However, it is not clear if this permission is based upon an informed decision since many of them do not appear to understand the potential benefits or drawbacks of their involvement in research with this -- for many of them, still unfamiliar -- technology. Thus, any proposal to incorporate direct-to-consumer genetic testing in the college classroom should include efforts to inform potential participants about all the foreseeable consequences and possible risks arising from their participation in long-term research programs conducted by a personal genome testing company, risks clearly described by Callier in her target article.

Finally, commentators were worried that the UC Berkeley students would not know enough about personal genomics to properly interpret the results of their genetic testing. This concern arose despite the limited scope of the testing: As Callier has noted, the Berkeley orientation project would have only involved genetic testing for three nutritional genes involving in the body's ability to metabolize alcohol, lactose, and folates. In contrast, direct-to-consumer tests screen a battery of genes, many involved in human disease, some of which do not have a known cure or remedy. Will undergraduate students be able to properly

interpret the probabilistic data linking numerous disease genes to their future health prospects?

Strikingly, the results of my survey suggest that the inability of college students to understand their test results is indeed a legitimate concern. A large number of the undergraduate respondents (66% strongly disagree or disagree) did not think that they knew enough to understand the results they would receive from a personal genome testing service. Coupled with this, a majority of students (55% Strongly agree or agree) were concerned that they may get genetic results that may be disturbing for themselves or for their families. Thus, it is not surprising, that nearly all (96% strongly agree or agree) intend to ask a physician to help them interpret the results of their personal genome test, and a similar number (92% strongly agree or agree) wanted personal genome companies to have a medical expert to help them to interpret their results. However, as numerous studies have discovered, many of these primary care physicians have neither the expertise nor the time to accurately interpret personalized genomics test results (Baars et al. 2005; McGuire and Burke 2008).

In sum, my study revealed that the college students who participated in the study are willing to use this technology, but that they also had concerns about the reliability, the confidentiality, and the interpretation of their genetic test results. The survey confirmed the legitimacy of many of the ethical concerns raised by Callier and others. As such, the pros and cons of such a curricular novelty would have to be considered by faculty and administrators with broad multidisciplinary representation to ensure that these concerns are adequately addressed.

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