



Personalized Genetic Testing as a Tool for Integrating Ethics Instruction into Biology Courses

Tenny R. Zhang* and Misti Ault Anderson

Presidential Commission for the Study of Bioethical Issues, Washington, DC 20005

Personalized genetic testing (PGT) has been used by some educational institutions as a pedagogical tool for teaching human genetics. While work has been done that examines the potential for PGT to improve students' interest and understanding of the science involved in genetic testing, there has been less dialogue about how this method might be useful for integrating ethical and societal issues surrounding genetic testing into classroom discussions. Citing the importance of integrating ethics into the biology classroom, we argue that PGT can be an effective educational tool for integrating ethics and science education, and discuss relevant ethical considerations for instructors using this approach.

INTRODUCTION

As science and technology advance—providing health, medical, and social benefits to much of society—the ethical considerations related to how society uses these advances become apparent. For example, progress in genetic sequencing technologies has led to improved diagnosis, and in some cases treatment, of certain medical conditions. However, these advances also have raised ethical questions, including when to report increased genetic risk of conditions with no treatments or late onset, and how to protect individuals' privacy in large-scale genetic data-sharing environments, among others (14). Important societal questions such as these need to be considered and addressed by the public and informed by the scientists most familiar with the technology.

Recently, personalized genetic testing (PGT) has been used by some educational institutions as a pedagogical tool for teaching human genetics. Citing the importance of integrating science and ethics, we argue that PGT can be an effective educational tool for incorporating ethics into the biology classroom, and provide suggestions for instructors using this approach.

Integrating science and ethics

There is consensus among science educators that it is necessary to educate students about the ethical and societal consequences of science to produce well-informed citizens

and future scientists (4). Current students will come of age in the genomic era, and their decisions will likely affect how personal genetic information is viewed and used in society; it is important to ensure they understand the scientific concepts and the ethical, legal, and societal issues related to genetic information, creating a “significant educational need for both the scientific and ethical aspects of genetics” (10).

This need can be addressed in part by integrating ethics into undergraduate and graduate science courses directly, for example, by incorporating discussion of relevant ethical considerations into biology and genetics courses. The Presidential Commission for the Study of Bioethical Issues asserts that bioethics is “fully consonant with a liberal arts and sciences education,” and emphasizes the need to develop and evaluate models and curricula that integrate bioethics and science education at all levels of education (13, 15). Just as it takes students years to learn the language and concepts of science, students require adequate time to learn the vocabulary and foundational principles of bioethics and develop ethical reasoning skills (12). To this end, ethics can be integrated throughout the science curriculum, exposing students to relevant bioethical issues each semester through case studies, discussions, or assignments that supplement course materials, and giving students the opportunity to build their ethical fluency (27).

Integrating ethics into existing undergraduate curricula does not sacrifice scientific content, but rather enriches it. Advantages to incorporating bioethics into science classes include the potential to spark student interest in both science and ethics, and the opportunity to teach students how to “make direct connections between what is being learned in the classroom with the bioethical challenges that are being presented in the public press and in professional journals” (12). This enhanced analysis prepares future scientists and policymakers to deal with ethical questions, increases awareness among future health professionals about the

*Corresponding author. Mailing address: Presidential Commission for the Study of Bioethical Issues, 1425 New York Ave NW, Washington, DC 20005. Phone: 202-233-3960. Fax: 202-233-3990. E-mail: Tenny.Zhang@bioethics.gov.

importance of ethical judgments, and enhances the scientific and ethical literacy of college-educated citizenry (27).

Many have argued that educators have a responsibility to expose students to diverse perspectives on course content, and that consideration of relevant ethical and societal issues broadens students' views and allows them to think about the implications of the science they study (4, 7, 21, 23). It is important that students considering careers in science and health care are able to apply basic ethical principles to address and contribute to the resolution of current and future bioethical concerns (12).

While early integration of ethics and science in education provides exposure to the principles that inform ethical reasoning—which helps students build skills to address ethical issues in future professional life—undergraduate science courses seldom address ethical questions and principles (24). One survey of core requirements for undergraduate biology programs at 104 colleges and universities found that none included a bioethics requirement (27). Another survey of introductory genetics instructors found that only 13% of undergraduate institutions in the United States require ethics for biology majors, and only a third of those require an ethics of science course (4). In the same survey, although 99% of instructors indicated a belief that students should be exposed to ethical issues, and 55% felt this should take place within the science classroom, most instructors reported spending less than 5% of class time on ethical issues (4).

Instructors can integrate ethics into regular coursework and minimize time lost to scientific content by selecting topics closely aligned with the syllabus (7). One strategy is to incorporate ethical concepts into discussion of real-world applications of the science being taught, which helps contextualize ethical concepts and guidelines, since their interpretation relies on situational details (18).

An area in which this integration method can be applied is genetics: as the scientific field evolves, education addressing relevant ethical and societal issues is needed to complement the growth of genetics education (8). Scholars suggest that considering relevant ethical issues engages and motivates students to learn more about genetics (10). For example, an instructor might teach a module simulating genetic testing, including consent forms and relevant regulations about informed consent to prompt consideration of ethical issues (7). A simulation module helps students to “consider case studies that raise the ambiguities faced by genetic counselors and physicians” (7).

Some instructors and educational institutions have begun conducting genetic testing with consenting students to generate real-world experiences using technology relevant to course content. Facilitating PGT, whether conducted in an academic or commercial laboratory, can increase student interest in course content, but educators have a responsibility to teach students about the many facets of genetic testing, including the interpretation, limitations, and potential impact of genetic information (21, 23). Although this obligation has been articulated, more evidence and guidance are needed for

how instructors using PGT in their teaching can integrate ethics into their classes.

Personalized genetic testing in the educational setting

Decreased cost and increased accessibility has enabled a growing number of colleges and universities in the United States to offer PGT in courses at the undergraduate, graduate, or professional school levels, including colleges at Pennsylvania State University, University of California, Berkeley, and University of Rhode Island; schools of medicine at Harvard University, Mount Sinai, Stanford University, and University of Pennsylvania; schools of pharmacy at Ohio State University and Temple University; and the school of nursing at Duke University (5, 6, 7, 11, 25).

There is ongoing discussion about the ethical implications of pursuing this pedagogical strategy (5, 19, 21, 23, 26). Many have raised issues of student vulnerability and coercion and concerns as to how to ensure fully informed consent in the classroom PGT process (5, 19, 21, 23). Learning about disease risk might cause psychological harm, and require schools to provide genetic counseling services. Maintaining privacy and confidentiality is important as students access personal genetic information and engage in open classroom discussions (19, 21, 23, 26). Some also have discussed issues of justice and fairness, including the cost and accessibility of PGT for students (19, 21, 23). The literature on PGT as a pedagogical tool focuses on undergraduate and higher levels of education rather than the high school level. The strategy might be less appropriate in high school classes due to the ethical implications of PGT and additional challenges inherent to obtaining parental permission and child assent to participate.

One way schools have offered students access to their own genetic information is through the use of direct-to-consumer (DTC) genetic testing services. Although a recent U.S. Food and Drug Administration action might curtail DTC genetic testing as it relates to health information, genetic testing delivered through medical professionals will continue and grow (28), offering new avenues of incorporating PGT into the classroom and raising additional issues. For example, if future PGT requires a physician order, must students visit their own doctors? Will there be a separate “referring physician” affiliated with the class? And what level of involvement should clinicians have in the course?

Instructors of courses incorporating PGT suggest that students who undergo self-testing might benefit more from lessons and gain a better understanding of the science (5, 22). By having their own DNA analyzed, students gain a personal stake that might encourage them to engage more deeply with the material (5, 25). Several studies examining the use of PGT in classrooms support these claims. In one survey, students indicated they were more likely to enroll in a genetics course if it offered PGT (60.2%), and that personalized course material is more interesting (94.6%) and easier to learn (87.3%); professors agreed that adding PGT

increases student interest, participation, and learning (6). Another study surveying PGT's impact on student learning found that the method enhanced both self-reported and assessed knowledge of genomics (20). Interviews conducted with students who chose to undergo PGT indicated that it could improve students' self-reported motivation and engagement with course content (25).

These findings are important in light of calls to enhance genetic literacy among students and young adults (8, 10). However, PGT also might be an innovative and useful tool to integrate ethical discussion and learning, in response to parallel calls to educate students on the ethical and societal aspects of genetics (7, 8, 10, 19, 23). Done well, PGT in the classroom might increase knowledge about viewing genetic information critically, help students make better use of such technologies in the future, train them to recognize the limits and benefits of genetic testing, and engender consideration of the broader ethical implications of genetic testing (5, 6).

Suggestions for incorporating ethics into personalized genetic testing courses

Educating students about ethical and societal issues surrounding genetics should be an essential part of PGT in the classroom, given the personal nature of these exercises (23). For instructors considering PGT in their classes, previous courses provide informative lessons and helpful examples of ways to integrate ethics. The following suggestions for integrating ethics into PGT courses can be applied broadly at the undergraduate, graduate, and professional school levels.

1. Consider ethical issues in the planning stage, with multidisciplinary input. The incorporation of PGT into classrooms deserves thoughtful discussion within the academic community (26). A multidisciplinary approach to course planning, perhaps undertaken by a high-level committee or task force, can anticipate and address the ethical issues incumbent in offering PGT in a classroom setting (25, 26). A diverse group including scientists, clinicians, genetic counselors, psychologists, bioethicists, legal counsel, and students should be consulted (1, 2, 5, 22). Such a committee could evaluate explicitly the ethical issues raised by PGT in the educational setting and propose safeguards. In addition, the committee could offer advice on specific approaches for integrating ethics into the course.

For example, when Tufts University School of Medicine conducted this type of deliberative process, the multidisciplinary faculty group recommended a smaller pilot course that would meet regularly to discuss topics including ethical issues and scientific limitations of PGT, early engagement with the institutional review board, and curriculum committees to explore ways to enrich educational content with a discussion of benefits and harms (26).

Similarly, the Icahn School of Medicine at Mount Sinai assembled a multidisciplinary group of experts in genetic

counseling, medical genetics, health psychology, and bioinformatics to develop a genomics course in which students, residents, and fellows had the option to access and interpret their whole genome sequences (22). Stanford School of Medicine also convened a diverse task force comprising faculty in genetics, genetic counseling, law, ethics, education, and clinical departments to evaluate its course before implementation, considering ethical issues and crafting safeguards which led to its approval; the course gave students the option to have their genomes sequenced by DTC genetic testing companies (3, 21, 25).

2. Include diverse faculty and pedagogical resources in the course curriculum. Including faculty in law, bioethics, genetic counseling, and other fields can be an enriching educational experience, and is a practical way to integrate ethics into the biology classroom (12). Parts of the Stanford University course were taught by a clinical geneticist, a genetic counselor, and a bioethicist and lawyer (20). This approach also can help address science instructors' concerns about lack of preparation for teaching ethics.

Instructors might consider using outside resources to supplement faculty-led lectures. For example, students in the Stanford University course screened *In the Family*, a documentary about a woman's struggle to cope with her BRCA test results (21). In addition, the Presidential Commission for the Study of Bioethical Issues has developed publicly accessible pedagogical materials to facilitate ethics integration, including modules on informed consent and a guide to incidental findings for consumers of DTC genetic testing services, which might help instructors guide discussion on consent in genetic testing (16).

3. Dedicate sufficient class time for structured discussion of ethical issues throughout the course. Instructors should dedicate time for discussion of ethical issues surrounding PGT. Structured, faculty-led discussion is important to facilitate a basic understanding and subsequent application of ethical principles; students should be encouraged to participate actively in classroom dialogue (12). The first lecture of the Icahn School of Medicine course focused on ethical and societal issues in genetic testing, and another lecture covered accuracy of results and informed consent in genetics (22). The Stanford University course included two weeks of instruction and discussion about the risks, benefits, uses, and limitations of PGT to provide students the necessary background to make an informed decision (20, 21).

Topics for discussion include those identified by the Stanford University task force: confidentiality, conflicts of interest, coercion, informational risks, informed decision-making, financial accessibility, genetic counseling needs, and the experimental nature of the course offering (25). At Stanford University, the debates that started in the high-level review percolated into the classroom, as faculty presented arguments for and against PGT to students (5); such "deliberation and debate could very well be the best way to

thoroughly explore the many ethical issues raised by [PGT] and to engage students in thinking about this controversial and cutting edge application of genomics” (5). Courses also could address foundational ethical theories and the regulatory landscape of genetic testing (7, 24).

These topics are more extensive than what is typically covered by research or professional ethics courses. For example, a Pennsylvania State University course gave undergraduates the opportunity to undergo genetic sequencing using a commercial DTC testing service and addressed research ethics as a lecture topic, but the course syllabus does not mention ethical or societal issues of genetic testing (17). Similarly, Temple University School of Pharmacy offered a laboratory course allowing students to extract their own DNA and perform genotyping analysis; it taught students the ethical aspects of collecting and handling genetic information, but not the broader ethical considerations of PGT (9).

It is important to introduce ethical and societal considerations and scientific limitations before students decide whether to get tested, as studies have indicated that students’ informed decision making can be influenced and enhanced by these discussions (1, 2, 20, 22). However, it also is useful to integrate broader discussions of ethical and societal issues throughout the course—before, during, and after students undergo PGT. Sustained engagement is important, as ethical issues arise at each step of the PGT process.

4. Assess students’ ethical awareness and reflection, and evaluate integrated courses for effectiveness. Instructors should consider formalizing the consideration of ethical and societal issues as a course objective, and include ways to evaluate learning in student assessments. One way to measure awareness of and engagement with bioethical issues is through a writing assignment, in which students can reflect upon relevant issues and how consideration of these issues influenced their decision of whether to undergo testing (19, 23, 24).

Many have called for additional research on PGT as an educational tool to confirm its effectiveness and better understand student perspectives (6, 20, 21). However, these calls have not emphasized evaluating the pedagogical usefulness of PGT for teaching ethics. The few existing studies focus primarily on whether PGT enhances scientific understanding or whether students made informed decisions regarding self-testing, and research is limited to the medical or graduate school contexts. For example, while post-course surveys at Temple University indicated increased student comprehension of the relevance of genetic analysis (9), and student questionnaires at the Icahn School of Medicine indicated that providing introductory education about genetic testing might facilitate informed decision making (22), neither assessment addressed whether students gained a deeper understanding of ethical and societal issues.

A Stanford University study offers one example of post-course evaluation which includes ethical issues in open response questions (25). Interviews with students who

chose to undergo PGT indicate that using personal genetic information motivated learning; the course provided them with insight into what future patients might experience; they thought more deeply about the risks and benefits of testing; and they benefited from reflecting on ethical and societal issues presented in class (25). Students valued discussion of ethical issues because it “allowed them to consider dimensions to their decision that they had not identified prior to the course” (25). These responses suggest that using PGT in an educational setting can help students gain a greater understanding of broader issues related to genetic testing (25). Combined with another study reporting improved grasp of biological concepts by students who elected to undergo PGT (20), these data point to the usefulness of PGT for teaching both science and ethics.

Investigations into the utility of PGT as a method for integrating ethics are necessary to ensure that all educational goals for students—including an increased understanding of ethical considerations—are well served (6, 12). Robust evaluation of the pedagogical impact of PGT as a tool for teaching ethics in various educational settings is needed to identify best practices and set standards for future courses.

CONCLUSION

Scientific and technological advances such as those made in genetics give rise to important and complex ethical issues. It is critical to educate students to become scientifically and ethically literate researchers, health professionals, and citizens who can engage effectively in discussions and decision making about science in personal, professional, and societal contexts. Science educators should work to ensure that students learn about the many aspects of genetic testing, including its benefits, risks, limitations, and relevant ethical and societal issues. Although further research on its pedagogical effectiveness is needed, the use of PGT in the classroom is an opportunity to incorporate ethics in an innovative, participatory, and engaging format. Done well, PGT can be a useful tool for integrating ethics into genetics education.

ACKNOWLEDGMENTS

The findings and conclusions in this paper are those of the authors and do not necessarily represent the official position of the Presidential Commission for the Study of Bioethical Issues or the Department of Health and Human Services. The authors declare that there are no conflicts of interest.

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