

The Gen-Ethics Bowl – an In-Class Activity Combining Genetics and Bioethics

Janet A. De Souza-Hart* and Dien Ho

Massachusetts College of Pharmacy and Health Sciences (MCPHS University), Boston, MA 02115

Recent advances in genetics have transformed the mere possibilities of genetic testing and pre-implantation genetic diagnosis into clinical realities. Although undergraduate science professors are able to explicate the science behind these new technologies, they are not always ready to discuss the ethical and social impacts of these new practices. In order to introduce to our students the complex ethical and social issues raised by these genetic procedures, we created a week-long interactive and interdisciplinary "Gen-Ethics Bowl." The aim is to provide the conceptual tools necessary for our students to identify ethical and social issues that often go unnoticed in a genetics course that covers only the scientific aspects. Our hope is that the Gen-Ethics Bowl will be one of many steps in training our students to become socially responsible and morally sensitive scientists.

Two principal formats that we have used successfully over the years include:

- I. We provide scenarios that raise ethical issues in relation to genetic technologies to groups of students. These groups consist of a mixture of three or four students drawn from a genetics course and a healthcare ethics course. On the first day of their meeting, they discuss the genetic and ethical issues involved in their assigned scenario. The students from the genetics course explain to their group members the science behind the case (e.g. explaining how diet impacts a genetic condition like phenylketonuria (PKU)), while the students from the ethics course identify the main ethical tensions, the relevant stakeholders, and the method they will use to tackle the ethical challenges. Students are required to formulate a group answer/ consensus to the ethical questions associated with their case, which they then present orally to the class on the second day of the Bowl.
- 2. Groups are assigned a scenario and a pro or con position. Similar to the format above, students identify the relevant medical and ethical issues and formulate arguments justifying why they believe the

position they advocate is correct. During day two of the Bowl, they present their arguments. The pro and con groups for the same case take turns reading their statements. Then, the groups are given two to three minutes to offer a rebuttal.

We prefer cases that contain a compelling narrative with plausible characters seemingly drawn from real life stories. The New England Journal of Medicine often serves as a great generator of ideas for cases (3). Likewise, Narrative Inquiry in Bioethics: A Journal of Qualitative Research also provides some compelling case studies. Topics that we have used and/or developed as cases, along with some references that can help with the development process, include:

- Testing asymptomatic minors (7) or adults (6, 2) for an incurable genetic disorder
- Implanting embryos that are positive for achondroplasia, based on the wishes of parents with achondroplasia
- Using pre-implantation genetic diagnosis to produce a "savior sibling" (4, 5)
- Testing a fetus for an incurable, adult-onset, autosomal dominant genetic disorder that may reveal the genetic status of a father who does not want to be tested (1, 9)
- Disclosing to a patient's family members, against the patient's wishes, that they are at risk for miscarriage if they are carriers of a genetic disorder that runs in that family
- Forcing a mother with PKU to comply with a strict diet in order to avoid birth defects (10)
- Using IVF (in vitro fertilization) to implant more than the recommended number of embryos at a patient's request (e.g. eight to ten) (8)
- Participating in genetic research on specific ethnic groups that might lead to discrimination against that group (12)

Assessment could be done in a variety of ways but here is our method:

Students receive five points for attendance for each day of the Bowl (10 points total).

^{*}Corresponding author. Mailing address: MCPHS University, 179 Longwood Avenue, Boston, MA 02115. Phone: 617-735-1028. Fax: 617-732-2959. E-mail: janet.hart@mcphs.edu.

^{©2014} Author(s). Published by the American Society for Microbiology. This is an Open Access article distributed under the terms of the Creative Commons Attribution-Noncommercial-NoDerivatives 4.0 International license (https://creativecommons.org/licenses/by-nc-nd/4.0/ and https://creativecommons.org/licenses/by-nc-nd/4.0/ legalcode), which grants the public the nonexclusive right to copy, distribute, or display the published work.

- Students receive up to 10 points for an electronic submission of a brief statement (one to two paragraphs) summarizing the discussion they did in their groups on day one of the Bowl. We use the plagiarism software *Turnltln* to make sure that students create their own unique statement.
- Groups were given between three and five points from the genetics instructor, depending upon how well they explained genetics concepts pertinent to the case.
- Groups were given between three and five points from the philosophy instructor, depending upon how well they supported their positions.

We have found the following to be best practices for both formats:

- Scheduling the Bowl toward the end of the semester when topics related to genetics and bioethics have already been taught/discussed in detail in class. The last week of class is particularly ideal as it gives students a break from new material before finals week, while reinforcing and applying concepts learned from both courses.
- Beginning the first day with talking points (principles covered in both the genetics and philosophy courses that might apply to their cases) from the instructors. This usually takes five to eight minutes. Instructors also check in with each group to answer any questions they might have during group discussions.
- Making sure that students briefly summarize the case before they launch into their consensus or supporting evidence for their position on day two of the Bowl.
- Using "clickers" (Classroom Response Systems) to keep all students engaged in the cases and to let them share their opinions anonymously. Students can either vote on how well a particular stance was supported (on a scale of 1 to 5) for the first format or they can vote for the group that provided the more persuasive argument (pro vs. con) for the second format. Because student clicker responses may be affected by their own personal opinions/ biases related to the case, clicker results are not factored into grades.
- If time permits, it could be good to have a third day with open discussion for students to share their personal opinions on each case. Students tend to have strong and interesting opinions on these topics.

We encourage biology faculty to reach out to their colleagues in the philosophy discipline for potential collaboration. If combining classes is not an option, one could invite a guest lecturer with expertise in bioethics to discuss key points that can help drive group discussions. The British Medical Association has created a helpful flow chart for students encountering ethical problems: http://bma.org.uk/ practical-support-at-work/ethics/medical-students-ethicstool-kit/approaching-an-ethical-dilemma. For a survey of major ethical principles, see the introductory chapter of *Ethical Issues in Modern Medicine* (11).

Feedback from students in both courses has been extremely positive since we first began the activity seven years ago and it ranks as one of their favorite activities during the semester.

ACKNOWLEDGMENTS

The authors declare that there are no conflicts of interest.

REFERENCES

- Bodurtha, J., and J. F. Strauss. 2012. Genomics and perinatal care. N. Engl. J. Med. 366:64-73.
- Burke, W., and D. Dimmock. 2014. Screening an asymptomatic person for genetic risk. N. Engl. J. Med. 370:2442–2445.
- Chung, D. C., S. S. Yoon, G. Y. Lauwers, and D. Patel. 2007. Case 22-2007 — A woman with a family history of gastric and breast cancer. N. Engl. J. Med. 357:283–291.
- 4. Dickens, B. M. 2005. Preimplantation genetic diagnosis and 'savior siblings.' Int. J. Gynaecol. Obstet. 88(1):91–96.
- Jungheim, E. S. 2014. Shared decision making about IVF for savior siblings. Virtual Mentor: AMA Journal of Ethics 16(1):24-29. [Online.] http://virtualmentor.ama-assn. org/2014/01/ecas4-1401.html.
- Kane, R. A., and R. L. Kane. 2009. Effect of genetic testing for risk of Alzheimer's disease. N. Engl. J. Med. 361:298–299.
- Mand, C., L. Gillam, M. B. Delatycki, and R. E. Duncan. 2012. Predictive genetic testing in minors for lateonset conditions: a chronological and analytical review of the ethical arguments. J. Med. Ethics 38(9):519–524.
- Otto, S., and W. J. Pinchk. 2009. Ethical dimensions in the case of the 'octomom': two perspectives. Pediatr. Nurs. 35(6):389–392.
- Roberts, J. S., and W. R. Uhlmann. 2013. Genetic susceptibility testing for neurodegenerative diseases: ethical and practice issues. Prog. Neurobiol. 110:89–101.
- Robertson, J. A., and J. D. Schulman. 1987. Pregnancy and prenatal harm to offspring: the case of mothers with PKU. Hastings Cent. Rep. 17(4):23-33.
- Steinbock, B., A. London, and J. Arras (ed.). 2012. Ethical Issues in Modern Medicine, 8th ed. McGraw-Hill, New York, NY.
- Stolberg, S. 1998. Concern among Jews is heightened as scientists deepen gene studies. New York Times, April 22, 1998. [Online.] http://www.nytimes.com/1998/04/22/us/ concern-among-jews-is-heightened-as-scientists-deepengene-studies.html.