

# Teaching Genetics and Genomics from Bioethics & Multicultural Perspectives: A Quality Improvement for Health Curricula

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## Abstract

As university students of all majors, particularly in the health professions, move into the genetic and genomic era, curricular development must keep pace with their learning needs, particularly if they are to succeed in successful management of careers where this knowledge base is essential to succeed over a forty to fifty year span. The purpose of this quality improvement (QI) project is to demonstrate how one such course has done so, and to share the initial success of that course in an undergraduate, baccalaureate nursing curriculum. The curricular change was made based on the American Nurses Association-Consensus Panel's (2008) *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators* (2<sup>nd</sup> ed.) Content delivery is based on a Writing Intensive (WI) approach that gives students a number of learning strategies other than objective examinations in order to apprehend content of a complex nature. Teaching strategies include traditional classroom lecture-style content presentation, online group testing, group breakout sessions, scholarly writing, informal classroom writing exercises, group project presentations on either assigned or group selected topics, use of online resources such as the National Human Genome Research Institute (NHGRI) of the National Institute of Health (NIH) and even poetry related to Genetics and Genomics, just for fun. Students with different levels of educational talent and skill respond well to this curricular quality improvement that is taught as a survey course which helps them relate knowledge about genetics and genomics to realistic clinical situations. Education of this nature evokes a quality of narrative medicine for students that is nearly lost in the fast-moving 21<sup>st</sup> century, where there is an inordinate reliance on objective testing as a measure of quality.

## Course Objectives & Assignments

This course explores genetic concepts and principles as major determinants of population health. Genetic theory and research is discussed with an emphasis on how genes interact with each other and the environment in ways that predispose individuals to common health conditions such as congenital anomalies, genetic illnesses, heart disease, arthritis, diabetes, cancer, and immune-pathologies. Translation of genetic and genomic principles into clinical practice, including recognition of disease patterns among genetically related groups is emphasized. Application of ethical principles to clinical practice situations is examined, based on national ethics standards. **This is a writing intensive course.** In all writing-intensive courses, students learn the conventions and the kinds of writing used in the course's discipline (in this case, nursing).

### The following are the writing objectives for this course:

- Engage in scholarly exploration of genetic disease through literature review; resulting in a creative and scholarly class presentation (group project).
- Create a scholarly paper that synthesizes information obtained from research studies, expert opinion, and evidence-based sources on a controversial issue related to genetic/genomic advances in health care.
- Incorporate peer and faculty feedback on both content and writing style in the preparation of the scholarly paper.
- Appreciate the professional demeanor and respect required in evaluating the work of colleagues.
- Recognize ethical and legal responsibilities in managing genetic and genomic information.

### Upon participating in this course, students will be able to:

- Assess individuals and families for genetic and genomic risk.
- Describe the importance of genetics and genomics in relationship to chronic illnesses.
- Discuss the ramifications of gene therapy at experimental and prescriptive level.
- Articulate Federal regulatory processes involved in the approval of gene therapy.
- Advocate for the ethical treatment of individuals and populations at genomic risk.

### Assignments Include: Family Pedigree Assignment – My Family Health Portrait

<https://familyhistory.hhs.gov/> Using My Family Health Portrait you can: Enter your family health history. Learn about your risk for conditions that can run in families. **Due as a printed hand in so that student and family information is protected and no electronic family genetic histories are collected;** Scholarly paper (Peer Reviewed, teacher graded draft & final submission); Group Project & Presentation (with 3-5 other classmates); Final Examination (Student written questions posted in an online exam that they may discuss with each other to consolidate their knowledge; & Class Participation & Online Course Discussion Boards (mandatory & graded.)

## QUALTRICS® Survey-2014 NewGrad RNs

All 26 BSN graduates from the class of 2014 were sent a QUALTRICS.COM® Survey on private email addresses that they provided upon graduation. Of these, 10 (38.4%) opened the survey and 5 (19.2%) completed it within 3 days. Another prompt was sent a week later with a closing date, but the total remained n=5. Sample description: 3 female & 2 male between 21 – 23 years of age, employed RNs, travel up to 50 miles for their first RN jobs. All report working in inpatient, hospital settings: Adult health (n=1); adult telemetry (n=1); pediatrics (n=2); obstetrical-neonatal (n=1). 100% expect to attend graduate school. Important findings of the survey include:

- **“Have you been able to use your knowledge of the principles of Genetics & Genomics in your nursing practice?”** 3 (60%) report “Yes, from time to time,” 1 reports “Rarely, but from time to time” & 1 reports “Never.”
- **“Have you have noticed any violations of the following Federal Laws that govern good G & G practice”** 1 each of 2 (40%) replied either the *Affordable Care Act of 2010* or “other.”
- **“Have you felt that there have been any ethical violations concerning the G & G information of patients for whom you have provided care?”** All but one (80%) reported NO .
- **“Would you consider moving into a career in Genetic & Genomic nursing?”** 100% of the respondents replied NO.
- **“Are you aware that the American Nurses Association (2015) has published an updated version of the ANA “Code of Ethics for Nurses with Interpretive Statements?”** (<http://www.nursingworld.org>) 3 (60%) replied YES & 2 (40%) replied NO
- **Anything else?** One of 5 responded, “The field is making important strides to discovering congenital disorders and helping parents adjust to this prior to birth, which can help with education and preventing shock.”

## 2014 Junior Student Comments

1. I found it helpful that topics overlapped with OB & pediatrics. It also makes me, as a healthy individual, greatly & deeply appreciate how blessed I am not to have a genetic problem or ethical issue decision at hand.
2. I felt that I learned a lot by writing my scholarly paper. I personally find it easier to learn something when it moves in a progression & I think that G & G encompasses so much that it is hard to learn in a linear fashion.
3. When I took genetics at another university, my biological focus being genetics, I fell in love with it. We had 4 hour labs with our course, but it was a science...This course brought a whole different aspect... I never stopped to consider ethical or social implications before.

4. I feel this class tied up a lot of loose ends left over from biology, micro & high school. This class took it a step further & related it in a way that I can use as a nurse.
5. I believe that this was a “genomic awareness” class. This is a compliment. There are too many genetic anomalies to lecture about in 1 semester. Doing so would be stressful & perhaps boring. In fact, we learned how to research certain issues & conditions.
6. I learned about a number of different genetic & ethical issues including familial diseases, genetic testing bias in different religions & the rights to privacy & consent in genetic & experimental research. I thoroughly enjoyed the class as a whole.
7. There is a lot of controversy regarding ethics in G & G!

## Selected Scholarly Paper Titles

1. Genetically Modified Foods: Do the Risks Outweigh the Supposed Benefits?
2. The Stem Cell Debate: Should Ethics Play a Role in Research?
3. Knowing is Half the Battle: The Genetics, Genomics and Ethics of Cancer
4. Genetic Testing and Eugenics: Ethical, Moral & Personal Viewpoints Surrounding Genetic Research
5. Ethical Concerns Involving Pre-implantation Diagnosis to Select for Genetic Deafness
6. The Ethical Issue of Multifetal Pregnancy Reduction

## Key References & Weblinks

- Consensus Panel (2006/2008). *Essential Nursing Competencies & Curricula Guidelines for Genetics & Genomics* (2<sup>nd</sup> ed.) [Essentials OF Genetic and Genomic Nursing: Competencies](#)
- [http://www.aacn.nche.edu/education-resources/Genetics\\_Genomics\\_Nursing\\_Competencies\\_09-22-06.pdf...](http://www.aacn.nche.edu/education-resources/Genetics_Genomics_Nursing_Competencies_09-22-06.pdf...)
- *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators*, 2nd Edition. Silver Spring, MD: American Nurses Association.
- <http://www.genome.gov/Pages/Health/HealthCareProvidersInfo/CompetencyImplementationStrategicPlan...>
- 2014-2020. A Report by the Genomic Nursing Competency Strategic Planning Committee.
- International Society of Nurses in Genetics, American Nurses Association (2006). *Statement on the Scope and Standards of Genetics Clinical Nursing Practice*. Washington, D.C.: American Nurses Association.
- Monsen, R.B. (2008). *Genetics and Ethics in Health Care – New Questions in the Age of Genomic Health*. Silver Spring, MD.: American Nurses Association.
- American College of Medical Genetics (ACMG) <http://www.acmg.net/>
- Ethical, Legal, Social Issues (ELSI) [http://www.ornl.gov/sci/techresources/Human\\_Genome/elsi/elsi.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/elsi/elsi.shtml)
- <http://www.genome.gov/genomemv/>
- GenomeTV is the National Human Genome Research Institute (NHGRI) collection of video resources. A wide variety of videos is available, from lectures, to news ... [NHGRI Lecture Videos - National Human Genome Research Institute](#)
- Human Genome Project [http://www.ornl.gov/sci/techresources/Human\\_Genome/home.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/home.shtml)
- International Society of Nurses in Genetics (ISONG) <http://www.isong.org/>
- March of Dimes (MOD) <http://www.marchofdimes.com/>
- National Coalition Health Professionals Education in Genetics (NCHPEG) <http://www.nchpeg.org/>
- National Society of Genetic Counselors (NSGC) <http://www.nsgc.org/>