Strategies for Genomic Integration into the Curriculum

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Models for Genomics Education

- Content integrated throughout the curriculum
- Standalone course
  - Required course
  - Elective course
Integrated Approach

- **Benefits**
  - Greater chance of students linking the genomic content they learned in one course to genetic content learned in future courses
  - More opportunities to reinforce genomic content

- **Challenges**
  - Some faculty may not be willing or feel comfortable with, integrating genomic content into “their” course
  - Greater chance of inconsistency in the quality of genomic content being taught – also greater chance of redundancy
Standalone Course

**Benefits**
- Easier to track genomic content being taught
- Quality of teaching more likely to be consistent/less chance of redundancy
- May be easier to justify having students purchase a genetics/genomics textbook

**Challenges**
- Finding room in the curriculum for another standalone course may be difficult
- Overreliance on a single faculty member/some schools may not have faculty with the necessary expertise
- Students may find it difficult to link what they learned in the standalone course into other courses
Integration of Content Throughout the Curriculum

- Pathophysiology
  - Basic genetic concepts
  - Patterns of inheritance
- Health Assessment
  - Dysmorphology
  - Family history/Pedigree
- Discipline Course
  - Nursing/PA roles in genomic healthcare
  - Ethnic, Racial & Cultural Considerations
- Nursing Research
  - Human Genome Project
  - Genetics/Genomics research & methodologies
- Pharmacology
  - Pharmacogenomics
- Medical-Surgical Courses
  - Care of patients with adult onset conditions & their families
  - Genomics and Cancer
- Maternity
  - Prenatal & newborn screening
- Pediatrics
  - Care of children with genetic conditions & their families
- Ethics
  - Ethical, legal, and social implications of advances in genomics
Creative strategies for getting students and clinicians interested in & excited about learning genomics
Examples of Strategies I have used in the following courses:

- **Family Centered Genomic Health**
  - Required course for all undergraduate nursing students at the University of North Carolina at Chapel Hill - School of Nursing

- **Clinical Genetics**
  - Required course for Nurse Midwifery DNP students at the Louise Herrington School of Nursing, Baylor University

- **Genomics and Society**
  - Elective course for graduate students at UNC-CH

- **Continuing Education Courses for nurses and other providers**
Lectures

- For certain topics, the lecture format probably works best
Other Topics Work Better in Different Formats
In-class activities
- Family history exercise
- Dysmorphology exercise
- Family assessment exercise
- Genomics and Ethics in the media exercise
- Case studies
- Enrichment activities
- Family and Genetics Project
- Reflection Paper
- Unfolding Case Study
In-Class Activity: Family History

- Divide students into groups of two
  - Have them take turns taking their teammate’s family history and constructing a family pedigree

- “Family History: The most valuable and least expensive genetic test”

https://familyhistory.hhs.gov/fhh-web/home.action
Make them aware of Family Medical History tools/resources

- **NHGRI**
  - Family Medical History and Tool Resources
  - NHGRI Family History Tool Conference 2016

- **Progeny**
- **Me Tree**
- **Family Healthware from Sanitas**
- **Proband**
- **CancerGeneConnect**
- **VICKY**
- **Cancer IQ**
- **CRA Health**
In-Class Activity: Dysmorphology

- Divide students into groups of 3-4
- Give each group an envelope filled with pictures of individuals who have genetic conditions with noticeable dysmorphic features
- Ask the students to identify:
  - Specific dysmorphic features
  - Genetic conditions
- After students are finished:
  - Discuss the correct answers
  - Make them aware of resources such as Face2Gene
Face2Gene
http://www.fdna.com/face2gene/

Facial Dysmorphology Novel Analysis At Your Fingertips

A free genetic search and reference mobile app powered by facial analysis technology
In-Class Activity: Family Assessment Exercise

- Show a video clip of a family living with a genetic condition
- Have the students assess the family using a family framework
- You Tube is a great resource
  - [http://www.youtube.com/watch?v=xCSzysu_fLY](http://www.youtube.com/watch?v=xCSzysu_fLY)
Genomics and Ethics in the Media Activity

- Have students find an example of ethical, legal, or social implications of genetics/genomics being discussed in the popular media (e.g., a cartoon, an article, a commercial, a video clip, a movie etc.) & have them come to class prepared to discuss it.
Structured Controversy

- Students are randomly assigned to groups of 4 students (2 advocacy teams per group)
  - One team is given a position on an argument
  - The other group is given a different position on the same argument
- Students review materials that support both positions.
- Each Advocacy team has 10 minutes to advocate for their position.
- Then, the positions are reversed and each group has 10 minutes to advocate for the other position.
- Finally there is general discussion in which they seek to reach the best decision possible.
Structured Controversy

- The role of regulation in pre-implantation genetic diagnosis
  - One team is given the position that more regulations are needed
  - The other team is given the position that fewer regulations are needed
Structured Controversy

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Case Studies

- Using a video clip

- Using data from a research study
  - I used data collected during my *K01 Family Experience of Genetic Testing: Ethical Dimensions* funded by NINR
Family Experience of Genetic Testing (Van Riper, 2005)

- BRAC 1&2 Testing for Hereditary Breast and Ovarian Cancer
Key:
Breast Cancer 🔴
Mental Retardation 🔵

BrCa 30, 36

BrCa 41
Sisters went as a group to a genetic counseling session – but their response was not a “group response”

“We learned in that session and shortly thereafter that even though we are blood sisters, raised together in the same household, in a very close family, with the same parents; we had totally different responses to this. Totally different!”
# 4 Sisters: 4 Responses

<table>
<thead>
<tr>
<th>Sister</th>
<th>Details</th>
<th>Response</th>
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</thead>
<tbody>
<tr>
<td>1&lt;sup&gt;st&lt;/sup&gt; Sister</td>
<td>BrCa X 2&lt;br&gt;BRCA testing+</td>
<td>Bilateral Mastectomy, Bilateral oophorectomy, No breast reconstruction</td>
</tr>
<tr>
<td>2&lt;sup&gt;nd&lt;/sup&gt; Sister</td>
<td>Hx BrCa x1&lt;br&gt;BRCA testing+</td>
<td>Bilateral Mastectomy, Bilateral oophorectomy, Br reconstruction</td>
</tr>
<tr>
<td>3&lt;sup&gt;rd&lt;/sup&gt; Sister</td>
<td>No Hx of BrCa</td>
<td>Increased Surveillance – Starting to “rethink” her decision</td>
</tr>
<tr>
<td>4&lt;sup&gt;th&lt;/sup&gt; Sister</td>
<td>No Hx of BrCa</td>
<td>Minimal Surveillance</td>
</tr>
</tbody>
</table>
Sisters agreed that it was “okay” to disagree

“We respected each other’s opinions, but I will probably never totally understand her decision and she’ll never understand my decision. And we found that’s okay. These decisions are so highly personal that even a sibling can’t relate to what you are going through.”
In contrast, in another family, they did not agree to disagree

“My sister said that because I didn’t use genetic testing to terminate a pregnancy affected by Down syndrome and make life better for the world, she wouldn’t use genetic testing to help me find out if we had a family thing... Personally for me there is a difference between a baby and a breast, but everybody sees the world differently. She just could never get past that. She could just never, to her dying day, believe that we brought this person (the child with Down syndrome) into the world. She said no woman on the planet would do what I did, refuse to have an amnio. She said that nobody who was sane would do what I did, nobody who was sane would bring a retarded person into the world.”
Enrichment Activities

- Movies
- TV Shows
- Books
- CDs
- Web-based activities
- Seminars
- Interview a genetic specialist

- Have students spend one hour outside of class doing something related to genomics
- Have them write a paper in which they answer the following questions
  - What did you do?
  - What were the key messages you learned?
  - How will you use what you learned in practice?
Examples of Movies/Documentaries

- ESPN 360 videos
  - Perfect (DS)
  - Flip of a Coin (HD)
  - Catching Kayla (MS)
  - Backup Catcher (HLH)
TV Shows

GREY'S ANATOMY

BORN THIS WAY

THE LITTLE COUPLE

CALL THE MIDWIFE

TWO IN A MILLION

HOUSE
Sites Where Students Can Search for ONLINE Activities

- Genome TV
  - http://www.genome.gov/genometv/
- CDC- Office of Genetics and Disease Prevention
  - http://www.cdc.gov/genomics/default.htm
- Learn Genetics http://learn.genetics.utah.edu/
- TED Talk on Genetics
  - https://www.ted.com/topics/genetics
- Telling Stories Website
  - http://www.tellingstories.nhs.uk/
- Genetic Alliance Website
  - http://www.geneticalliance.org/
- Global Genes
The purpose of this project is to explore the family experience of living with a genetic condition.
Family & Genetics Project

- Family Composition/Pedigree
- Genetic Condition
  - Incidence /Variation in factors such as risk and expression related to gender, ethnicity and/or religion
  - Genetic Basis of Condition
  - Typical Pattern of Inheritance
  - Pathophysiology
  - Symptoms/Clinical Features
- Nursing Priorities

Family Assessment using Resiliency Model of Stress, Adjustment and Adaptation

References
<table>
<thead>
<tr>
<th>Diseases/Disorders</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Achondroplasia</td>
<td>Real Family on TV Show (<em>Little People</em>)</td>
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<tr>
<td>Alpha Antitrypsin Deficiency</td>
<td>Real Family</td>
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<tr>
<td>Adrenoleukodystrophy</td>
<td>Movie (<em>Lorenzo’s Oil</em>)</td>
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<tr>
<td>Alzheimer’s Disease</td>
<td>Real Family / Book / Movie (<em>Iris</em>)</td>
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<tr>
<td>Aspergers</td>
<td>Real Family</td>
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<tr>
<td>Autism</td>
<td>Real Family / Book (<em>Just this side of normal</em>) / Movie (<em>I am Sam</em>)</td>
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<tr>
<td>BiPolar Disorder</td>
<td>Real Family / Book (<em>An Unquiet Mind</em>)</td>
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<td>Cystic Fibrosis</td>
<td>Real Family / Book (<em>Alex-Life of a Child</em>)</td>
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<tr>
<td>Diabetes</td>
<td>Real Family / Movie (<em>Steel Magnolias</em>)</td>
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<td>Factor V Leidan</td>
<td>Real Family</td>
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<tr>
<td>Fragile X</td>
<td>Real Family / Book (<em>Spelling Love with an X</em>)</td>
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<tr>
<td>Huntington Disease</td>
<td>Real Family / Book (<em>Mapping Fate</em>)</td>
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<td>Osteogenesis Imperfecta</td>
<td>Real Family / Book (<em>Handle with Care</em>)</td>
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<tr>
<td>Parkinson’s Disease</td>
<td>Real Family / Book (<em>Lucky Man</em>)</td>
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<tr>
<td>Schizophrenia</td>
<td>Real Family / Movie (<em>A Beautiful Mind</em>)</td>
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<tr>
<td>Sickle Cell Disease</td>
<td>Real Family</td>
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<tr>
<td>Wilson’s Disease</td>
<td>Real Family</td>
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### Spring 2016: Most groups chose to focus on a group member’s family or a family known by a group member

<table>
<thead>
<tr>
<th>Genetic Condition</th>
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<tbody>
<tr>
<td>Alzheimer’s Disease (Still Alice)</td>
<td>Hamaachromatosis</td>
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<tr>
<td>Asperger’s</td>
<td>Hemophilia</td>
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<tr>
<td>BiPolar Disorder</td>
<td>Huntington Disease (Twitch)</td>
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<tr>
<td>Chromosomal Deletion (rare)</td>
<td>Lupus</td>
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<tr>
<td>Chronic Mucotaneous Candidiasis</td>
<td>Mitochondrial Disease</td>
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<tr>
<td>Cystic Fibrosis</td>
<td>Muscular Distrophy</td>
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<tr>
<td>Cleft Palate</td>
<td>Oromandibular Limb Hypogenesis</td>
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<tr>
<td>Congenital Adrenal Hyperplasia</td>
<td>PCOS (Reality TV Show)</td>
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<td>Congenital Glaucoma</td>
<td>Polycystic Kidney Disease</td>
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<td>Cri-Du-Chat</td>
<td>Phenylketonuria</td>
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<tr>
<td>Crohn’s Disease</td>
<td>Schizophrenia</td>
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<tr>
<td>Dense Deposit Disease</td>
<td>Spherocytosis</td>
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<tr>
<td>Down Syndrome</td>
<td>Spinal Muscular Atrophy</td>
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<tr>
<td>Fibrodysplasia Ossificans</td>
<td>Type 1 Diabetes</td>
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<tr>
<td>Progressive Fragile X</td>
<td>Turner Syndrome</td>
</tr>
<tr>
<td>William Syndrome</td>
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Opportunities to Share Their Work with Others

- In-Class Group Presentations
  - 5 minute presentations
- Poster Presentation on display during Nursing in the Genomic Era Conference
  - Creativity is encouraged
  - Chance for students to teach others about “their condition”
- Handout/Powerpoint presentation
Reflection Paper

Chance for students to reflect on what it was like doing the family and genetic project (1-2 pages)

- Was it a worthwhile activity?
- If so, what made it a worthwhile activity?
- What did you learn from doing it?
- How will it influence the way you practice?
- Or, how has it already influenced the way you practice?
Unfolding Case Study

Opportunity for students to apply what they have learned during the course/workshop
Anna, 32 year old woman - annual physical appointment

- While you are in the process of updating her family history, Anna says, “I have decided to get tested for Huntington’s disease and Alzheimer’s disease.”
Slides for the remainder of the case study will be available after the case study has been presented.
Questions?