

<b>Topic:</b> Professional Responsibilities in the Provision of Family-Centered Genomic Care
<b>Group members:</b> Agnes Burkhard, Sue Dugal, Ellen Eckes, Sharon Flynn, Melissa Franke, Mary Lou Lyons, Trish Kiladis, Elisa Mancuso, and Debbie Whittemore
<b>Target group:</b> Undergraduate nursing students
<b>Introduction</b>
<p>“Genomics is a central science for all nursing practice because essentially all diseases and conditions have a genetic or genomic component” (American Nurses Association, 2009, p. 1). It is essential that nursing students learn to integrate genetic and genomic competencies in their provision of culturally sensitive family-centered care. This lesson plan was developed to assist students to develop competencies in professional practice responsibilities. Students are asked to assess and reflect upon their personal values and biases, because this awareness is important to know prior to developing a therapeutic relationship with any client. Additionally, students need to recognize when these personal values and biases may impact the care they deliver to clients with genetic/genomic healthcare needs. The second component of this lesson plan engages students in the nursing process to develop a prioritized list of genetic/genomic assessments that are needed for the family in this case study. Finally, students are given the opportunity to role-play. This will assist students to develop the hands-on skills that are needed to ask questions and communicate with the client and family, peers, and other health care providers, to practice advocacy to facilitate referral to genetic/genomic services, and to remain non-judgmental and unbiased in providing care to a client/family in need of culturally sensitive care.</p> <p>Reference  American Nurses Association. (2009). <i>Essentials of genetic and genomic nursing: Competencies, curricula guidelines, and outcome indicators</i> (2nd ed.). Retrieved from <a href="http://www.genome.gov/17517037">http://www.genome.gov/17517037</a></p>
<b>Learning Objectives</b>
<ul style="list-style-type: none"> <li>• Articulate one’s attitudes, values and beliefs that influence one’s perspective about difficult genetic or genomic healthcare decisions.</li> <li>• Incorporate cultural, social, ethnic and religious perspective and literacy level when delivering genetic and genomic care.</li> <li>• Advocate for client’s access to desired genetic/genomic services and or resources including support groups.</li> </ul>
<b>Genetic/Genomic Nursing Competencies Addressed</b>
<ul style="list-style-type: none"> <li>• Recognize when one’s own attitudes and values related to genetic and genomic science may affect care provided to clients</li> <li>• Demonstrate in practice the importance of tailoring genetic and genomic information and services to clients based on their culture, religion, knowledge level, literacy and preferred language</li> </ul>

- Advocate for the rights of all clients for autonomous informed genetic and genomic related decision making and voluntary actions

Source: *Consensus Panel on Genetic/Genomic Nursing Competencies* (2009)

### **Learning Activities**

#### **Pre-class readings:**

Jenko, M. and Moffitt, R. Sr. (2006). Transcultural nursing principles: An application to hospice care. *Journal of Hospice and Palliative Care*, 8(3), 172-180.

Paniagua, C.T., and Taylor, R. E. (Jan. 2008). The cultural lens of genomics. *OJIN*, 13. Retrieved from:

<http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/vol132008/No1Jan08/CulturalLens.html>

Al Gazali, L and Hamamy H. (2014). Consanguinity and Dymorphology in Arabs. *Human Heredity*, 2014:77, 93-107.

#### **Pre-class activities:**

1. Read the “pre-class” assigned articles.
2. Complete the “Know Thyself Self Discovery” questionnaire (Table 1 in Jenko and Moffitt, 2006).
3. Write a summary journal reflection that includes awareness of one’s own heritage (cultural, ethnic and religious background) and demonstrates comprehensive insight regarding personal values and biases that impact nursing care provided to clients. (Refer to Rubric –Table 2)
4. Read the case study
5. Websites to visit:
  - a. United Mitochondrial Disease Foundation - Understanding Mitochondrial Disease at <http://www.umdf.org/site/pp.aspx?c=8qKOJ0MvF7LUG&b=7934627>
  - b. CDC Information on the Disease: <http://www.cdc.gov/ncbddd/autism/mitochondrial-faq.html>
6. Write a journal summary describing how cultural, religious, economic, and educational/literacy factors may impact the care of the couple in the case-study. Explain the significance of gathering a family history in this situation. Describe what resources are available for this couple both locally and nationally.

#### **Other helpful resources:**

Foundation for Mitochondrial Medicine

<http://mitochondrialdiseases.org/mitochondrial-disease/>

Children’s Mitochondrial Disease Network UK

<http://www.emdn-mitonet.co.uk/mito.htm>

**Classroom activities:**

1. Form a group (simulation) or groups of 5 students (classroom). Assign the roles of mother, father, admitting nurse, change-of-shift nurse, and recorder.
2. Participation in the evolving case study simulation/role play.
3. A student (simulation) or students (small groups) will complete the Recorder Checklist during the role play.
4. Faculty-Student guided debriefing activity.

**Student Assessment**

1. Know Thyself Self-Discovery Questionnaire
2. Journal

## **Appendix 1**

### **Case Study/Student Role Play**

#### **Introduction to Role Play** (introduced by faculty member)

As a novice practitioner you are evolving in diverse areas: physical assessment, direct caregiving skills, organization management, therapeutic communication, delegation, collaboration, and developing professional ethics for patient and family advocacy.

The objective of the following learning activity is to:

1. Identify personal attitudes and values related to genetic and genomic competencies
2. Discuss nursing interventions to promote optimal health outcomes for individuals and families with genomic issues.

#### **Background**

*(Information shared with all students at the beginning of the activity)*

At 1:30 in the afternoon an Egyptian couple presents to the Labor and Delivery Unit. Akila, the wife, is in her 12<sup>th</sup> week of pregnancy and has come in with some vaginal bleeding. The amount of bleeding is very small however the physician orders an ultrasound and wants the patient observed for 2 hours. Fetal heart sounds and vital sounds are within normal limits. Upon reviewing the prenatal record the nurse finds that the family had a first child who has a mitochondrial disorder with significant problems. She also learns that the parents are first cousins.

*Instructions to be the only shared with students playing the mother and father role*

The following is your scenario. You are Mr. and Mrs. Abboud. You both are college educated. You recently emigrated to US. Mr. Abboud is starting as a graduate student at MIT. Mrs. Abboud is a housewife caring for their child and is pregnant with her second child. You come to the hospital because Mrs. Abboud is bleeding and she is pregnant at 12 weeks. Her first child is 3 years old. He has a Mitochondrial Disorder which you know nothing about. You both are very anxious and concerned about the present pregnancy. In response to the nurse's questions you have the following responses.

When you were pregnant with your first child the pregnancy was fine but now our child has this disease.

We are wondering if there is any way to know ahead of time whether this baby will have the disease. What do you think?

You just want to continue with the present pregnancy and will not terminate no matter what the circumstances. You want to have many more children.

The nurse suggests some genetic tests. Your response is: "How will this help us?"

While educated people you know very little about the disease your son has or anything to do with genetics. You are very worried about the nurse's questions.

*Instructions for student in the admitting nurse role:*

Perform an assessment with the following components- Significant family medical history, OB history, socio-economic status, cultural health practices, and educational level/literacy

**Focus on the following questions:**

1. Ask couple if they are comfortable speaking English?

2. Ask family what is most important for them at this moment?
3. Tell me what happened and what brought you here?
4. Can you tell me about the current pregnancy?
5. Were there any problems or complications with your first pregnancy?
6. Can you tell me more about what you know about this disease?

*Instructions for students in the change of shift change role:*

Student giving report to 3-11 charge nurse and nurse taking care of the patient; using SBAR and then includes information about patient and husband being first cousins, history of mitochondrial disease and plan not to terminate pregnancy and have many children. One nurse responds: "Did you say they were 1<sup>st</sup> cousins and they don't plan to terminate." That is really stupid!"

### **End of learning activity – faculty-student debriefing**

Faculty facilitator questions–

What went well with the role play?

What else might have been addressed?

Based on this role-play what else do you see as being important actions for the nurse in the provision of care? *Make sure they have identified that although mitochondrial disease is only related to the mother that this couple is still at risk of a different genetic condition based on the fact that they are first cousins.*

How will your participation in this learning activity influence your future nursing practice?

**Table One Recorder Check-list**

Recorder Checklist	Check if done	Comments
Uses therapeutic communication		
Demonstrates non-judgmental attitude		
Demonstrates an understanding of mitochondrial disease		
Assesses cultural/religious health practices		
Assesses pertinent family history		
Refer to genetic resources		
Report to Colleague (change of shift) -Uses SBAR -Demonstrates patient advocacy regarding culturally sensitive needs -Identifies need for a genetic referral		

Table 2

**Professional Responsibilities Essential Competency  
Grading Rubric  
Undergraduate Nursing**

<b>Rating Criteria</b>	<b>Exceptional 100</b>	<b>Proficient 90</b>	<b>Average 80</b>	<b>Below Average 70</b>
<p><b>Journal –Reflective Summary</b> Student performs “Know Thyself” questionnaire and writes a personal reflection regarding their self-discovery and understanding of their own culture.</p>	Journal entry describes the student’s heritage (cultural, ethnic, and religious) and cites three concrete examples of how these personal values and bias may impact nursing care	Journal entry describes the student’s heritage and cites two examples	Journal entry describes the student’s heritage and cites one example	Journal entry does not completely describe the student’s heritage and no examples are cited
<p><b>Journal –Assessment summary</b> Summary should include all of the following:</p> <ul style="list-style-type: none"> <li>• Cultural health practices</li> <li>• Religious health practices</li> <li>• Socioeconomic status</li> <li>• Education/literacy</li> <li>• Significant family health history</li> <li>• Relevant genomic services</li> </ul>	Journal entry includes all 6 of the assessment components	Journal entry includes 4-5 /6 of the assessment components.	Journal entry includes 3/6 of the assessment components	Journal entry contains 2 or less of the assessment components

Add both numbers and divide by two for the grade