NHGRI Nurse Faculty Project
2012

Application of a Family Pedigree for Nursing Practice: Lesson Plan and Grading Rubric

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Citation**:** Witt, D. E., Choudhury, R., Cusack, G., Greene, N. Lange-Otsuka, P., Minchew, L., … Vargo, D. (2012). Application of a Family Pedigree for Nursing Practice: Lesson Plan and Grading Rubric. Available at Genome.gov website http://www.genome.gov/17517037#al-2 and National Human Genome Research Institute Summer workshop in Genomics short course website http://www.genome.gov/10000217

Introduction

The following lesson plan is the combined effort of the nursing faculty members who participated in the 2012 National Human Genome Research Institute Summer workshop in Genomics short course at the National Institutes of Health in Bethesda, Maryland. During the workshop participants were given the task of completing a genetics/genomics lesson plan and assessment. Nursing faculty are encouraged to use this lesson plan or an amended version of this lesson plan to facilitate learning in nursing students. This lesson plan was developed with both undergraduate and graduate nursing students in mind. Please feel free to utilize any or all components in courses to help students meet the genetic and genomic competencies.

Background

Pedigrees are a representation, or visual diagram, of family relationships used as a means to assess the level of risk an individual or family has for the development of a disease or disorder. Pedigrees account for genetic factors as well as environmental exposures and shared lifestyle practices. Symbols represent people while lines represent relationships. Understanding how to complete a family history, draw a pedigree, and complete a risk assessment are important components of patient-centered nursing care. This lesson plan will assist nursing faculty members to incorporate genetic/genomic concepts to facilitate student success in meeting the genetic/genomic nursing competencies through the completion of a pedigree and risk assessment.

Learning assessment can be defined as how students will demonstrate their understanding of the content and/or key concepts being taught. Faculty may utilize assessments to: (a) determine ability to perform a skill or task; (b) measure ability to solve real-world problems; (c) gain feedback on the effectiveness of instruction or to improve instruction; and/or (d) provide student feedback (Frey & Schmitt, 2007). Important concepts to consider in assessments of adult learners include assessment methods, learning outcomes, and evaluation criteria.

Purpose and Type of Assessment

This performance assessment incorporates the professional responsibilities and practice domains of the genetic/genomics competencies. Performance assessments can take on many different forms, including written and oral demonstrations and activities that can be completed by either a group or an individual (Gronlund & Waugh, 2009). For this learning assessment, the assignment is an interview conducted by individual students to achieve the competencies described in the grading rubric (Appendix A). The hypothetical learning subject for the interview will be a student partner who represents the case study basis for the assignment requirements. This performance assessment will allow students the opportunity to apply their skills and knowledge in preparation for real clinical situations. The target learning population for this assessment is the undergraduate and graduate nursing student (i.e. pre-licensure, RN-BSN, Master's, and Doctoral).

Performance Assessment Rationale

Performance assessments are used when performance of skills cannot be adequately measured solely by paper-and-pencil assessments (Gronlund & Waugh, 2009). Instructors may utilize performance assessments to evaluate complex learning outcomes and skills related to reasoning, oral communication, and physical skills. Performance assessments comprehensively measure components of cognitive, psychomotor, and affective domains of learning. Additionally,

this method of assessment may motivate students to retain knowledge through meaningful learning experiences that can be applied in real life situations (Gronlund & Waugh, 2009).

Procedures for preparation of a performance assessment include: (a) specifying performance outcomes; (b) selecting the focus of the assessment; (c) selecting the appropriate degree of realism; (d) selecting the performance situation; and (e) selecting the method of observing, recording, and scoring (Gronlund & Waugh, 2009). The performance outcome is the description of the performance that learners should be able to exhibit to be deemed competent. Performance outcomes must be stated clearly and are necessary for determining what should be included in the instructional content. Furthermore, clearly stating performance outcomes provides the basis for setting learner expectations, thus enabling learners to prepare adequately in organizing their efforts for accomplishing the required tasks successfully (Gronlund & Waugh, 2009). The focus of the assessment is on the procedure or process by which the learners will apply knowledge, skills, and attitudes in conducting an interview to obtain information for constructing a three-generation pedigree. The simulated setting provides an opportunity for learners and instructors to evaluate readiness to attempt actual performance (Gronlund & Waugh 2009).

The Interview & Pedigree Construction Grading Rubric (see Appendix A) is based on a criterion-referenced assessment. Criterion-referenced assessments are appropriate for evaluating learner knowledge and skills based on specified standards of performance measure (Gronlund & Waugh, 2009). The assessment results are interpreted using a relevant and clearly defined set of related tasks in the cognitive, psychomotor, and affective domains of learning. The levels of standards are established for each criterion, and are aligned with the expected learning outcomes for the genetics/genomics competencies. With criterion-based assessments, learners are measured against the defined performance standards, and not against other learners. Therefore, criterion-referenced assessments are valuable in individual instruction and identifying learner remediation needs (Gronlund & Waugh, 2009).

The grading rubric utilizes both an analytic and holistic approach to scoring the competencies with defined criteria (Gronlund & Waugh, 2009). The following genetics/ genomics competencies will be evaluated: (1) obtain health information to construct a three-generational pedigree using standardized symbols and terminology; (2) perform basic analysis of family history findings for genetic and genomic influences; (3) utilize available genetic and genomic technologies and information; (4) perform a reflective analysis regarding one's own attitudes and values related to genetic/genomic science that may affect care provided to clients; and (5) assess self-competence, identifying areas of strength, as well as areas in which professional development related to genetics/genomics assessment skills would be beneficial (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). Each of the competencies will be rated based on the criteria listed for each. Holistic feedback will be provided in the form of comments for the overall content, relevance, and insightfulness.

Lesson Plan

Topic
Application of a Family Pedigree for Nursing Practice
Learning Objectives
1. Apply universal symbols and terminology in developing a three generational pedigree related to genetics/genomics. 2. Identify and distinguish family history tools appropriate for client assessment. 3. Utilize evidence-based resources to complete a disease-specific case scenario that includes genetic/genomic information. 4. Acknowledges personal values and beliefs related to assessing genetics/genomic information.
Genetics/ genomics nursing competencies addressed:
1. Demonstrates ability to elicit a minimum of three-generation family health history information. 2. Constructs a pedigree from collected family history information using standardized symbols and terminology. 3. Perform basic analysis of family history findings for genetic and genomic influences 4. Incorporates genetic and genomic technologies and information in nursing practice. 5. Collects personal, health, and developmental histories that consider genetic, environmental, and genomic influences and risks. 6. Critically analyzes the history and physical assessment findings for genetic, environmental, and genomic influences and risk factors. 7. Assess self-competence, identifying areas of strength, as well as areas in which professional development related to genetics/genomics assessment skills would be beneficial. (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). 8. Identify clients with inherited predispositions to diseases as appropriate to the nurse's practice setting. 9. Analyze a pedigree to identify potential inherited predisposition to disease. 10. Estimate risks for Mendelian and multifactorial disorders in affected families as appropriate. (Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees, 2012)
Activities
1. Pre-class activities: a. Selected readings from genetics or pathophysiology text of faculty member's choice. b. Students will develop a three generation pedigree to assess personal family history information using the following website https://familyhistory.hhs.gov/fhh-web/home.action. The pedigree should represent three generations (student, parent, grandparents). c. Review a Genetic Fact Sheet related to disease-specific content. Example: An

Alzheimer's disease fact sheet may be found at http://www.nia.nih.gov/alzheimers/publication/alzheimers-disease-genetics-fact-sheet

d. Articles:
   - Bennett, R. l., Steinhaus French, Resta, R. G., & Lochner Doyle, D. (2008). Standardized Human Pedigree Nomenclature: Update and Assessment of the Recommendations of the National Society of Genetic Counselors. Journal of Genetic Counseling, 17, 424–433. Available at: http://geneticcounselingtoolkit.com/cases/pedigree/Bennett%20JGC%202008%20-%20Standardized%20Human%20Pedigree%20Nomenclature%20-%20Update%20and%20Assessment%20of%20the%20Recommendations%20of%20the%20National%20Society%20of%20Genetic%20Counselors.pdf
   - Wattendorf, D. J., & Hadley, D. W. (2005). Family history: The three-generation pedigree. [Review]. American Family Physician, 72(3), 441-448. Available at: http://www.aafp.org/afp/2005/0801/p441.html

e. Web sites to visit:
   - CDC Family Health History http://www.cdc.gov/genomics/famhistory/index.htm
   - Guidelines and Tools to Assess Family History for Common Diseases http://www.genome.gov/27527602
   - National Human Genome Research Institute, Talking Glossary of Genetic Terms, http://www.genome.gov/Glossary/index.cfm
   - National Society of Genetic Counselors, http://www.nsgc.org/
     NIH State-of-the-Science Conference Statement: Family History and Improving Health
     http://consensus.nih.gov/2009/Fhx%20images/familyhistory_draftstmt.pdf
   - US Department of Health and Human Services, My Family Health Portrait, https://familyhistory.hhs.gov/fhh-web/home.action

2. In-class activities:
   a. Introduce disease-specific topic (i.e. Alzheimer's disease).
   b. Review pre-class activities.
   c. Facilitate completion of a three-generation family history pedigree to evaluate a disease-specific case scenario for genetic/genomic family history information in class. (See Appendix B: Alzheimer's disease case scenario/activity).
   d. Optional activities to engage students might include a personal anecdote (nurse faculty or guest speaker), historical event (local, state, national, or international), thought-provoking dilemma, real-world example, short video clip, or legal issue surrounding lack of screening.

3. Post-class activities:
    a. Peer-To-Peer interview to assess a three-generation family history pedigree using tools described in class. This may be video-recorded to facilitate student self-critique and for faculty grading. (See Appendix C: Assignment Guidelines)
    b. Create a journal to express personal values and beliefs towards genetics/genomics. In first person format, journal your personal beliefs related to genetics/genomics and how it relates to the practice of nursing by responding to the following questions:
        - What are your personal beliefs/attitudes regarding genetics/genomics and nursing care. How do you see genetics/genomics impacting your clinical practice?
        - Describe what you learned through this learning activity. What are your strengths? What are your growth areas? Identify at least two realistic learning goals focused on your growth areas.
        - How do you see family pedigrees used in clinical practice? How beneficial do you believe this information is when planning and carrying out nursing care?
        - What are the risks of people disclosing family history information with health care providers? What are the benefits? What are some of the ethical considerations of collecting family history information?
        - Describe how the client's and your culture, religious views, and any prior experiences may create bias and/or affect the care of the client.

        If the faculty member chooses to have the students record (audio, video, or digital) the Peer-To-Peer interview the students can respond to these additional questions to self-evaluate their therapeutic communication skill performance:
        - What were your verbal and non-verbal communication skill strengths during the interview?
        - What were your verbal and non-verbal communication skill growth areas during the interview?
        - What would you do differently with a real client?

Assessments

1. Faculty and Student Guidelines for the Peer to Peer Interview assignment.
    a. The guidelines for faculty include necessary preparations for the learning assessment (Appendix B). The preparations include:
        - Assignment materials for the students (i.e. interview guidelines and pedigree tools resources)
        - Facilitating the process for forming student dyads, and
        - Setting expectations for the learning assessment (i.e. assignment guidelines and grading rubric).
    b. The content and skills that students will use to prepare for the assessment will be

provided through lecture material and class learning activities. Students will be provided guidelines for the assignment as well (Appendix B), along with the performance expectations and grading rubric (Appendix C).

References

Consensus Panel on Genetic/Genomic Nursing Competencies. (2009). Genetic and genomic nursing: Competencies, curricula guidelines, and outcome indicators, (2nd ed.). Silver Spring, MD: American Nurses Association.

Frey, B. B., & Schmitt, V. L. (2007). Coming to terms with classroom assessment. Journal of Advanced Academics, 18(3), 402-423.

Gronlund, N.E. & Waugh, C.K. (2009). Assessment of student achievement, (9th ed.). Upper Saddle River, NJ: Pearson Education.

Additional Resources

- Christensen, K. D., Roberts, J. S., Royal, C. D., Fasaye, G., Obisesan, T., Cupples, L. A., Whitehouse, P. J., Butson, M. B., Linnenbringer, E., Relkin, N. R., Farrer, L., Cook-Deegan, R., & Green, R. C. (2008). Incorporating ethnicity into genetic risk assessment for Alzheimer disease: the REVEAL study experience. *Genetics in Medicine*. 10(3), 207-214. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2483343/

- Consensus Panel on Genetic/Genomic Nursing Competencies (2009). Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators, 2nd Edition. Silver Spring, MD: American Nurses Association. Available at: http://www.genome.gov/Pages/Careers/HealthProfessionalEducation/geneticscompetency.pdf

- Genetics Home Reference http://ghr.nlm.nih.gov/

- Genetics/Genomics Articles for Nursing Educators, http://www.genome.gov/27543639

- Genetics/Genomics Competency Center for Education, http://www.g-2-c-2.org/

- Global Genetics and Genomics Community Interactive Unfolding Case Studies http://g-3-c.org/

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- Greco, K. E., Tinley, S. & Seibert, D. (2012) Essential Genetic and Genomic Competencies for Nurses with Graduate Degrees. Silver Spring, MD: American Nurses Association and International Society of Nurses in Genetics. Available at: http://www.genome.gov/Pages/Health/HealthCareProvidersInfo/Grad_Gen_Comp.pdf

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- Genetic Alliance (2009) Healthcare Provider Card. Resource repository website available at: http://www.resourcerepository.org/documents/632/healthcareprovidercard/#

- National Coalition for Health Professional Education in Genetics (2013). Genetic Red Flags. Available at: http://www.nchpeg.org/index.php?option=com_content&view=article&id=59:colorectal-cancer&catid=36:point-of-care&Itemid=75

- National Coalition for Health Professional Education in Genetics (2013). Core Principles in Family History: Rationale. Available at: http://www.nchpeg.org/index.php?option=com_content&view=article&id=201:rationale&catid=64:core-principles-in-family-history&Itemid=124

- Scheuner, M. T., Wang, S. J., Raffel, L. J., Larabell, S. .K., & Rotter, J. I. (1997). Family history: a comprehensive genetic risk assessment method for the chronic conditions of adulthood. *American Journal of Medical Genetics*. 22(71) 315-23. http://www.ncbi.nlm.nih.gov/pubmed/9268102

- Yoon, P. W, Scheuner, M. T., & Peterson-Oehlke, K. L. (2004). Can family history be used as a tool for public health and preventive medicine? Genetics in Medicine 4(4) 304-310. Available at: http://snhs-plin.barry.edu/Research/FamHist_yoon.pdf

- Yoon, P. W, Scheuner, M. T., & Khoury, M. J. (2003). Research priorities for evaluating family history in the prevention of common chronic diseases. *American Journal of Preventive Medicine*. 24(2) 128-135. Available at: http://www.ajpmonline.org/article/S0749-3797%2802%2900585-8/fulltext

Appendix A: Grading Rubric

Interview & Pedigree Construction Assignment Grading Rubric				
Rating Criteria	**Exceptional** **(## Points)**	**Proficient** **(## Points)**	**Needs Improvement** **(## Points)**	**Not Addressed** **(## Points)**
Pedigree Construction **(25%)**	Student included ***3 or more generations*** using standardized symbols and terminology OR the U.S. Surgeon General's My Family Health Portrait Tool. Student included the cause of death and collected information about common diseases and age of diagnosis for ***at least 80%*** of the family members in the pedigree. Indicates unable to assess (UTA) as appropriate. Individuals with the trait of interest are clearly diagramed in the pedigree.	Student included minimum 3 generation (grandparents, aunts and uncles, parents, siblings and first cousins) using standardized symbols and terminology OR the U.S. Surgeon General's My Family Health Portrait Tool. Student included as much as possible the cause of death and collected information about common diseases and age of diagnosis ***for at least 60%*** of the family members in the pedigree. Indicates unable to assess (UTA) as appropriate. Individuals with the trait of interest are clearly diagramed in the pedigree.	Student included most data from family members but is missing data from some individuals. Trait of interest is clearly diagramed in the pedigree. Student included as much as possible the cause of death and collected information about common diseases and age of diagnosis ***for less than 50%*** of the family members in the pedigree. Indicates unable to assess (UTA) as appropriate. Individuals with the trait of interest ***are not*** clearly diagramed in the pedigree.	No pedigree is included.
Pedigree Analysis **(25%)**	Analysis of the pedigree is **comprehensive**, accurate, **AND** addresses relevant genomic factors that impact the client's health. Identifies potentially significant	Analysis of the pedigree is complete, accurate, **AND** addresses relevant genomic factors that impact the client's health. Identifies potentially significant	Analysis of the pedigree is incomplete, inaccurate, ***and/or does not address*** relevant genomic factors that impact the client's health. Minimally identifies potentially	No analysis included.

Graduate level	information from a family history including environmental exposures and lifestyle ***and discusses related issues/ concerns*** demonstrating awareness of the potential impact of genetic/ genomic information on the individual and other family members. Completes a thorough risk analysis for the identified patient based on their pedigree, culture, environmental exposures, and lifestyle.	information from a family history including environmental exposures and lifestyle. Completes a risk analysis, missing one of the components.	significant information from a family history. Minimally completes the risk analysis, missing two or more components.	Risk analysis not completed.
Reflective Analysis: **Professional Development** **and** **Communication Skills** **(30%)**	**Discusses 3-4:** areas of strength and growth areas in professional development related to genetics/ genomics assessment skills, including privacy and confidentiality measures. ***Comprehensively*** discusses communication skills during interview assessment of the client, including examination of verbal and non-verbal communication skills, techniques used, and identified barriers to communication. Discussion is ***insightful and thoughtful with comprehensive planning*** for development/ enhancement in achieving competencies and strategies to improve future communication. Limited to 2 pages double-space.	**Discusses at least <u>one</u> of each:** areas of strength and growth areas in professional development related to genetics/genomics assessment skills, including privacy and confidentiality measures. ***Adequately*** discusses communication skills during interview assessment of the client, including examination of verbal and non-verbal communication skills, techniques used, and identified barriers to communication. Discussion is ***thoughtful with adequate/appropriate planning*** for development/enhancement in achieving competencies and strategies to improve future communication. Limited to 2 pages double-space.	**Discusses ONLY 1:** areas of strength OR growth areas in professional development related to genetics /genomics assessment skills. ***Does not include*** privacy and confidentiality measures. ***Minimally*** discusses communication skills during interview assessment of the client, including examination of verbal and non-verbal communication skills. Discussion ***lacks thoughtfulness with inadequate and/or inappropriate planning*** for development/ enhancement in achieving competencies and strategies to improve future communication. Less than one page OR over 2 pages in length, double-spaced.	No reflective analysis on professional development and/or communication skills included.

	Conveys thoughts with clarity and conciseness.			
Reflective Analysis: Attitudes, Values, & Beliefs **(20%)**	***Comprehensive discussion*** of own attitudes, values, and beliefs about how genetic and genomics will fit into future nursing practice. Identifies actual or potential ethical issues (dilemmas), ***with insightful and thoughtful analysis*** of feelings and thoughts. Discussion is ***insightful and thoughtful*** regarding implications for practice and with strategies for achieving competency.	***Clearly articulates own*** attitudes, values, and beliefs about how genetic and genomics will fit into future nursing practice. Identifies actual or potential ethical issues (dilemmas), ***with thoughtful analysis*** of feelings and thoughts. Discussion is ***thoughtful*** regarding implications for practice and with strategies for achieving competency.	***Limited discussion of own*** attitudes, values, and beliefs about how genetic and genomics will fit into future nursing practice. ***Minimally*** identifies actual or potential ethical issues (dilemmas), ***with vague/superficial analysis*** of feelings and thoughts. ***Superficial/Minimal*** discussion of implications for practice and with strategies for achieving competency	No reflective analysis on attitudes, values, and beliefs included.

OVERALL Rating:

☐ **Exceptional (**on ALL 4 areas**)** ☐ **Above Expectations** (2-3 Exceptional/1-2 Meets Expectations)

☐ **Meets Expectations** (for ALL 4 areas) ☐ **Needs Improvement** (in any one or more areas)

Formative Feedback:

Appendix B: Alzheimer's Disease Scenario/Activity

Leslie, a 38 year old African-American female, is accompanying her parents Margaret (age 63) and Sylvester (age 66) to the health care clinic. Margaret presents with complaints that Sylvester forgot his way home after a drive to the grocery store. The police returned Sylvester home after a two hour search for his blue truck in their rural county. Additionally, Margaret reports Sylvester's memory has slowly declined for about one year, and he has been more argumentative. Sylvester interrupts by stating, "She treats me like I am a child. She asks me all the time if I know how to do simple things that a kid would have learned. I am a retired cook after working 35 years at our local hospital, and I have raised two children. Our daughter is here right now as proof." At the end of his office visit and multiple tests, Sylvester is diagnosed with early stage Alzheimer's disease.

Leslie walks outside her dad's room to ask a nurse if she should be tested for Alzheimer's disease. Leslie tearfully reports that her paternal grandmother is fine at age 92, and her paternal great aunts (4 total) and great uncles (2 total) developed Alzheimer's disease in their late 80's. All died from the disease by age 95. She also has two paternal cousins that developed Alzheimer's disease at age 62 and age 66. Both cousins are living with advanced stages of Alzheimer's disease. One cousin is her paternal great uncle's child while the other is the child of her paternal great aunt.

Case Scenario Activities:

Inform Students
All students will create a pedigree for Leslie. Details to begin the three generation pedigree are provided in the case scenario. Additional required details will be provided by nurse faculty during a "mock interview" by the students.

Nurse faculty note: The nurse faculty member will provide pedigree details for Leslie during a "mock interview" by the students. Students will randomly ask relevant questions to obtain personal history, family history, and environmental history. The nurse faculty will provide positive answers for Leslie's exposure to exercise, smoking, and frequent use of non-steroidal anti-inflammatory drugs (NSAIDs). Other answers may be provided according to the nurse faculty's preferences. For example, the nurse faculty may decide that Leslie has two paternal aunts who conceived three girls and that Leslie has smoked one pack per day for 10 years.

Ask Students: **How should the nurse explain to Leslie the opportunity to have genetic counseling and the process by which this would be established? To whom should Leslie be referred?**
Ask Students: **How should the nurse explain Leslie's genetic risk for Alzheimer's disease?**
Ask Students: **Should the nurse refer Leslie for genetic testing? Why or why not? Are there risks (psychological or physical) that might be incurred by Leslie?**
Ask Students: **What family history resources and/or tools are available for Leslie to evaluate her risk in private and determine her own desire to proceed to counseling or further evaluation?**

Appendix C: Assignment Guidelines

Assignment Guidelines for Faculty

Interview & Pedigree Construction Assignment

for Genetics/Genomics Competency

Beginning of course:

- Announce assignment due date/post on course schedule
- Provide to students: guidelines and expectations for the assignment
- Allow students to begin thinking about partners for the interview dyad

Two weeks prior to assignment due date:

- Determine/Assign student partners for the interview dyad.
- Review assignment guidelines and Interview & Pedigree Construction Grading Rubric (see Appendix A) with students.
- Answer any questions related to the assignment.
- Address any student concerns about completing the assignment related to nontraditional family structure or living situation.
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Follow-up

- Debrief/Have discussions about most common observations noted from the assessment evaluation (i.e. provide summary of results findings - refer to grading rubric)
- Ask for student feedback on the assignment, i.e. areas most relevant to their learning, perceived challenges/barriers related to completing the assignment, and suggestions for enhancements