

THE ACQUISITION OF STUDENT NURSES' KNOWLEDGE OF GENETICS
AND GENOMICS AND ATTITUDES TOWARD THE APPLICATION OF
THEIR KNOWLEDGE IN CLINICAL PRACTICE

by

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ABSTRACT

BACKGROUND: Nurses have the opportunity to bring a unique perspective to genetic and genomic healthcare through their emphasis of health promotion, prevention, screening, caring, and patient, family, and community relationships. Nurses are expected to have genetic and genomic knowledge that can be integrated into clinical practice. However, researchers today are finding nursing students are not competent or comfortable in the clinical applications of genetics and genomics, even though these students will soon be working in healthcare as it advances in these fields. The purpose of this research was to evaluate the genetic and genomic knowledge of nursing undergraduate students and explore their attitudes about using this knowledge in practice. **METHOD:** A pre- and posttest design was used. Student knowledge was measured online using the Genomic Nursing Concept Inventory (GNCI©) in both tests. Demographic questions were included in the pretest and questions regarding attitudes toward comfort and readiness to apply that knowledge were included in the posttest. The pretest was administered at the beginning of the Spring 2014 semester. The posttest was administered at the end of the same semester, after the nursing students received the majority of genetic and genomic instruction from their program's curriculum. Descriptive statistics were used to examine all data. Total and subscale knowledge scores on the GNCI© were computed for each test. A paired *t*-test was used to compare pre- and post-GNCI© total and subscale scores. Correlations were calculated at both time points. A Spearman correlation was used to examine the relationship between prior experience with genetic education or exposure to people with a genetic condition and total pre-score knowledge on the pretest. For the posttest, a total attitude score was calculated to examine

the relationship between attitude and post total knowledge scores using a Pearson's r correlation.

FINDINGS: 109 undergraduate junior nursing students participated. Gains in total and subscale knowledge between the pre- and posttest were statistically significant ($p < 0.05$), except for the Mutations subscale. For the pretest GNCI©, the average mean score was 45%, which improved to 50% at the time of the posttest. Lowest scoring items were in the Genome Basics subscale, whereas highest scoring items were found within the Inheritance subscale for the posttest. Mean total attitude scores were 28.33 ($SD = 5.17$) indicating students had a relatively positive attitude towards using their knowledge base in practice. The majority of students (87.1%) agreed that it is important for the nurse to incorporate genetic and genomic knowledge into clinical practice although only 34.9% felt ready to do so. **DISCUSSION:** Genetics and genomic knowledge and preparedness were low among nursing students. This demonstrates a need for more integration of genetic and genomic content within nursing curriculum, including a review of basic concepts. Nurses are expected to perform comprehensive health assessments by incorporating knowledge of genetic, environmental, and genomic influences and risk factors. Lack of a basic understanding could lead to patient consequences related to inadequate risk assessment, referrals for genetic counseling, and patient education.

DEDICATION

This thesis is dedicated to my incredible husband, family, and friends.

To my husband, Carter, thank you for all your support in this endeavor. I owe much of this work to you and your encouragement. Thank you for keeping me company during the late night writing sessions and for what seemed to be the never-ending times of brainstorming, proofreading, and breakdowns. Your personal drive to be the best you can be is inspirational and has kept me accountable to strive for the same. Thank you for keeping God and family first. I love you so much and look forward to more free time, fun, and just plain old life with you.

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CHAPTER 1: INTRODUCTION

Statement of the Problem

Nurses are expected to have a genetic and genomic knowledge that can be integrated into clinical practice (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). This expectation is more than 50 years old, yet researchers today are finding nurses are still not competent or comfortable in the clinical applications of genetics and genomics. As early as 1962, nursing pioneers recommended the greater inclusion of genetics education in nursing curriculum (Lea, Cooksey, Flanagan, Williams, & Forte, 2005). In the 1970's, nurses were encouraged to acquire education about genetics in order to simplify scientific language for patients (Maclean, 1976). More recently, several organizations were created to promote genetics and genomics in healthcare. In 1988, the International Society of Nursing in Genetics (ISONG) was created as part of a national effort to bring the fields of nursing and genetics and genomics together (International Society of Nursing in Genetics, 2013). In 1996, notable groups such as the American Medical Association, the American Nurses Association, and the National Human Genome Research Institute developed the National Coalition for Health Professionals Education in Genetics (NCHPEG) to help incorporate genetics and genomics into healthcare by providing resources to healthcare professionals and students (NCHPEG, 2014). Lashley (2001) described many of these organizations' efforts as having a beginning impact on the genetic knowledge of healthcare providers; however, these efforts must continue in order to meet the demands of the "genetic revolution" occurring in healthcare.

The completion of the Human Genome Project (HGP) in 2003 marked a turning point in the history of genomic knowledge and resources available for healthcare professionals including nurses (Thompson & Brooks, 2010). It was not until after the completion of the HGP that 49 nursing organizations came to a consensus on the need to develop core genetic and genomic competencies for every nurse and nursing student (Calzone, Jenkins, Prows, & Masny, 2011). These standards are known as the *Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines, and Outcome Indicators* (the “*Essentials*”) and were formed by the Consensus Panel on Genetic/Genomic Nursing Competencies in 2006. It was this benchmark that sought to prepare the nursing workforce to respond to present genetic and genomic advances by incorporating this learned level of care into their own clinical practice. Since its development, nursing researchers and educators have pushed to create an awareness among practicing nurses, educators, and students of the *Essentials* by encouraging its implementation as a guiding standard for genetic and genomic education. To date, no study has evaluated how well the recommendations for education from the *Essentials* are known by or are being met for any level of nurse (Thompson & Brooks, 2010).

An understanding of how student nurses, registered nurses, and nurse educators are meeting the set standards is important since the Centers for Disease Control and Prevention (2013a) stated 9 out of the 10 leading causes of death in the United States, such as heart disease for example, have a genomic component. Approximately 600,000 people die of heart disease each year in the United States (Centers for Disease Control and Prevention, 2013b).

Additionally, the National Cancer Institute (2012) reported approximately 10% of all breast

cancers are due to an inherited mutation for American women. Genomics also plays a role in how effective medication may be in an individual. For example, an estimated 30 genes interact with warfarin, a widely prescribed anticoagulant, which could contribute to determining appropriate dosages given the medication's narrow therapeutic range (Wadelius & Pirmohamed, 2007).

As of 2013, The Genetic Nursing Credentialing Commission (GNCC) listed 66 nurses nationwide with specialty certification in genetics. The majority of these nurses were advanced practice nurses (N=50), and only two nurses (one registered and one advanced) were located in Florida. These numbers demonstrated how likely nurses *without* specialized training will be responsible for teaching and caring for patients with genetic and genomic issues. Nursing has the opportunity to bring a unique perspective to genomic healthcare through its emphasis of health promotion, prevention, caring, screening, and patient, family, and community relationships (Calzone, Jenkins, Nicol, Skirton, Feero, & Green, 2013). However, without genetic knowledge, nurses could provide incorrect information to patients with genetic conditions (Maclean, 1976), and fall short of their role in identifying health risks that correlate with genomic factors (Jenkins, Grady, & Collins, 2005), being familiar with screening tests, and coordinating care for genetically involved families (Lashley, 2001).

A systematic review of research evaluating nurses' achievements in genetic core competencies reported poor genetic knowledge for registered nurses across 13 studies (Skirton, O'Connor, Humphreys, 2012). In addition, there was little evidence of the extent to which nursing *students* have achieved competency, a population Collins and Stiles (2011) do argue to

be the most important since current students will soon be working in healthcare that is advancing in genetic knowledge. Four studies have examined *perceived* or self-reported knowledge of nursing students (Dodson & Lewallen, 2010; Hsiao, Van Riper, Lee, & Chen, 2011; Maradiegue, Edwards, Seibert, Macri, & Sitzler, 2005; Vural, Tomatir, Kurban, & Taspinar, 2009), and only one study evaluated the *actual* knowledge of genetics in nursing students and practicing nurses (Cohen, 1979). These studies call for future research to determine the *actual* genetic knowledge of nursing students, and the need for wide-scale testing through a unified tool so that data can be generalized to other populations (Collins & Stiles, 2010; Hsiao et al., 2011; Dodson & Lewallen, 2010).

Therefore, the goal of this research was to further the understanding of the genetic and genomic knowledge of nursing undergraduates. The Genomic Nursing Concept Inventory©, developed by Dr. Linda Ward of Washington State University, was used as a measure of genetic and genomic literacy (Ward, 2011). In addition, student attitudes, comfort, and readiness were also surveyed to analyze the students' view of implementing their knowledge in clinical practice.

Purpose of the Study

The purpose of this thesis was to evaluate the level of genetic and genomic literacy of students, and student attitudes, readiness, and comfort toward using their knowledge in clinical practice. This study was conducted at a large state university in Florida using a sample of undergraduate nursing students.

Research Questions

The research aims to answer the following questions:

1. What is the genetic and genomic literacy as measured by the Genomic Nursing Concept Inventory© of undergraduate nursing students?
2. What are nursing student attitudes toward using their genetic and genomic knowledge in clinical practice? Do nursing students feel comfortable and prepared?
3. What is the relationship between genetic and genomic literacy and nursing student attitudes toward using their knowledge in clinical practice?

Definitions

The term genomics can be defined as the “study of all the genes in the human genome together, including their interactions with each other, the environment, and the influence of other psychosocial and cultural factors” (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009, p. 9). Genetics can be defined as the “study of individual genes and their impact on relatively rare single gene disorders” (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009, p. 8). Ward (2013), the creator of the Genomic Nursing Concept Inventory (GNCI©) used in this thesis, differentiated the term genomics from genetics by describing how genomic conditions involve multiple genes and environmental influences, whereas a *genetic* condition involves a single gene. It is important to note that the two terms overlap and will continue to evolve as genome research continues (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). For the purposes of this paper, both terms were used and were often coupled together to encompass the slight differences of the definitions. At times, the term “genetics” was used alone if stated as such by the literature, or when the familiarity of the term was beneficial, like when surveying the undergraduate students.

CHAPTER 2: REVIEW OF LITERATURE

The literature available related to the topic of nursing student genetic and genomic knowledge and comfort was limited. Four studies were found that examined nursing students' *perceived* knowledge of genetics and attitudes towards applying that knowledge in practice. Only one study was found to examine *actual* genetic knowledge. The studies that examined perceived knowledge all used a similar instrument first designed by Maradiegue et al (2005). The original questionnaire included 109 multiple-choice and dichotomous items to survey demographics, perceived knowledge level of genetic topics (such as genetic terms and conditions), clinical comfort in applying genetic knowledge, previous genetic educational experiences, and educational methods for genetic curriculum integration. Although each study modified the number of survey items for their study sample, the subsection themes from the original questionnaire remained mostly the same. Perceived knowledge was rated on a scale that included the choices of "none", "minimal", "some", and "high". Clinical comfort was rated on a scale that included the choices of "definitely not", "probably not", "probably yes", and "definitely yes". A limited number of survey items common to all studies were compared within the literature review.

Perceived or Self-Report Knowledge of Genetics

Maradiegue and colleagues (2005) examined advanced practice nursing students' genetic knowledge and perceptions of integrating genetics into clinical practice using a descriptive design. Their goal was to use the results of the study to incorporate genetic healthcare issues into future curriculum. This convenience sample of students (N=46) had at least a bachelor's degree

in nursing. The study found that 95% of participants reported no prior training on the majority of genetic conditions presented on the survey during their undergraduate nursing program. The majority of students reported being familiar with genetic terms like mitosis (95%) responding that they had a “some” to “high” –level of knowledge. The perceived knowledge of specific genetic conditions varied among students. Approximately half of the students reported “some” to “high” knowledge of breast cancer (59%), colon cancer (63%), Turner syndrome (52%), and cystic fibrosis (46%). In contrast, only 8% and 13% of students reported “some” to “high”-level of knowledge for Gaucher’s disease and neurofibromatosis, respectively. Few students felt comfortable integrating genetics into their clinical practice. Approximately one-third of students (34%) responded “probably yes” or “definitely yes” to feeling comfortable about speaking with a family about their genetic condition and only 22% responded with the same conviction when asked if comfortable drawing a pedigree.

Vural et al. (2009) used a cross-sectional design to examine self-reported genetics knowledge among 162 junior and senior Turkish undergraduate nursing students who had taken a genetics course before their junior year. In this study, mitosis was the most known term among students with 90.7% reporting “some” to “high” knowledge of the term. For genetic conditions, 96.2% reported “some” to “high” knowledge for breast cancer, 83.9% for colon cancer, 77.8% for Turner syndrome, and 66.6% for cystic fibrosis. Fewer students were familiar with Gaucher’s disease (10.5%) and neurofibromatosis (14.9%), which were similar finding in the study by Maradiegue et al (2005). The majority of students (82%) felt comfortable (“probably yes” or

“definitely yes”) to speaking to a family about their genetic diagnosis and drawing a pedigree (87.6%).

Dodson and Lewallen (2010) also examined perceived knowledge and attitudes toward genetics at the undergraduate level. Undergraduate nursing students (N=275) pursuing their bachelor’s in nursing across the freshman, sophomore, junior, and senior academic levels were surveyed. The majority of students reported having a “some” to “high” level of perceived knowledge of common genetic terminology (mitosis = 92%). In fact, Dodson and Lewallen (2010) reported that similar to Maradiegue et al. (2005), students reported more perceived knowledge of basic genetic terms than specific conditions. Greater than half of the students had “some” to “high” knowledge regarding the genetic conditions of breast cancer (71%), colon cancer (64%), and cystic fibrosis (64%). Only 2% students were familiar with Gaucher’s disease, 5% with neurofibromatosis, and 21% with Turner syndrome. Sixty-one percent and 68% of students reported feeling comfortable (“probably yes” or “definitely yes”) when asked to speak to a family regarding their genetic diagnosis and drawing a pedigree, respectively.

Hsiao et al. (2011) examined the perceived genetics knowledge and clinical comfort with 434 nursing students at all undergraduate levels at a university in Taiwan. All students had taken at least taken a basic bioscience course. Hsiao et al. had the most notable revisions to the Maradiegue et al. survey in order to reflect the recent efforts of integrating genetics into nursing curriculum. Many nursing students in this study perceived themselves as having a “some” to “high” knowledge of genetic terms like mitosis (89.9%) and the conditions of breast cancer (71.6%) and colon cancer (71.6%). Approximately 45.1% of students had a “some” to “high”

knowledge level of Turner syndrome, 27% of cystic fibrosis, and 9% of Gaucher’s disease. In comparison to all four studies, this study had the highest number of students (36.8%) who were knowledgeable in neurofibromatosis. Almost 80% of students were reported “definitely yes” or “probably yes” to feeling comfortable with drawing a pedigree, whereas only 46.1% were comfortable discussing a genetic diagnosis with a family.

Table 1 compiles the results from the four studies on perceived knowledge of a limited number of items common to all versions of the surveys: (M) Maradiegue et al. (2005), (V) Vural et al. (2009), (D) Dodson and Lewallen (2010), and (H) Hsiao et al. (2011).

Table 1: Perceived Knowledge Results from Four Studies

	M	V	D	H
Mitosis	95%	90.7%	92%	89.9%
Breast cancer	59%	96.2%	71%	71.6%
Colon cancer	63%	83.9%	64%	63.1%
Turner syndrome	52%	77.8%	21%)	45.1%
Cystic fibrosis	46%	66.6%	64%	27%
Gaucher’s disease	8%	10.5%	2%	9%
Neurofibromatosis	13%	14.9%	5%	36.8%
Comfortable talking to family about genetic condition	34%	82%	61%	46.1%
Drawing Pedigree	22%	87.6%	68%	78.5%

Actual Knowledge of Genetics

In contrast to the four studies that examined perceived knowledge, Cohen (1979) assessed the *actual* genetic knowledge of 366 senior nursing students from different nursing degree level programs and 114 registered nurses in the United States using an investigator developed multiple choice exam. Each multiple-choice question was worth one point if correctly

answered, and students were tested on nine categories. Topics of the categories included basic genetic knowledge, human genetics, genetic diseases, and risk interpretation. Total scores and subscores of each topic were calculated, and students were tested at one time point. Findings for practicing and student nurses were combined since there was no significant difference in knowledge between the 2 groups. Overall, only 4.2% of the subjects (students and nurses) demonstrated an “adequate” knowledge of genetics. “Adequate” knowledge was determined by achieving 75% or better on the questionnaire. The average total score was 47%. The average subscore for basic genetic knowledge (7 items) was 68.6%, and only 49.9% of the sample chose the correct answer for the 1 risk assessment question.

Conclusions from the Review of Literature

The studies about nursing students’ perceived knowledge showed interesting findings. While overall knowledge of genetic conditions was low, many students stated they would be comfortable discussing a genetic diagnosis with a family. However, Vural and colleagues (2009) questioned a student’s ability to discuss genetic conditions with patients given students mostly reported “minimal” knowledge about genetic concepts. Limitations of measuring perceived knowledge were discussed by 3 of these studies. The biggest concern among these studies was that perceived knowledge does not allow for an accurate reflection of students’ “true knowledge status” with genetics (Vural et al., 2009, p. 231). While perceived knowledge does help identify student nursing knowledge needs, data on the *actual* knowledge of genetics would provide a better indication because there is no opportunity for the student to over-report what they know (Dodson & Lewallan, 2010; Hsiao et al., 2011; Vural et al., 2009). Given that there was only

one article found to evaluate *actual* knowledge of genetics, this research project sought to further investigate the genetic and genomic knowledge of undergraduate nursing students by using the Genomic Nursing Concept Inventory© as a measure of genetic and genomic literacy. Student attitudes, comfort, and readiness were also surveyed to evaluate students' perspective of implementing their actual knowledge in a clinical setting.

CHAPTER 3: METHODS AND PROCEDURES

Design

A pre- and posttest design was used to compare students' genetic and genomic knowledge before and after receiving the majority of their genetic and genomic content in an undergraduate nursing program. Participants were asked to complete two online tests in a setting of their choice (home, school computer lab, etc.). Each test was expected to take 30-40 minutes to complete and both were administered over the course of one semester. The pretest was open for a two-week time period in February, and the posttest was open for a two-week time period in April. This study was approved by the university's Institutional Review Board (Appendix A).

Subjects and Setting

Students enrolled in the generic undergraduate Bachelor of Science in Nursing (BSN) program were invited to participate. The study took place over the course of one semester. Students were recruited from the core Pathophysiology course offered in the 2014 spring semester during their junior year. At this time, most students were concurrently enrolled in the pharmacology course and had also completed their health assessment lecture and lab the previous semester. These three courses include much of the genetic and genomic content assessed by the GNCI©. All pathophysiology classes during the 2014 spring semester were held as scheduled; only the completion of the two tests was considered research activity. Eligible students were included if they were at least 18 years of age and enrolled in the pathophysiology

course. Students were excluded only if they chose not to participate. The pretest was administered in February and the posttest was administered in April.

Recruitment

During a live class at the start of the spring semester, students enrolled in the pathophysiology course were informed about the study by the principal investigator (PI) and given an introductory letter for the research. Students were informed that the study was voluntary and choosing not to participate would not affect their grade in the course.

Participants were given four extra credit points added to their final pathophysiology exam grade as an incentive for participating. Points were given only if students completed both tests. An alternative extra credit assignment worth the same amount of points was offered to students who chose not to participate in the study.

Instruments

GNCI©

Permission for use of the Genomic Nursing Concept Inventory (GNCI©) can be reviewed in Appendix B. The 31-item GNCI© was developed as a measure of genetic and genomic literacy (Ward, 2011) and was included in both the pre- and posttests for this study (see Appendix C and D). The 31-items are presented as multiple-choice questions with one correct answer. The content domain of the GNCI© covers 18 concepts in 4 topical categories derived from the *Essentials* document. The 4 topical categories, or subscales, include Human Genome Basics (12 items), Mutations (3 items), Inheritance Patterns (8 items), and Genomic Healthcare Applications (8 items) (Ward, 2011). Examples of the 18 concepts found within the 4 subscales

include gene function and expression for Genome Basics, mutations and disease for the Mutation subscale, autosomal dominant and recessive patterns for Inheritance, and family history and pharmacogenomics in the Genomic Healthcare subscale. During initial testing of the tool and using a sample of 514 students, the total score for the GNCI© before formal nursing genetic/genomic instruction was 44% (with a reliability of .74) (Ward, 2013). After a nursing genetics course, students (N=353) at the same university had a total mean score of 79% on the GNCI© with a reliability of .70.

Pretest

Two similar tests were used in this study. The pretest was available in February and contained several parts (see Appendix C). Part I consisted of consent, which was implied if students continued with the testing. In Part II, the students created a unique identifier that was later used to match with posttest. This also ensured that students had completed both tests in order to be given the extra credit for participation. Part III confirmed age eligibility (18 years or older) and students' willingness to work individually on the tests and not in a group. Part IV included six demographic questions related to gender, age, previous genetics education, and personal knowledge of family members, friends, and/or patients with genetic conditions. Lastly, Part V consisted of the 31-item Genomic Nursing Concept Inventory (GNCI©).

Posttest

Like the pretest, Part I of posttest implied consent with the continuation of the test (see Appendix D). Part II required students to enter the same unique identifier that was used for the pretest. Part III consisted of the 31-item GNCI©. Part IV had 8 additional questions to

determine students' attitudes (2 questions), comfort (3 questions), and readiness (3 questions) toward using their knowledge in clinical practice. Each question in Part IV was answered on a Likert scale from 0-4 if the students "strongly disagreed", "disagreed", were "unsure", "agreed", or "strongly agreed", respectively, with the statements. Part V asked 2 questions related to prior genetic curriculum content.

Procedures

After the study was introduced to students, the pretest was opened in February. Students gained access to the pretest's link on Qualtrics© through an electronic announcement in the online class forum. Students had a two-week time period to complete the pretest online at a location of their choice (home, school computer lab, etc.). A reminder email about the availability of the pretest was sent to students by the course instructor after week one. At the end of the test, students were asked to email their unique identifier and name to the PI's thesis chairperson. The thesis chairperson was not the instructor for the pathophysiology course and was responsible for keeping track of participation for extra credit purposes only. In order to maintain student confidentiality, the unique identifiers and names were separated (deidentified) and not shared with the PI. In addition, the pathophysiology course instructor did not have access to student's individual answers on the tests. Students who chose not to participate in the research study had the same two-week window to complete and turn in an essay explaining the pathophysiology of cystic fibrosis. Essays were to be sent to the thesis chairperson also.

The same protocol stated above was followed for the posttest. The posttest was opened in April after student received a specific lecture on genetics in genomics in their pathophysiology

course. Genetics content was also presented throughout the semester in Pathophysiology, Pharmacology, Nursing Care of the Families, as well as in Health Assessment in the semester before. Students had a two-week time period to complete the test. For those students who chose not to participate in posttest, an alternative assignment on Gaucher's disease was offered. At the completion of the posttest, students were again asked to email their unique identifier and name to the PI's thesis chairperson. Once the two-week time period for the posttest was closed, both the pretest and posttest were downloaded into an ExcelTM spread sheet from Qualtrics®. The thesis chairperson matched the tests using the unique identifiers and sent the list of student names to the course instructor so extra credit could be awarded to the appropriate students. No students chose the alternate assignment. Once the test data was matched, the data was uploaded into SPSS Version 21 software for analysis. All collected information was kept confidential, and all deidentified data remained in a password-protected file on the PI's and thesis chairperson's computer.

Data Analysis

All data were analyzed using descriptive statistics (frequencies, percentages, and means). Total and subscale knowledge scores on the GNCI© were computed for each test. To calculate total and subscale knowledge scores, answers to each question were transformed into a dichotomous variable where the correct answer equaled "1" and an incorrect answer equaled "0". A "0" was given to any question left unanswered by the student. The number of correct answers per subject was then added to create a total score; the higher the score, the higher the knowledge. Paired *t*-tests were used to compare total and subscale knowledge scores between the pretest and

posttest. Reliability statistics were also calculated for both versions of the test. Both demonstrated reliability with a Chronbach's alpha of 0.764 for the pretest and 0.775 for the posttest.

A total attitude score was also calculated. The 0-4 Likert scale was transformed into a 1-5 scale, which when added, became the total attitude score. Again, the higher the score, the better the attitude towards implementing their genetic and genomic knowledge in clinical practice. Descriptively, "strongly agree" and "agree" were combined to make a single category of "agree", where "strongly disagree" and "disagree" were combined to make a single category of "disagree."

Correlations were calculated at both time points. For the pretest, a Spearman correlation was calculated using dichotomous variables to determine if prior experience with education (yes/no) or exposure to people with a genetic condition (yes/no) was related to total pre-score knowledge (high knowledge/low knowledge). The mean total score (13.83) on pretest was used to indicate high versus low score. In the posttest, a Pearson's r correlations was used to explore the relationship between the total knowledge scores and the total attitude score.

CHAPTER 4: FINDINGS

Sample Demographics

Participants consisted of 109 undergraduate junior BSN students with a mean age of 23.07 ($SD = 5.270$). Students were predominantly female (82.6%). Many students (76.1%) had previously taken a course that had some genetics content; whereas only 2.8% had taken a course completely dedicated to genetics prior to taking the pretest. Courses reported with some genetics content included pre-nursing courses (biology courses, anatomy and/or physiology courses), and core nursing courses (Pathophysiology, Health Assessment, and Nursing Care of Families). Some students (27.5%) reported having a family member or friend with a known genetic condition. The top three conditions reported were cystic fibrosis, Down's syndrome, and sickle cell anemia. Even more students (45%) reported working with a patient in clinical with a known genetic condition. The most frequent reported conditions seen in clinical were cystic fibrosis, sickle cell anemia, diabetes, and Down's syndrome. There were no significant correlations between having prior educational content or prior exposure to people with genetic conditions and knowledge level on the pretest ($p > 0.314$ for all correlations).

Research Question 1: What is the Genetic and Genomic Literacy of Undergraduate Nursing Students as Measured by the GNCI©?

The minimum and maximum score of the pretest were 4 and 27 (out of 31-items), respectively (see Table 2). The minimum and maximum score of the posttest were 6 and 28, respectively. The GNCI © mean total-knowledge score from the pretest improved from 13.83

($SD = 4.447$) to 15.49 ($SD = 4.696$) at the time of the posttest. This improvement was statistically significant ($p = .000$). Considering the GNCI consisted of 31-items, a mean score of 13.83 equates to students answering approximately 45% of the questions correctly for the pretest. A mean score of 15.49 at the time of the posttest equates to students answering approximately 50% correct. For both the pretest and the posttest, the mode total score was 15, or 48% of the 31-items answered correctly.

Table 2: Mean Total and Subscale Scores for the Pre- and Posttest with Paired t -test Results

	Pretest	Posttest	<i>p</i>	<i>t</i>
Total scores			.000	-5.363
Mean	13.83	15.49		
<i>SD</i>	4.447	4.696		
Minimum	4	6		
Maximum	27	28		
Genome Basics			.001	-3.365
Mean	3.68	4.27		
<i>SD</i>	2.068	2.316		
Minimum	0	0		
Maximum	10	12		
Mutations			.134	-1.510
Mean	1.12	1.24		
<i>SD</i>	.825	.971		
Minimum	0	0		
Maximum	3	3		
Inheritance			.000	-3.989
Mean	4.43	5.07		
<i>SD</i>	1.863	1.762		
Minimum	1	0		
Maximum	8	8		
Genomic Healthcare			.040	-2.054
Mean	4.60	4.91		
<i>SD</i>	1.599	1.444		
Minimum	0	1		
Maximum	8	8		

Note. Significance based on $p < 0.05$.

Subscale score also improved over time (as seen in Table 2). The Genome Basics mean subscale score increased from 3.68 ($SD = 2.068$) to 4.27 ($SD = 2.316$), Mutations subscale scores improved from 1.12 ($SD = .825$) to 1.24 ($SD = .971$), Inheritance subscale scores improved from 4.43 ($SD = 1.863$) to 5.07 ($SD = 1.762$), and Genomic Healthcare subscale scores increased from 4.60 ($SD = 1.599$) to 4.91 ($SD = 1.444$). All of the knowledge gains were statistically significant ($p < 0.05$) except for the Mutations subscale ($p = 0.134$). Eight out of the 10 lowest scoring items for the pretest and 7 out of the 10 lowest scoring items for the posttest were within the Genome Basics subscale (see Table 3). The Inheritance subscale questions were also among the top 15 questions answered correctly in the posttest.

Table 3 indicates that each individual item showed either a knowledge gain or knowledge loss (Min: -6.42, Max: 24.77). The greatest knowledge gain was seen with question 24, where 30.3% of students answered the item correctly in the pretest and 55% answered correctly in posttest. Question 24 was from the Inheritance subscale, which asked students to choose the best answer that defined an autosomal disorder. The greatest knowledge loss was seen in Question 9 with 37.6% of students answering correctly in the pretest and only 31.2% in the posttest. Question 9 was from the Genome Basics subscale, which asked students about the role of an insulin gene.

Table 3: Individual Item Differences Between the Pre- and Posttest (N = 109)

GNCI© Question	Subscale	Pretest: % Correct	Posttest: % Correct	Pre- and Post- Differences
11	Genome Basics	4.6	7.3	2.75
13	Genome Basics	9.2	14.7	5.50
4	Genome Basics	17.4	21.1	3.67
23	Genomic Healthcare	20.2	27.5	7.34
18	Mutations	24.8	27.5	2.75
6	Genome Basics	27.5	28.4	0.92
9	Genome Basics	37.6	31.2	-6.42
29	Genome Basics	22	33.9	11.93
8	Genome Basics	27.5	38.5	11.01
7	Genome Basics	32.1	38.5	6.42
20	Genomic Healthcare	43.1	42.2	-0.92
3	Genome Basics	36.7	44	7.34
1	Genome Basics	28.4	45.9	17.43
19	Mutations	38.5	47.7	9.17
25	Inheritance	41.3	51.4	10.09
21	Mutations	53.2	53.2	0
27	Genomic Healthcare	52.3	54.1	1.83
24	Inheritance	30.3	55	24.77
28	Genomic Healthcare	55	57.8	2.75
10	Inheritance	55	61.5	6.42
30	Inheritance	59.6	61.5	1.83
5	Genome Basics	59.6	62.4	2.75
17	Inheritance	52.3	64.2	11.93
22	Genomic Healthcare	57.8	71.6	13.76
14	Genomic Healthcare	70.6	78.9	8.26
15	Inheritance	78	78.9	0.912
16	Inheritance	78	79.8	1.83
2	Genome Basics	86.2	80.7	-5.50
31	Inheritance	70.6	81.7	11.01
26	Genomic Healthcare	96.3	91.7	-4.58
12	Genomic Healthcare	86.2	92.7	6.42

Note. Table is arranged in order from questions answered least correct to most correct on the posttest.

Research Question 2: What Are Student Attitudes Toward Using Their Genetic and Genomic Knowledge in Clinical Practice? Do Students Feel Comfortable and Prepared?

Most students (87.1%) agreed that it is important for the nurse to incorporate genomics into their clinical practice, specifically when performing health risk assessments (see Table 4). Over half of the students (58.7%) agreed to feeling comfortable with the information presented on the GNCI©. Additionally, many students agreed that they feel responsible to provide genomic education to patient and families (68.6%) and feel prepared to identify patients in need of a genomic referral (57%). More than half of the students agreed they felt comfortable drawing a pedigree (63.3%) and with identifying inheritance patterns (56.9%). Approximately 40.0% reported that they felt their curriculum has prepared them to incorporate genetics into practice. However, when asked if they felt ready to use their knowledge in clinical practice, only 34.9% of students agreed with this statement.

Students' total attitude scores showed a mean of 28.33 ($SD = 5.17$) and mode of 32 (11% of students). With the maximum total attitude score as 40, 45% of students scored a 30 or higher indicating relatively positive attitudes towards using their knowledge in practice. The lowest total attitude score was 13 (.9%) and the highest was 40 (1.8%).

Table 4: Student Attitudes Towards Using Genomic Knowledge (N=109)

	Agree	Unsure	Disagree
1. I feel it is important for the nurse to incorporate genetic health risk assessment into their clinical practice	87.1%	7.4%	5.6%
2. I feel comfortable with the information presented on this survey.	58.7%	32.1%	9.2%
3. I feel prepared from my educational experiences to incorporate my genetic knowledge base into clinical practice.	40.4%	38.5%	21.1%
4. I feel responsible as a nurse to discuss and teach genetics to patients and their families	68.6%	22.2%	9.3%
5. I feel ready to use my genetic knowledge base in clinical practice.	34.9%	45%	20.2%
6. I feel prepared to identify patients who should be referred to a genetics counselor for genetic testing.	57%	29.9	13.1%
7. I feel comfortable with drawing a pedigree for a patient in order to depict their family history.	63.3%	17.4%	19.3%
8. I feel comfortable with identifying inheritance patterns of genetic diseases.	56.9%	28.4%	14.7%

Research Question 3: What is the Relationship Between Genetic and Genomic Literacy and Student Attitudes Toward Using Their Knowledge in Clinical Practice?

The Pearson correlation between the post-total knowledge score and post-total attitude score was statistically significant ($r(107) = .218$ and $p = 0.023$). Table 5 highlights the positive relationship between the post-total knowledge and post-total attitude score, as well as the post-inheritance subscale score and post-total attitude ($r(107) = .226$ and $p = 0.018$). No other knowledge subscale scores were significantly correlated to the total attitude score.

Table 5: Correlations of Post-Total and -Subscale Knowledge Versus Post-Total Attitude

Knowledge		Total Attitude
Total Knowledge Score	Pearson Correlation	.218*
	Sig. (2-tailed)	.023
	N	109
Inheritance Subscale Score	Pearson Correlation	.226*
	Sig. (2-tailed)	.018
	N	109

Note. Correlation is significant at the 0.05 level (2-tailed).

CHAPTER 5: DISCUSSION

Student Genetic and Genomic Knowledge

Student total-knowledge of genetics and genomics improved from February to April. Although a paired *t*-test showed these knowledge gains were statically significant ($p < 0.05$), student scores only increased a modest 5% between the pretest (45%) and the posttest (50%). These findings differ from the GNCI© pre- and posttest total knowledge scores originally reported by Ward (2013). Prior to a genetics course, students scored a 44%. Post course, their total knowledge score was 79% (a 35% difference). However, unlike Ward's sample who's knowledge was evaluated after taking a semester long genetics course, students in this study received the majority of their genetics and genomic instruction from one targeted lecture in Pathophysiology and information presented in other concurrent, core-nursing classes such as Pharmacology, Nursing Care of the Families, and Nursing Care of the Adult I during the same semester. Genetic and genomic content was also taught in a Health Assessment class taken one semester prior to the administration of the pretest.

The integration of genetics into American nursing programs has been described as “sporadic at best” (Dodson & Lewallen, 2010, p. 339). Hetteberg et al. (1999) surveyed faculty members from nursing programs around the United States to find that 73% included a median of only 4 instructional genetic content hours in their nursing courses. The 5% improvement from the pre- and posttest total knowledge scores in this study suggest that the genetic and genomic content within the curriculum was not enough to substantially increase these students knowledge of genetics and genomics over the study period. These students are in need of more genetics and

genomics instruction, and placement and amount of instruction should be considered as it may influence student genetic knowledge (Dodson & Lewallen, 2010).

Some Individual GNCI© items showed poor genetic and genomic basic knowledge. Given the dense curriculum of a nursing program, students are expected to come into a nursing program with basic knowledge learned in prerequisite courses such as Biology or Anatomy and Physiology. In addition, nursing faculty may devote little time to reviewing basic information or suggest students review this information on their own. This may result in a review of basic knowledge not being done. Other studies with undergraduate nursing students have shown that knowledge can be lost if not reinforced over time (Loerzel, 2013). This may account for the poor recall of basic knowledge reflected in this study. It is also important to note that not all students reported receiving genetics instruction in previous courses where basic genetics would have been discussed.

Despite, poor basic knowledge, it was interesting that students could still answer questions from other subscales that involved knowledge application. The higher scores in the Inheritance subscale can be related to the content and application nursing students did receive in their core nursing courses. For example, students were taught how to record family histories and transfer the information into a pedigree in Health Assessment. Inheritance patterns (autosomal dominant, recessive, etc.) were also heavily taught in their Pathophysiology course. More students were also successful in the subscale of Genomic Healthcare, which included the concepts of family history, pharmacogenomics, cancer genetics, and genetic testing. In fact, the question that the greatest number of students got correct in the posttest addressed a

pharmacogenomics topic. This content would have been covered in the students' concurrent Pharmacology course. This supports that students are learning about critical genomic topics and can apply this knowledge in some situations. However, issues in practice can arise when students are able to identify inheritance patterns and the pharmacogenomics of a medication but are unable to explain these concepts to patients because of a poor basic knowledge of genetics and genomics. Absence of basic knowledge could lead to giving patients false information (Cohen, 1979).

Knowledge scores in this study were similar to Cohen's (1979) findings. Cohen found that students and practicing nurses had a low mean total score of 47%, which was within the range of this study's pre- and posttest scores. While Cohen's survey was not derived from the *Essentials* document, these findings may suggest that student and practice nurses, in general, only have a moderate level of knowledge related to genetics and genomics and more specific courses and reinforcement may be necessary to increase or reinforce knowledge among nurses overall. While assuming full responsibility of patient genetic counseling is not expected, knowledge and consciousness of genetic issues must be increased to avoid serious consequences related to inadequate risk assessment, education, and referral (Cohen, 1979).

Student Attitudes

The *Essentials* states a registered nurse must be able to perform a "comprehensive health and physical assessments which incorporate knowledge about genetic, environmental, and genomic influences and risk factors" among other competencies (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009, p. 11). This study's findings suggested that

most students would agree with this standard. However, results also revealed that student readiness toward using this genetic knowledge in clinical practice was low. These results are comparable to previous research, which has also shown that many students do not feel prepared to take care of patients and their families with genetic disorders (Dodson & Lewallen, 2010; Hsiao et al., 2011; Maradiegue et al., 2005). However, in this study most students did feel prepared to refer patients to a genetic counselor, which could ensure expert care for the patients.

Knowledge and Attitude Relationships

Over half of the students reported feeling comfortable with the knowledge needed to take the GNCI©, but low posttest total-knowledge scores suggests students perceived their knowledge to be higher than it actually was. The Inheritance subscale scores from the posttest were among the top questions answered correctly. This subscale was significantly correlated to total attitude scores suggesting students have a more positive attitude when they know more about a subject.

Limitations

Limitations were present for this study. First, the convenience sample used for this study may not adequately represent undergraduate nursing students in other programs. The average student age was approximately 23 years old and students were predominantly females. This sample lacked men and the distribution of student race or ethnicity was unrecorded and unknown. Second, a two to three month period (the timeframe for this study) allowed minimal time for students to study and absorb the necessary information for the GNCI©. The two-week window for the posttest opened immediately after a Pathophysiology lecture on genetics and two

weeks before final exams. Students may have rushed to complete the posttest given the end-of-semester demands. Third, it is also unknown if the students were motivated to perform at their highest level as participation was not tied to a course grade. Compensation involved extra credit for participation only. Students did not have to receive a specific score to be awarded extra credit.

Fourth, another limitation could be the GNCI© itself. The GNCI© lacks wide-scale testing (Ward, 2011). GNCI© results from this study could only be compared with one other university who previously used the instrument; of which the two universities differed in genetics content delivery (a genetics course vs. genetics content dispersed in multiple courses).

Implications for Future Research

Because of the lack of sample diversity and limited number of students in this study, more research is needed to continue to assess the genetic and genomic knowledge base of nursing students. Examining the level of genetics and genomic knowledge of different populations who practice under the *Essentials*, such as associate-degree seeking students, practicing registered nurses, and advanced practice nurses, is recommended. Attitudes and application of knowledge in these populations' could also be surveyed. Future research could also determine the patient outcomes and benefit to nurses having such knowledge and practice of genetics and genomics.

Further wide scale testing of the GNCI© with various populations is needed in research. Wide scale testing will increase the generalizability of the GNCI©, and further validate the

instrument. Continued item analysis is needed to ensure each question is examined for clinical relevance given the evolving applications of genetics and genomics in healthcare.

Implications for Education

More exposure to genetic conditions and applications for nursing students through curriculum content is needed. Educators can begin by identifying curriculum gaps in genetic and genomic content and by evaluating their own level of comfort and knowledge with the subject. Increasing faculty awareness about the standards set by the *Essentials* could help ensure students are being properly prepared for incorporating genetics and genomics into their nursing care. This study supports the need for review of genetic and genomic basic concepts so students have a solid knowledge foundation prior to learning how to apply their knowledge in practice.

Students also need practice talking to patients about genetic conditions. In addition to lectures, different educational delivery techniques, such as simulation, case studies, and discussion, could be used in order to make students feel more comfortable discussing these topics with patients. This will provide students with the opportunity to practice their therapeutic communication skills when discussing genetic diagnoses, performing health risk assessments, drawing pedigrees, and identifying when to refer a patient to a genetics counselor.

Practice Implications

A greater knowledge of genetics and its implications will enable students and practicing nurses to feel more comfortable and proficient in providing holistic care for patients with genetic conditions. Without education, genetics and genomics in clinical practice will be limited and patient care may be inadequate. Continuing education credits and more training at hospitals on

genetic conditions would allow practicing nurses to receive adequate information on how to care for a genetically involved patient. Nurses need basic knowledge in order to emphasize better health risk assessment and referrals for these patients. With this knowledge base and practice, nurses could also develop educational and coping interventions, such as support groups, to assist patients and families with genetic conditions.

Conclusion

Student and practicing nurses are expected to incorporate a genetic and genomic knowledge into their clinical practice. Previous research has shown that perceived knowledge and comfort is low and actual knowledge has lacked in testing. Education can improve genetics knowledge, however this study suggests education needs to be focused instead of spread out among core nursing courses. This study's findings indicated that students feel responsible for *Essentials* standards like genetic risk assessment and referral, but do not feeling comfortable or prepared to integrate such tasks into clinical practice. Providing more genetic and genomic education, including a basics review, within nursing curriculum is needed. Knowledgeable nurses will only enhance care for genetically involved patients and families.

APPENDIX A: IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
 Office of Research & Commercialization
 12201 Research Parkway, Suite 501
 Orlando, Florida 32826-3246
 Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1
 FWA00000351, IRB00001138**
 To: **Victoria Loerzel and Co-PI: Theresa Munroe**
 Date: **February 17, 2014**

Dear Researcher:

On 2/17/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
 Project Title: The Acquisition of Student Nurses' Knowledge Base of Genetics and Genomics and Attitudes Toward the Application of Their Knowledge Base in Clinical Practice
 Investigator: Victoria Loerzel
 IRB Number: SBE-14-10046
 Funding Agency:
 Grant Title:
 Research ID: N/A.

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewska, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

Signature applied by Joanne Muratori on 02/17/2014 02:21:45 PM EST

IRB Coordinator

APPENDIX B: GNCI© APPROVAL LETTER

January 27, 2014

Victoria Loerzel, PhD, RN, and Theresa Munroe, student nurse
University of Central Florida College of Nursing

Dear Dr. Loerzel and Ms. Monroe,

Thank you for your interest in utilizing the Genomic Nursing Concept Inventory (GNCI) © 2011 at University of Central Florida College of Nursing. I understand that you are planning to import the intact 31-item inventory into Qualtrics® and survey a cohort of students in your undergraduate BSN program.

I have sent (separately) the beta (current) version of the GNCI as a Word document. As you know, the content domain for this instrument was drawn from essential nursing genetic-genomic competencies and validated with more than 100 genetic nurse experts. Item distractors reflect the most common misconceptions of each concept among a convenience sample of approximately 100 baccalaureate nursing students. Testing with 700 BSN students to date has indicated mean preinstructional difficulty of 47% (range 13% to 84%, SD 4.63) and Cronbach's alpha of .775. Because each item is mapped to a particular concept, results provide useful measures of understanding of individual genetic-genomic concepts.

You have my permission to use the intact 31-item inventory in the context of the study you propose. You may edit demographic questions to meet your needs, although I am interested in data sharing and, in particular, being able to correlate inventory scores to participant age, gender, and prior completion of a specific genetics course. No fee is involved. I do ask that you provide appropriate citations in any presentations or publications related to this study.

Because the GNCI is still in development, I request that you share raw data (including participant demographic information and item responses). I am happy to perform psychometric analysis of that data and share that with you, or, if you complete the psychometric analysis, I would appreciate your sharing of the results. I would be interested in collaborating on a manuscript if you choose to disseminate your findings, but that is not a requirement of this permission.

Best wishes with your research. Please don't hesitate to contact me if I can provide any further information.

Linda D. Ward, PhD, ARNP
Assistant Professor
Washington State University College of Nursing
PO Box 1495
103 E Spokane Falls Blvd
Spokane, WA 99210-1495
509 324 7450
linward@wsu.edu

Sincerely,

Linda D Ward
1/27/14 Digital
Washington State University

APPENDIX C: PRETEST

Pretest (February)

Part I

1. Thank you for your interest in this study! Choosing to answer the survey questions will act as your consent to be involved in this research study. Please check “Yes” if you wish to continue.

Yes	No
-----	----

Part II

1. Please type in the first 4 letters of your mother’s first name and your personal birth year (with no spaces in between). This will act as your personal identifier and means of extra credit. For example: Joyc1967

--

Part III

1. I am 18 years or older, and I agree to work individually on this survey (without the help of another person, search engine, etc.)

Yes	No
-----	----

Part IV

1. I am a

Male	Female
------	--------

2. I am _____ years old.

--

3. I have taken a course completely dedicated to genetics before.

Yes	No
-----	----

4. I have taken a course that has incorporated some genetics into the curriculum.

Yes	No
Course Title(s):	

5. Do you have a family member or friend with a known genetic disease or condition? If so, what?

Yes	No
Condition(s):	

6. Have you encountered a patient in clinicals with a known genetic disease or condition? If so, what?

Yes	No
Condition(s):	

Part V

GNCI©

Please mark your answer to each question. If you are not sure about an answer, please make your best guess. Try not to leave any questions blank.

- The primary function of a gene is to
 - determine a particular trait
 - regulate tissue development
 - direct the formation of specific protein(s)
 - control a particular physiologic function
 - replicate DNA
- DNA “sequence” refers to the order of
 - nucleotides
 - genes
 - chromosomes
 - proteins
 - RNA
- Imagine you are examining the DNA of two unrelated people. What percentage of their DNA sequence do you anticipate will be the same?
 - 100%
 - about 99%
 - about 50%
 - 10 to 20%
 - less than 1%

4. The human insulin gene has been identified and designated *INS*. Which cells in your body contain the insulin gene?
 - a. cells in the liver
 - b. cells in the blood
 - c. cells that utilize glucose
 - d. pancreatic beta cells
 - e. all nucleated cells

5. Which statement **INCORRECTLY** describes the amount of DNA in a single human cell?
 - a. 23 pairs of chromosomes
 - b. 1 million genes
 - c. 3 billion base pairs
 - d. 6 billion nucleotides

6. Cells carry out transcription and translation to create
 - a. DNA
 - b. RNA
 - c. proteins
 - d. amino acids
 - e. new cells

7. “Genotype” refers to
 - a. a specific type of gene
 - b. a set of dominant genes
 - c. the traits or characteristics determined by one’s genes
 - d. an individual’s total collection of gene variants

8. Rank the following genetic structures in terms of size starting with the **largest** and proceeding to the **smallest**: chromosome, gene, genome, nucleotide.
 - a. genome, chromosome, gene, nucleotide
 - b. genome, gene, chromosome, nucleotide
 - c. chromosome, genome, gene, nucleotide
 - d. chromosome, nucleotide, genome, gene
 - e. chromosome, nucleotide, gene, genome

9. What role does the insulin gene have in regulating glucose levels?
 - a. allows glucose to enter cells
 - b. encodes enzymes involved in glucose regulation
 - c. signals the pancreas to release insulin
 - d. allows insulin to be produced

10. A dominant genetic disease or health condition
 - a. affects all offspring of an affected parent
 - b. occurs when a single copy of the disease gene is inherited
 - c. requires two copies of the disease gene to be present
 - d. is transmitted to offspring of the same gender
 - e. occurs due to mutations in several genes on the same chromosome

11. A laboratory test of gene expression might examine
 - a. the DNA sequence of the gene
 - b. the order of bases within the mRNA
 - c. the quantity of amino acids available for protein building
 - d. the amount of mRNA transcribed from the gene

The next two questions are about Emma, who is about to begin treatment with warfarin, an anticoagulant medication. Emma had a genetic test showing she has a mutation in a gene that is associated with response to warfarin.

12. What should the nurse giving Emma a standard dose of warfarin expect?
 - a. Emma will most likely be anticoagulated too much.
 - b. She will most likely not be anticoagulated enough.
 - c. Her response to warfarin may be different from expected.
 - d. She is at high risk to have an allergic reaction to warfarin.

13. The genetic test shows that Emma is heterozygous for the gene mutation. What does that mean?
 - a. She has a single copy of the gene.
 - b. She has two copies of the gene; one is dominant and one is recessive.
 - c. She has two copies of the gene, both of which are altered.
 - d. She has two non-identical copies of the gene.
 - e. She inherited an altered gene from her mother.

***** End of situation about Emma *****

14. In the United States, every newborn is screened for various genetic diseases. A baby with a positive newborn screen
 - a. has a genetic disease
 - b. may have genetic disease and requires more testing
 - c. may develop a genetic disease
 - d. is a carrier for a genetic disease

The next two questions are about Sophia, a 2-year-old girl with an unusual autosomal recessive condition called Kindler syndrome.

15. Based on the information above, which statement is most likely true about Sophia's parents?
- At least one parent is also affected with Kindler syndrome.
 - Both parents must be affected.
 - Each parent has at least one copy of the disease gene.
 - There is insufficient information to make any of the above inferences.
16. Sophia's parent are expecting a new baby. What is the chance that the new baby will also have Kindler syndrome?
- 25%
 - 50%
 - 75%
 - it depends on the sex of the baby

*** * * End of situation about Sophia * ***

17. Jacob has Fabry disease, an X-linked condition. Given that information, which of the following statements is most likely to be true about Fabry disease in Jacob's family?
- His father also has Fabry disease
 - His father is a carrier
 - His mother is a carrier
 - Either his mother or his father is a carrier
 - Both his mother and father are carriers

The next few questions concern Anna, a 35-year-old woman who has tested positive for a hereditary breast cancer mutation in a gene known as *BRCA1*.

18. Which of Anna's cells contain the *BRCA1* mutation?
- her breast cells
 - only tumor cells
 - adipose cells
 - cells in her breasts and reproductive organs
 - all her cells that contain a nucleus
19. Anna joins a support group of women with *BRCA1* mutations. Which statement best describes the DNA sequence of these women's *BRCA1* genes?
- Their *BRCA1* sequence is most likely identical
 - Although their *BRCA1* sequence may vary, they likely have identical mutations
 - Their sequence varies according to whether they have a dominant or recessive form of the gene
 - The women are likely to have unique *BRCA1* mutations

20. Anna's sister, Nicky, also had *BRCA1* testing, and her test result was normal. Based on that information, which of the following statements is most likely to be true?
- Anna's DNA contains a *BRCA1* gene; Nicky's DNA lacks that gene
 - Both sisters have *BRCA1* genes but Anna has an altered copy
 - Anna has a dominant form of the *BRCA1* gene; Nicky has a recessive form
 - Both sisters have identical *BRCA1* genes, but the gene is expressed only in Anna

***** End of situation about Anna *****

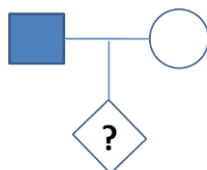
21. The most common way for a mutation to contribute to disease is by
- increasing the rate of DNA replication
 - directing the formation of altered proteins or unexpected amounts of proteins
 - interfering with the body's immune response
 - silencing the gene containing the mutation
22. Carrier testing might be done to see if an asymptomatic individual
- carries a recessive gene that could be passed to offspring
 - carries either a dominant or recessive gene that could be passed to offspring
 - carries a pathogen that could be transmitted to others
 - carries a gene or genes that could cause disease in the future
23. When creating a genetic pedigree, the nurse should consider which of the following findings to indicate a possible need for a genetic referral?
- a previous miscarriage
 - breast cancer in her mother at age 64
 - a heart attack in her father at age 43
 - a sister and a grandmother who had twins
24. An autosomal disorder
- is automatically expressed when a single altered gene is inherited
 - results in production of antibodies to one's own tissues
 - is inherited equally by male and female offspring
 - occurs due to several mutations on the same chromosome
 - occurs due to an incorrect number of chromosomes
25. The genetic contribution to complex disorders like hypertension and diabetes is thought to be
- an incorrect number of chromosomes
 - genes that have not yet been identified
 - genes with multiple alleles
 - a collection of genes, each contributing a small risk
 - relatively minor; environmental factors contribute most of the risk for complex diseases

26. The primary benefit of including common conditions such as hypertension and diabetes in a genetic family history is to
- identify mutations associated with common conditions
 - track diseases in populations
 - inform reproductive decisions
 - help establish diagnoses
 - predict disease risk and plan care
27. A drug receptor is best described as a(n)
- enzyme
 - antigen
 - protein
 - structure or organelle
 - cell
28. Patients respond variably to standard doses of medications. Which statement best describes how genes influence human drug response?
- Genes interact variably with drugs, according to the gene's DNA sequence
 - Genes cause the immune system to react variably to drugs
 - Genes change cells to make them more or less responsive to drugs
 - Genes direct the formation of proteins which interact variably with drugs

The last questions are about Joe and Sally, a young couple who are beginning their family. Joe has an autosomal dominant condition, which Sally is known NOT to have.

29. Which statement is most likely true about Joe's genotype for the condition?
- He most likely has two altered copies of the disease gene
 - He most likely has one normal copy and one altered copy of the disease gene
 - (a) and (b) are equally likely

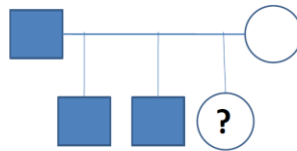
Joe and Sally are expecting their first child, whose gender is unknown. Please consider the following pedigree:



**The dark square indicates Joe, who has an autosomal dominant condition.
The open circle indicates Sally, who does not have that condition
The diamond indicates their unborn child.**

30. Which statement best predicts the child's risk to have inherited Joe's condition?
- a. 100%
 - b. 75%
 - c. 50%
 - d. 25%
 - e. The baby's risk varies according to whether it is a boy or a girl

Years later, Joe and Sally have had two sons, both affected with Joe's condition. They are expecting a new baby, a girl. Please consider this pedigree.



31. Which statement best predicts their daughter's risk to be affected with the same condition?
- a. Her risk is the same as that of each of her brothers
 - b. Her risk is greater than that of her brothers, since both brothers are known to be affected
 - c. Her risk is less than that of her brothers, since both brothers are known to be affected
 - d. Her risk is less because she is female

APPENDIX D: POSTTEST

Posttest (April)

Part I

1. Thank you for your interest in this study! Choosing to answer the survey questions will act as your consent to be involved in this research study. Please check “Yes” if you wish to continue.

Yes	No
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Part II

1. Please type in the first 4 letters of your mother’s first name and your personal birth year (with no spaces in between). Be sure this matches the identifier used for the February survey. Extra credit will only be given if identifiers match. For example: Joyc1967

Part III

GNCIO

Please mark your answer to each question. If you are not sure about an answer, please make your best guess. Try not to leave any questions blank.

1. The primary function of a gene is to
 - a. determine a particular trait
 - b. regulate tissue development
 - c. direct the formation of specific protein(s)
 - d. control a particular physiologic function
 - e. replicate DNA
2. DNA “sequence” refers to the order of
 - a. nucleotides
 - b. genes
 - c. chromosomes
 - d. proteins
 - e. RNA
3. Imagine you are examining the DNA of two unrelated people. What percentage of their DNA sequence do you anticipate will be the same?
 - a. 100%
 - b. about 99%
 - c. about 50%

- d. 10 to 20%
 - e. less than 1%
4. The human insulin gene has been identified and designated *INS*. Which cells in your body contain the insulin gene?
- a. cells in the liver
 - b. cells in the blood
 - c. cells that utilize glucose
 - d. pancreatic beta cells
 - e. all nucleated cells
5. Which statement **INCORRECTLY** describes the amount of DNA in a single human cell?
- a. 23 pairs of chromosomes
 - b. 1 million genes
 - c. 3 billion base pairs
 - d. 6 billion nucleotides
6. Cells carry out transcription and translation to create
- a. DNA
 - b. RNA
 - c. proteins
 - d. amino acids
 - e. new cells
7. “Genotype” refers to
- a. a specific type of gene
 - b. a set of dominant genes
 - c. the traits or characteristics determined by one’s genes
 - d. an individual’s total collection of gene variants
8. Rank the following genetic structures in terms of size starting with the **largest** and proceeding to the **smallest**: chromosome, gene, genome, nucleotide.
- a. genome, chromosome, gene, nucleotide
 - b. genome, gene, chromosome, nucleotide
 - c. chromosome, genome, gene, nucleotide
 - d. chromosome, nucleotide, genome, gene
 - e. chromosome, nucleotide, gene, genome
9. What role does the insulin gene have in regulating glucose levels?
- a. allows glucose to enter cells
 - b. encodes enzymes involved in glucose regulation
 - c. signals the pancreas to release insulin

- d. allows insulin to be produced
10. A dominant genetic disease or health condition
- a. affects all offspring of an affected parent
 - b. occurs when a single copy of the disease gene is inherited
 - c. requires two copies of the disease gene to be present
 - d. is transmitted to offspring of the same gender
 - e. occurs due to mutations in several genes on the same chromosome
11. A laboratory test of gene expression might examine
- a. the DNA sequence of the gene
 - b. the order of bases within the mRNA
 - c. the quantity of amino acids available for protein building
 - d. the amount of mRNA transcribed from the gene

The next two questions are about Emma, who is about to begin treatment with warfarin, an anticoagulant medication. Emma had a genetic test showing she has a mutation in a gene that is associated with response to warfarin.

12. What should the nurse giving Emma a standard dose of warfarin expect?
- a. Emma will most likely be anticoagulated too much.
 - b. She will most likely not be anticoagulated enough.
 - c. Her response to warfarin may be different from expected.
 - d. She is at high risk to have an allergic reaction to warfarin.
13. The genetic test shows that Emma is heterozygous for the gene mutation. What does that mean?
- a. She has a single copy of the gene.
 - b. She has two copies of the gene; one is dominant and one is recessive.
 - c. She has two copies of the gene, both of which are altered.
 - d. She has two non-identical copies of the gene.
 - e. She inherited an altered gene from her mother.

***** End of situation about Emma *****

14. In the United States, every newborn is screened for various genetic diseases. A baby with a positive newborn screen
- a. has a genetic disease
 - b. may have genetic disease and requires more testing
 - c. may develop a genetic disease
 - d. is a carrier for a genetic disease

The next two questions are about Sophia, a 2-year-old girl with an unusual autosomal recessive condition called Kindler syndrome.

15. Based on the information above, which statement is most likely true about Sophia's parents?
 - a. At least one parent is also affected with Kindler syndrome.
 - b. Both parents must be affected.
 - c. Each parent has at least one copy of the disease gene.
 - d. There is insufficient information to make any of the above inferences.

16. Sophia's parent are expecting a new baby. What is the chance that the new baby will also have Kindler syndrome?
 - a. 25%
 - b. 50%
 - c. 75%
 - d. it depends on the sex of the baby

*** * * End of situation about Sophia * ***

17. Jacob has Fabry disease, an X-linked condition. Given that information, which of the following statements is most likely to be true about Fabry disease in Jacob's family?
 - a. His father also has Fabry disease
 - b. His father is a carrier
 - c. His mother is a carrier
 - d. Either his mother or his father is a carrier
 - e. Both his mother and father are carriers

The next few questions concern Anna, a 35-year-old woman who has tested positive for a hereditary breast cancer mutation in a gene known as *BRCA1*.

18. Which of Anna's cells contain the *BRCA1* mutation?
 - a. her breast cells
 - b. only tumor cells
 - c. adipose cells
 - d. cells in her breasts and reproductive organs
 - e. all her cells that contain a nucleus

19. Anna joins a support group of women with *BRCA1* mutations. Which statement best describes the DNA sequence of these womens' *BRCA1* genes?
 - a. Their *BRCA1* sequence is most likely identical
 - b. Although their *BRCA1* sequence may vary, they likely have identical mutations
 - c. Their sequence varies according to whether they have a dominant or recessive form of the

gene

- d. The women are likely to have unique *BRCA1* mutations
20. Anna's sister, Nicky, also had *BRCA1* testing, and her test result was normal. Based on that information, which of the following statements is most likely to be true?
- Anna's DNA contains a *BRCA1* gene; Nicky's DNA lacks that gene
 - Both sisters have *BRCA1* genes but Anna has an altered copy
 - Anna has a dominant form of the *BRCA1* gene; Nicky has a recessive form
 - Both sisters have identical *BRCA1* genes, but the gene is expressed only in Anna

***** End of situation about Anna *****

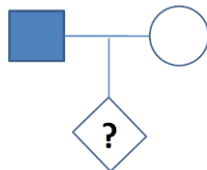
21. The most common way for a mutation to contribute to disease is by
- increasing the rate of DNA replication
 - directing the formation of altered proteins or unexpected amounts of proteins
 - interfering with the body's immune response
 - silencing the gene containing the mutation
22. Carrier testing might be done to see if an asymptomatic individual
- carries a recessive gene that could be passed to offspring
 - carries either a dominant or recessive gene that could be passed to offspring
 - carries a pathogen that could be transmitted to others
 - carries a gene or genes that could cause disease in the future
23. When creating a genetic pedigree, the nurse should consider which of the following findings to indicate a possible need for a genetic referral?
- a previous miscarriage
 - breast cancer in her mother at age 64
 - a heart attack in her father at age 43
 - a sister and a grandmother who had twins
24. An autosomal disorder
- is automatically expressed when a single altered gene is inherited
 - results in production of antibodies to one's own tissues
 - is inherited equally by male and female offspring
 - occurs due to several mutations on the same chromosome
 - occurs due to an incorrect number of chromosomes
25. The genetic contribution to complex disorders like hypertension and diabetes is thought to be
- an incorrect number of chromosomes
 - genes that have not yet been identified
 - genes with multiple alleles

- d. a collection of genes, each contributing a small risk
 - e. relatively minor; environmental factors contribute most of the risk for complex diseases
26. The primary benefit of including common conditions such as hypertension and diabetes in a genetic family history is to
- a. identify mutations associated with common conditions
 - b. track diseases in populations
 - c. inform reproductive decisions
 - d. help establish diagnoses
 - e. predict disease risk and plan care
27. A drug receptor is best described as a(n)
- a. enzyme
 - b. antigen
 - c. protein
 - d. structure or organelle
 - e. cell
28. Patients respond variably to standard doses of medications. Which statement best describes how genes influence human drug response?
- a. Genes interact variably with drugs, according to the gene's DNA sequence
 - b. Genes cause the immune system to react variably to drugs
 - c. Genes change cells to make them more or less responsive to drugs
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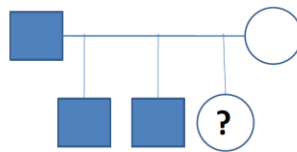


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 - 50%
 - 25%
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Years later, Joe and Sally have had two sons, both affected with Joe's condition. They are expecting a new baby, a girl. Please consider this pedigree.



31. Which statement best predicts their daughter's risk to be affected with the same condition?
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 - Her risk is greater than that of her brothers, since both brothers are known to be affected
 - Her risk is less than that of her brothers, since both brothers are known to be affected
 - Her risk is less because she is female

Part IV

Please select the response that best reflects the way you feel.

- I feel it is important for the nurse to incorporate genetic health risk assessment into their clinical practice.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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- I feel comfortable with the information presented on this survey.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
-----------------------	--------------	------------	-----------	--------------------

- I feel prepared from my educational experiences to incorporate my genetic knowledge base into clinical practice.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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4. I feel responsible as a nurse to discuss and teach genetics to patients and their families.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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5. I feel ready to use my genetic knowledge base in clinical practice.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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6. I feel prepared to identify patients who should be referred to a genetics counselor for genetic testing.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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7. I feel comfortable with drawing a pedigree for a patient in order to depict their family history.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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8. I feel comfortable with identifying inheritance patterns of genetic diseases.

Strongly disagree (0)	Disagree (1)	Unsure (2)	Agree (3)	Strongly Agree (4)
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Part V

1. Please estimate the total number of hours dedicated to genetic material in your nursing curriculum. Type in your number estimate below.

2. Please name the courses that provide genetics content in your nursing curriculum.

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