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The purpose of this study was to assess the knowledge base of nursing students regarding the topic of genetics and how this may change as a student progresses through the nursing program. A 70 item multiple-choice and dichotomous survey was given to freshman, sophomore, junior, and senior nursing students at a university school of nursing in the eastern part of the United States. Two hundred and seventy five pre-licensure nursing students, 255 females and 18 males, comprised the sample.

A one-way analysis of variance (ANOVA) was performed and the results concluded that there was a significant difference among the freshman, sophomore, juniors, and seniors in regards to having at least a 'minimal' knowledge or better of medical genetic terminology and conditions. Seniors reported a higher number of terms which they had at least a 'minimal' knowledge level or better than freshman or sophomores. Also the juniors reported a higher number of terms which they had at least a 'minimal' knowledge level or better than sophomores.

PERCEIVED GENETIC KNOWLEDGE OF PRE-LICENSURE NURSING STUDENTS

by

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APPROVAL PAGE

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CHAPTER I

BACKGROUND AND RATIONALE FOR STUDY

Introduction

The completion of the Human Genome Project in 2003 has created an amazing start to the understanding of many genetic diseases. According to Williams, Tripp-Reimer, Schutte, and Barnette (2004), the field of genetics has exponentially increased its knowledge base during the 21st century. Even though the scientific world has began to understand more about the field of genetics, public understanding of genetic information has not kept pace (Bates, Lynch, Bevan, & Condit, 2005; Hietala et al., 1995; Jallinoja, Hakonen et al., 1998).

The medical community believes that there will be great benefits in the world of medicine due to genetic research (Henneman, Timmermans, & van der Wal, 2004). According to Henneman et al. (2004), genetic technology may improve the outcomes of a variety of genetic disorders and the quality of life of many individuals and families. The mission of the National Coalition for Health Care Professionals Education in Genetics (NCHPEG) is to promote the integration of genetics into healthcare education in order to use this information to improve the outcomes of health throughout the nation (Maradiegue, Edwards, Seibert, Macri, & Sitzer, 2005). Due to the fact that genetic information is invaluable to the education and recognition of many genetic disorders, nursing needs to be well informed of the components of genetic information. Nurses feel

that a better understanding of genetic information and implications for practice would permit nurses to provide more holistic care, advocate for their patients, and incorporate genetics into nursing care (Jenkins, Dimond, & Steinberg, 2001). The integration of genetic information in patient care depends on the knowledge base of nurses in the field of medical genetics.

Although studies have been done about the knowledge base of physicians (Michie, Drake, Bobrow, & Marteau, 1995; Toiviainen, Jallinoja, Aro, & Hemminki, 2003), Williams et al. (2004) revealed that there has been an absence of research on the knowledge of nurses in the field of genetics. This is unfortunate because nurses must understand genetic information in order to incorporate this information into providing holistic care to their patients. The purpose of this study was to determine the experiences, knowledge, and comfort level within the field of medical genetics among nursing students in an undergraduate program.

This study was conducted in order to understand the knowledge base of nursing students regarding the topic of genetics and how this may change as a student progresses through the nursing program. The survey was given to freshman, sophomore, junior, and senior nursing students. This study replicated a previous study that surveyed graduate nursing students about their medical genetic knowledge and perceptions (Maradiegue et al., 2005). The results of the two studies were compared to determine whether knowledge and perceptions about genetics changes throughout undergraduate nursing school and the difference in knowledge of medical genetics between graduate and undergraduate nursing students. The results of this study were compared to the results available in the literature

about the knowledge base of the general public. This information can be used to assess the need for more extensive genetic curriculum needs to be incorporated into the nursing program.

The International Society of Nurses in Genetics (ISONG) stated that "nurses in all health care delivery settings will need to integrate knowledge of genetics into clinical care" (Jenkins, Dimond, & Steinberg, 2001, p.191). Jenkins et al. (2001) revealed that the Pew Health Professions Commission indicated that future health care practitioners are expected to be professionally competent in genetics in order to successfully fulfill their roles as professional nurses. This study will provide information about nursing students' knowledge of and attitudes toward genetics and genetic testing, which will be useful in assessing the need for genetics content in the nursing curriculum, in order to produce genetically competent nurses in the future.

Theoretical Framework

This study is based on the assumption that nurses need to be competent in order to provide exceptional nursing care. This assumption is supported by the theory of Faye Abdellah. In 1960, Faye Abdellah and colleagues created Abdellah's 21 nursing problems that emphasized the fact that the delivery of nursing care should include the whole person (Abdellah, 1960). In order to provide this holistic care, the nurse not only needs to be caring, but also intelligent, competent, and technically skilled (Potter and Perry, 2001). Abdellah and her colleagues identified 21 nursing problems, which were divided into three areas: 1. physical, sociological, and emotional needs of the patient, 2. types of interpersonal relationships between nurse and patient, and 3. common elements

of patient care. This problem list was created to evaluate a nurse's competency based on measurable outcomes (Cardinal Stritch University Library, 2007).

Abdellah further delineated her theory to include the development of the importance of providing holistic care to all patients. In order to provide satisfactory care to patients, care should not only be focused on the individual, but it should also include family, society, and the environment (Marriner-Tomey & Alligood, 1998). Abdellah believed that in order to provide holistic care, nursing care must encompass all of these components. The rapid growth of knowledge about genetics has the potential to change society's expectations about health care, and nurses need to be competent in this knowledge.

Abdellah's theory stresses the importance of competent nurses. Competency not only includes caring, technical skills, and intelligence, but the recognition of the need to acquire continuing education as new information emerges. This study fits well with the premises of Abdellah's theory as it describes an emerging competency that nurses will need to have. In order to give the best nursing care to patients, nursing students need to be given the opportunity to become competent in a variety of areas, including competency in the realm of genetics.

Assumptions of this Study

(1) The knowledge base is growing in the field of medical genetics.

(2) Certain genetic components predispose individuals to the development of specific diseases.

(3) There is a lack of genetic knowledge in the general public (Henneman, 2004).

(4) Medicine will be greatly benefited due to genetic research (Williams, 2004).

(5) The field of nursing needs to incorporate medical genetics knowledge into practice in order to provide holistic care.

(6) There is an absence of research on the knowledge of genetics in nurses (Williams, 2004).

(7) Medical genetics can be incorporated into the curriculum of nursing schools

(8) Nurses will be able to incorporate genetic information into educating their patients.

(9) Knowledge and expectations about genetics and genetic testing can be accurately measured with a paper and pencil survey.

Research Questions

The following research questions were developed for this study: What do undergraduate nursing students know about genetics and inherited diseases? Do undergraduate nursing students feel comfortable disseminating genetic information? What educational activities do undergraduate nursing students feel would improve their knowledge and understanding of genetics? How do freshmen, sophomore, junior, and senior nursing students vary in their knowledge and perceptions of genetics and genetic testing?

Definition of Terms

Genetics is the science of human variation and heredity. Medical genetics is the application of genetics to medicine. Genetic disease/disorder is a condition caused by abnormalities in genes or chromosomes or the interaction between the environment and

genes or chromosomes. Genetic testing determines the susceptibility of acquiring a genetic disorder. A questionnaire is a formulated survey of relevant questions for each of the research questions posed in this study. For this study a nursing student is one who is registered in an undergraduate nursing course.

CHAPTER II

REVIEW OF LITERATURE

Medical genetics and genetic testing have the potential to provide benefits to a variety of individuals. According to Henneman, Timmermans, and van der Wal (2006), genetic tests may help people make informed decisions in regards to their health care choices and conceiving children. There has been a wide variety of research conducted on public attitudes about medical genetics. Both positive and negative attitudes have been identified.

There are a few negative attitudes among the general public that have been consistent within the review of the literature. Henneman et al. (2006), in their survey of 817 people, state that most Europeans and Americans fear the misuse of test results, such as the exclusion of disabled people from society. Another negative attitude toward genetic testing seems to be a moral objection against tampering with nature (Human Genetics Commission, 2001). Overall, the main concern with genetic testing was the possibility of discrimination from either employment or insurance (Bates et al., 2005; Henneman et al., 2006; Hietala et al., 1995; Jallinoja, Hakonen et al., 1998).

Even though there are some negative connotations involving genetic testing, the majority of the literature revealed that the general public feels that genetic testing should be available to anyone who wants to have a genetic test performed (Bates et al., 2005; Hietala et al., 1995; Henneman et al., 2006; Jallinoja, Hakonen et al., 1998). Michie et al.

(1995) compared attitudes of the general public and three professional groups: clinical geneticists, obstetricians, and medical ethicists. The general public was more likely to express negative attitudes than the obstetricians and geneticists.

Another study by Toiviainen et al. (2003) compared physicians', midwives' and the general public's attitudes towards genetic testing. The overwhelming difference between the groups was that the general public chose the 'don't know' option more often. Some examples of the questions that the general public answered 'don't know' included if genetic testing should be controlled by the state, if the public healthcare system should finance genetic screening for serious diseases, and if it was important to be informed of the possibility of genetic tests. Also a study by Jallinoja and Aro (2000) revealed that people with only a primary or secondary school level of education gave more 'don't know' responses than people with a high school level of education or higher. The questions that many of these respondents answered ‘don’t know’ to involved whether or not genetic tests may improve one's quality of life, if they are worried about genetic tests becoming mandatory, or if genetic tests should be done at all.

The knowledge deficit about medical genetics and genetic testing in the general public is concerning, due to the fact that medical genetics and genetic tests may become a part of the standard care provided to the public because these advances could improve the quality of life for many individuals and families (Jallinoja, Hakonen et al., 1998). Henneman et al. (2004) conducted a study to assess the knowledge, experiences, and future expectations of genetic testing in the Dutch population. Over half of the participants believed that they had a lower level of genetic knowledge compared to

others. Also 79% of the participants did not know that they were genetically related to their siblings (Henneman et al., 2004). Jallinoja and Aro (1999) conducted a similar research study in Finland. The study revealed that students and upper-level white-collar workers were more knowledgeable about genetics than were blue-collar workers. This study also revealed that the most knowledgeable group was university graduates. Most of the studies reviewed revealed a deficit in public knowledge of medical genetics.

After reviewing the literature, there was a lack of research found concerning the knowledge, perceptions, and attitudes of nursing students about medical genetics. Only one research study was found, and this study looked at advanced practice nursing students. Maradiegue et al. (2005) revealed that most advanced practice nursing students professed a very minimal knowledge base concerning medical genetics. These authors concluded that there are significant gaps in the nursing curriculum concerning medical genetics. Maradiegue et al. declared that a good deal of education is needed in order to improve the genetic competency of the nursing field.

Nursing leaders have expressed the need for nurses to know about medical genetics. Williams et al. (2004) revealed that the incorporation of genetics is a necessary component in the field of nursing in the 21st century. In the past 10 years, the American Academy of Nursing (AAN) and the Institute of Medicine (IOM) have addressed the need for nursing staff that is prepared to take part in future genetic health care services (Williams et al.). Also, nursing research is needed in this area in order to learn the relationship between genetic factors and the outcomes of nursing interventions (Williams et al.). Clearly, medical genetics needs to be incorporated into nursing curricula.

Jenkins et al. (2001) performed a research study to determine changes that need to be made to nursing curricula in order to include innovative medical genetics. This study revealed that education is the first step in making sure that every nurse will be able to utilize genetic information and skills to consciously formulate health care choices. This study provided a template for the addition of medical genetics information into nursing curriculum. After this template was developed in 2001, only three articles were published that reported how medical genetics education was delivered in their nursing curriculum. Nicol (2002) reported on the integration of medical genetics in the nursing curriculum in New Zealand undergraduate nursing programs. The United Kingdom published a report on the integration of genetic education in diploma level training (Kirk, 1999). Finally, Cragun, Couch, Prows, Warren, and Christianson (2005) reported on the success of genetic education intervention for nursing and dietetic students at the University of Cincinnati. More information is needed about the knowledge of undergraduate nursing students regarding medical genetics. This information will hopefully lead to additional integration of genetics in to nursing curriculum worldwide.

CHAPTER III

METHODOLOGY

Research Design

This descriptive, cross-sectional study was a replication of a study done by Maradiegue, et al. (2005) with graduate nursing students, and used the same survey instrument. The population of interest for this study is undergraduate nursing students.

This study was conducted by distributing paper-and-pencil surveys to all nursing students; freshman through senior years, registered for seven nursing classes held in the Spring semester of 2008.

Setting

The study was conducted over a period of one month at a university school of nursing in the eastern part of the United States. The survey was given to all undergraduate nursing students with a major in pre-nursing or nursing at the end of specified nursing classes (NUR 110, 220, 310, 320, 340, 360, 430). A return envelope was provided in the classroom for the students who chose to complete the survey on site, and also in the student lounge for the students who chose to complete the survey later.

Population and Sample

The target population is freshman, sophomore, junior, and senior undergraduate pre-licensure students who have chosen nursing as their major. The junior and senior

students have been admitted into the school of nursing. The freshman and sophomore students have only proposed an interest in the field of nursing by declaring pre-nursing as a major. The freshman and sophomore nursing students that were given the survey were enrolled in a pre-nursing course within the school of nursing.

Protection of Human Subjects

Approval to conduct this study was obtained from the institutional review board at the University (see Appendix A). A cover letter reflecting the elements of informed consent was given to each of the subjects prior to the receipt of the survey(see Appendix B). The potential subjects were told that their participation was voluntary, that the information would be kept confidential and they would not be penalized for answering the questions incorrectly, and that their standing in the nursing class would not be affected whether or not they participated. Subjects were instructed not to put their names on the survey.

Instrument

The paper and pencil survey consisted of 70 multiple-choice and dichotomous items. Three items assessed demographics, 52 items evaluated the student's perceived knowledge level of various genetic concepts, 9 items examined the student's comfort level of genetics in the clinical setting, and 6 items assessed the way students would like educational activities to be conducted in regard to genetics.

A senior medical student and a geneticist developed this survey, called the "Genetics Needs Assessment Survey" (Maradiegue et al., 2005) (see Appendix C), and permission was granted for use in this study (see Appendix D). The survey developers

established content validity by the use of a panel of people experienced in medical genetics and healthcare evaluation (Maradiegue et al.).

Data Collection and Field Procedures

All currently enrolled undergraduate students who were taking a nursing class in the spring of 2008 were surveyed. The following classes were targeted: NUR 110, 220, 310, 320, 340, 360, 430. After obtaining permission from the instructors of the classes, surveys were distributed at the end of class and a brief oral and written explanation of the study, which included all elements of informed consent, was given. Consent was assumed if the survey was returned. A return envelope was placed on the desk at the front of the classroom for the students who wished to stay and fill out the survey in the classroom. The researcher returned to the room after 30 minutes to retrieve the envelope. If the student chose to complete the survey later, an envelope was available in the student lounge of the school of nursing. These envelopes were checked regularly and completed surveys removed. The envelope was removed one month after the last survey was distributed.

Data Analysis

Data were coded and entered into an SPSS database. Descriptive statistics such as frequencies and percentages were used to describe the demographics, perceived knowledge about medical genetics, comfort level with integrating medical genetics into practice and educational activities that integrate medical genetics into curriculum that were most often chosen by the undergraduate nursing students. These frequencies were compared to those reported in the original study (Maradiegue et al., 2005). Additionally,

the mean total of students who answered the 39 multiple-choice knowledge questions with at least “minimal” knowledge in each level (freshman, sophomore, junior, senior) was compared using one-way analysis of variance (ANOVA). A significance level of $p < 0.05$ was used to indicate significant differences among the levels of students.

Limitations

Some of the limitations of the research design included the following. The survey used technical genetic terms that may have been intimidating to undergraduate nursing students. These students may or may not have any knowledge of genetics, and some students may have felt reluctant to admit little knowledge, and therefore may have overestimated their knowledge on the survey. Additionally, some students may have chosen not to complete the survey or may have been absent from class on the day of the survey distribution, thus limiting the sample. Since this was a convenience sample, the results are not generalizable to the larger population of undergraduate nursing students.

CHAPTER IV

RESULTS

Demographics

Two hundred and ninety nine surveys were distributed to pre-licensure nursing students. Sixteen freshman, 112 sophomores, 77 juniors, and 70 seniors completed and returned the survey, which totaled a return of 275 surveys. Ninety four percent of all the freshmen, 98% of all sophomores, 91% of all juniors, and 82% of all seniors returned the surveys, which gave an overall return rate of 92%. The lower response by the junior and senior level participants may have been due to the fact that these classes ran later than their allotted time and many participants did not stay to complete their surveys after class nor did they return them to the marked folder in the student lounge.

The majority of the participants were women (93%), and the mean age of the participants was 23 years. Also, the majority of the participants were first-degree (79%) students. Table 1 illustrates additional demographic information on the participants.

Prior to analysis to answer the research questions, the sample was examined to see if ANOVA assumptions were met. The assumptions for the use of ANOVA are typically as follows: it is assumed that each group is determined by random selection, that the dependent variable is normally distributed, and that the groups have equal variances. However, ANOVA is a robust test, which means that even if these assumptions are not

Table 1: Pre-licensure Nursing Student Demographics

Demographics	
Age (years)	
Mean	23.36
	N (%)
Gender	
Male	18 (7)
Female	255 (93)
Nursing School Enrollment	
Freshman	16 (6)
Sophomore	112 (41)
Junior	77 (28)
Senior	70 (25)

met, it will likely not affect the ability of the test to detect significant differences if they are present (Pilot, 1996). In this study, the population is a convenience sample, rather than a random sample. Unfortunately in nursing research, a random sample can frequently not be achieved. By examining skewness and kurtosis, the normal distribution of the dependent variable was assessed. The skewness of the curve was –0.154 and the kurtosis was –0.095, which reveals a nearly normal distribution.

In addition, the mean total score for each of the 39 medical genetics knowledge questions was computed. An ANOVA was performed on these data; after a square root transformation was performed a more normal distributed curve was obtained. The square root transformation was performed due to the moderate skewness of the data (Pilot, 1996).

Knowledge of Medical Genetic Terminology

The survey contained 39 multiple-choice questions that assessed the participants' perceived knowledge of medical genetic conditions and terminology. The participants could answer the questions by choosing "no,"- "minimal,"- "some," - "high" -level of knowledge for each item. Most of the participants revealed that they had "some" to "high" knowledge of common genetic terms such as DNA structure, RNA structure, mitosis, translation, and transcription. However, the majority of the participants chose "no" or "minimal" knowledge of terms such as Myotonic Dystrophy, Thalassemias, and Hardy-Weinberg Equilibrium. Eighty eight percent of the participants chose "no" knowledge of Gaucher Disease. Table 2 depicts the overall number and percentage of all pre-licensure students' knowledge perceptions of selected genetic topics, which are broken down into genetic terms, genetic conditions, and other.

The answers to these 39 multiple-choice questions were then grouped into two categories: either having “no” knowledge or at least an answer of “minimal’ knowledge or better. Having at least a “minimal” knowledge was coded as “1” and having “no” knowledge was coded as “0.” The total score on all 39 items was computed in this way for each individual participant. None of the participants answered at least “minimal” knowledge to all 39 multiple-choice questions. Overall, 11 participants did respond to 36 multiple choice questions with at least a “minimal” knowledge level. In the freshman class, the total number of questions answered with at least a “minimal” knowledge level was 33 questions, whereas all of the sophomores, juniors, and seniors answered at least a “minimal” knowledge level for a total number of 36 questions.

Table 2: Number and Percentages of Pre-licensure Nursing Students' Knowledge of Certain Genetic Topics

	Knowledge Level			
Genetic Topics	None N (%)	Minimal N (%)	Some N (%)	High N (%)
Genetic terms				
Mitosis	0 (0)	21 (8)	151 (56)	102 (36)
Meiosis	1 (1)	26 (9)	145 (54)	99 (36)
Translation	2 (1)	28 (9)	150 (55)	95 (35)
Transcription	2 (1)	28 (9)	149 (55)	95 (35)
DNA replication	0 (0)	21 (8)	148 (54)	106 (38)
RNA structure/function	0 (0)	33 (12)	147 (53)	95 (35)
DNA structure/function	0 (0)	16 (6)	144 (52)	115 (42)
Genetic conditions				
Hemachromatosis	140 (51)	90 (33)	41 (15)	4 (1)
Breast Cancer	9 (3)	71 (26)	144 (52)	51 (19)
Familial hypercholesteremia	150 (55)	58 (21)	41 (15)	26 (9)
Huntington's disease	55 (20)	125 (46)	82 (30)	13 (4)
Phenylketonuria	84 (31)	95 (35)	79 (29)	17 (5)
Gaucher's Disease	242 (88)	26 (10)	7 (2)	0 (0)
Myotonic dystrophy	216 (79)	42 (15)	15 (5)	1 (1)
Sickle cell disease	7 (3)	58 (21)	149 (54)	61 (22)
Thalessemia	181 (66)	59 (22)	30 (11)	5 (1)
Fragile X	118 (43)	93 (34)	52 (19)	12 (4)
Neurofibromatosis	203 (74)	58 (21)	13 (4)	1 (1)
Trisomy 21	98 (36)	64 (23)	83 (30)	30 (11)
Trisomy 18	152 (55)	86 (31)	29 (11)	8 (3)
Trisomy 13	157 (57)	83 (30)	29 (11)	5 (2)
Turner Syndrome	134 (49)	83 (30)	48 (18)	10 (3)
Klinefelter syndrome	160 (58)	77 (28)	32 (12)	6 (2)
Osteogenesis imperfecta	199 (72)	54 (20)	19 (7)	3 (1)
Tay Sachs	48 (18)	112 (41)	91 (33)	24 (8)
Cystic fibrosis	11 (4)	88 (32)	133 (48)	43 (16)
Colon cancer	15 (6)	82 (30)	138 (50)	40 (14)
Duchenne muscular dystrophy	151 (55)	90 (33)	28 (10)	6 (2)
Other				
PCR	191 (70)	50 (18)	21 (8)	12 (4)
Gene therapy	82 (30)	103 (37)	76 (28)	14 (5)
Genogram	18 (7)	44 (16)	114 (42)	98 (35)
Pharmacogenetics	106 (39)	101 (37)	54 (20)	12 (4)

Table 3: One-way ANOVA of the mean number of responses indicating at least "minimal" knowledge or better

	Sum of Squares	df	Mean Square	F value	p value
Between Groups	516.280	3	172.093	5.574	.001
Within Groups	7996.381	259	30.874		
Total	8512.662	262			

A one-way analysis of variance (ANOVA) was used to determine if there was a significant difference among the classes on the mean number of responses indicating at least "minimal" knowledge of the 39 terms. The analysis determined that there was a significant difference among the freshman, sophomore, juniors, and seniors with an F ratio of 5.575 ($p = 0.001$), which is represented in Table 3. Since this overall ANOVA was significant, the differences between each class were examined, using a multiple comparison adjustment called Fisher's least significant difference (LSD) test. This revealed that there was a significant difference between freshman and seniors with a p value of 0.01, as well as a significant difference between sophomores and juniors with a p value of 0.032. Furthermore, a significant difference was found between sophomores and seniors with a p value of 0.000 (refer to Table 4). Figure 1 illustrates the mean total score of each class level.

Finally the raw score for each question (maximum range 0-5 on each of the 39 items, with a maximum possible score of 195) was added up for each individual participant. The distribution was examined for normality and a skewness of 1.124 and a kurtosis of 2.984 were found, indicating that scores were not normally distributed. To

Table 4: Multiple Comparisons of dependent variable with Fisher's least significant difference (LSD) test

		Mean Difference (I-J)	Standard Error	p value
Freshmen	Sophomore	-1.18875	1.63120	.467
	Junior	-2.99480	1.67097	.074
	Senior	-4.34615	1.68195	* .010
Sophomore	Freshmen	1.18875	1.63120	.467
	Junior	-1.80606	.83850	* .032
	Senior	-3.15741	.86018	* .000
Junior	Freshmen	2.99480	1.67097	.074
	Sophomore	1.80606	.83850	* .032
	Senior	-1.35135	.93341	.149
Senior	Freshmen	4.34615	1.68195	* .010
	Sophomore	3.15741	.86018	* .000
	Senior	1.35135	.93341	.149

* $p < 0.05$

normalize the distribution to meet the assumption of ANOVA, a square root transformation was performed. The ANOVA was computed using the transformed variables, but there were no significant differences among the four groups on the total score of the 39 item knowledge instrument (F ratio of 1.645, $p = 0.179$).

Additional knowledge questions on the instrument had to do with the ability to define 13 genetic terms by selecting either "yes" or "no." When asked whether or not they could define the term "dominant," 100% of the participants chose "yes," whereas only 23% of the participants stated they could define the term "missense mutation." Figure 2 illustrates the overall number and percent "yes" or "no" responses to each of the 13 items.

Figure 1: Plot of Mean Scores with at Least a 'Minimal' Response or Better

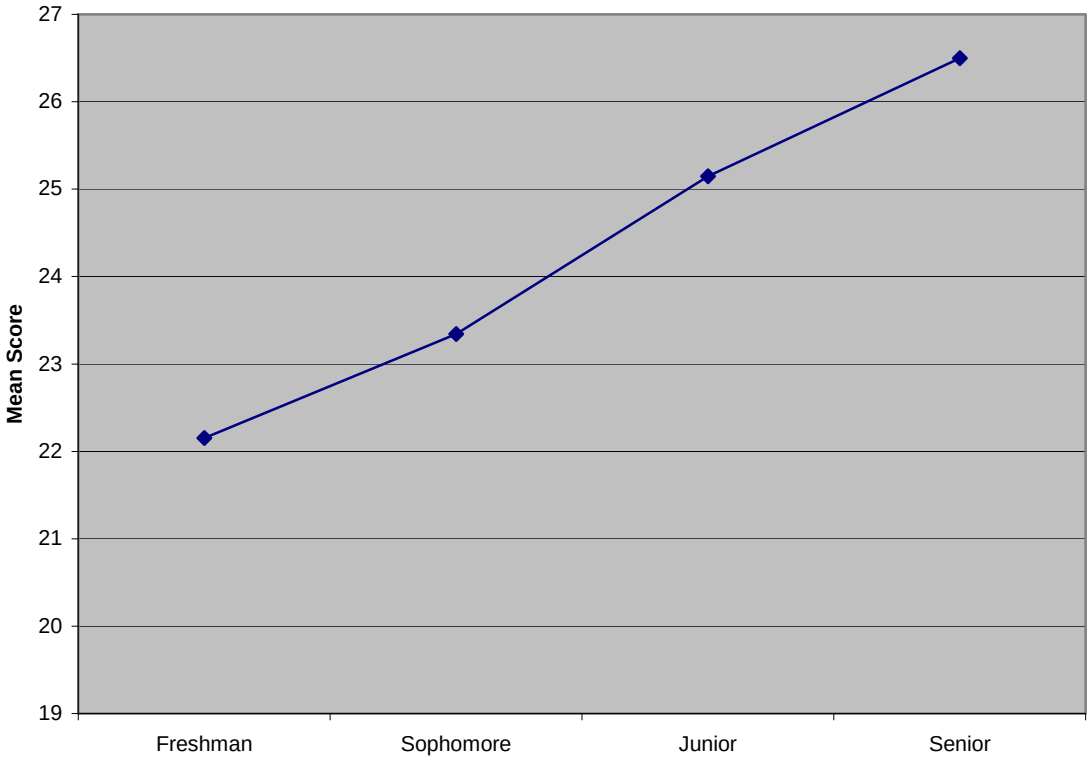
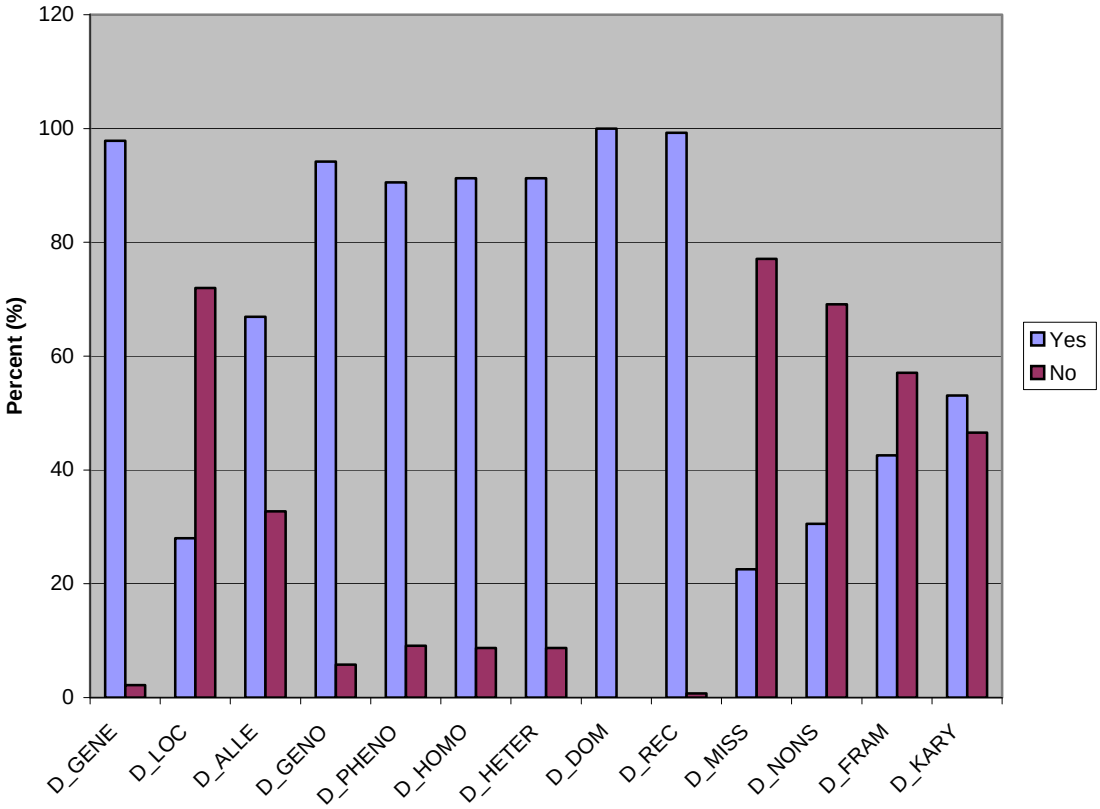


Figure 2: Percent of 'Yes' or 'No' Responses to Definition of Genetic Terms by Pre-licensure Nursing Students



Clinical Comfort Level with Genetics

The survey also asked for information about participants' opinion of their own clinical comfort level concerning medical genetics. Nine questions were asked about their comfort level in a particular area such as finding information about genetics on the Internet, drawing a pedigree or speaking to a patient about family history. Four choices could be selected to answer the questions: "definitely not," probably not," probably yes," or "definitely yes."

Despite the fact that 96% of the participants answered, "probably yes" or "definitely yes" to feeling comfortable finding information about genetics on the Internet, only 61% of participants felt comfortable speaking to a family about a diagnosis of a specific genetic disease. Table 5 reviews the data relating to the participants' comfort level regarding medical genetics.

Table 5: Comfort Level of Pre-licensure Nursing Students Regarding Integration of Genetics in Clinical Settings

Genetic Topics	Definitely Not, N (%)	Probably Not, N (%)	Probably Yes, N (%)	Definitely Yes, N (%)
Accessing genetic information on the Internet	0 (0)	11 (4)	134 (49)	129 (47)
Speaking to family/ patient about genetic diagnosis	18 (7)	88 (32)	107 (39)	61 (22)
Drawing a pedigree	24 (9)	64 (23)	121 (44)	65 (24)
Predicting outcomes of a pedigree	39 (14)	64 (23)	134 (49)	35 (14)

Integration of Educational Activities into Nursing Curriculum

Finally, participants were asked to answer six multiple-choice questions regarding educational activities that would improve their knowledge of genetics. The response choices included "no," "probably not," "probably yes," and "definitely yes." Participants were asked to choose the effectiveness of certain educational activities such as lectures, small group discussions, role-play, practice with standardized patients, readings, and problem sets. Out of these educational activities, 93% of the participants responded "probably yes" or "definitely yes" to practice with standardized patients, followed by lectures (91%), small group discussions (86%), problem sets (85%), readings (74%), and finally, role play (55%).

CHAPTER V

DISCUSSION

Overall, the findings from this study reveal that there is a significant difference among the groups on the perceived knowledge of medical genetics, and these differences occurred between the freshman and seniors, sophomores and juniors, and sophomores and seniors. The seniors were determined to have a higher perceived knowledge of genetic terms than either freshman or sophomores. The junior class revealed a significantly higher perceived knowledge than the sophomore class. Also, the majority of the participants felt comfortable defining common genetic terms; however, most of the participants were not comfortable when it came to speaking with patients about genetic diseases.

When the total scores on the 39-item knowledge portion of the tool were computed and compared, there were no significant differences among the groups. When used previously (Maradiegue et al., 2005), a total score was not computed; rather, the scores were only examined individually. Perhaps the items were not meaningful in assessing genetic knowledge when combined, which may be a reason for the non-significant results in this sample. Additional research needs to focus on the best way to measure genetic knowledge in an instrument that yields a total score.

Maradiegue et al. (2005) only obtained 46 surveys from advanced practice nursing students compared to 275 surveys collected from pre-licensure students in this study. The majority of the participants in the Maradiegue et al. (2005) study were women (70%), which is comparable to this study in which 93% of the participants were women. Thus both studies had fewer males than females. On the other hand, the participants in the two studies differed in age. The mean age of the pre-licensure students was 23 years, whereas the most frequently chosen age category of the advance practice nursing student was between 30-39.

The advanced practice nursing students and the pre-licensure students answered "no" or "minimal" knowledge for specific genetic disorders such as Gaucher's Disease, 92% and 98% respectively. Also both research groups answered "some" to "high" knowledge on basic genetic terms such as DNA structure/function, 60% and 94% respectively. However, overall the pre-licensure students (37%) on average chose more "high" level knowledge on basic genetic terms than advanced practice nursing students (5%). Both research studies revealed that the students perceived more knowledge of basic genetic terms versus more specific conditions.

Furthermore, all of the advance practice nursing students as well as the pre-licensure students stated that they could define the genetic term "dominant." However, only one (2%) advanced practice nursing student stated that they could define missense mutation, nonsense mutation, or frameshift mutation, whereas 117 (43%) pre-licensure students stated that they could define at least one of the previously mentioned genetic terms.

In addition, based on the results from both studies the advance practice nursing students felt less comfortable integrating genetics into the clinical setting. Pre-licensure nursing students (68%) chose "probably yes" or "definitely yes" to the ability of drawing a pedigree than the advance practice nursing students (22%). Also, 61% of the pre-licensure students chose "probably yes" or "definitely yes" in regard to speaking with a family about a diagnosed genetic disease versus only 34% of the advance practice nursing students.

Overall, the studies indicate that a knowledge deficit in the topic of medical genetics exists among both pre-licensure and advanced practice nursing students. However, the results show that the pre-licensure nursing students perceive that they have a higher level of knowledge about genetic terms and the ability to define more technical genetic terms than advanced practice nursing students. This result may be due to the fact that they have more genetic information integrated within their nursing curriculum than the advanced practice nursing students did while they went through their pre-licensure nursing program. On the other hand, pre-licensure students may have been less willing to admit lack of knowledge or the inability to define genetic terms because they felt that they should be able to in this stage of nursing school.

The studies revealed a lack of comfort when integrating medical genetics into practice. However, the pre-licensure students felt more comfortable than licensed nurses in integrating medical genetics into practice. This result may be due to the fact that pre-licensure students have a better understanding of genetics due to an increased amount of medical genetics within their curriculum. On the other hand, the pre-licensure students

may be overestimating their degree of comfort with integrating genetics into practice due to the fact that they have not cared for patients except in the clinical setting as a student nurse, whereas the advanced practice nurses may have a more realistic view of their abilities and comfort level.

Based on the research performed on the knowledge of genetics among the general public, pre-licensure students seem to have a better grasp of medical genetics as compared to the general public. The difference between the groups was that the general public chose the 'don't know' option often, whereas the pre-licensure students had a lower response of ‘no’ knowledge to the genetic terms (Toiviainen et al., 2003). Thus, this study reveals that pre-licensure nursing students have a greater perceived knowledge of genetic terms than the general public. However, nursing students may have been less willing to admit lack of knowledge than the general public, due to a perception that they “should” know the information.

Implications

The need for genetic knowledge and understanding has rapidly been increasing over the past few years sine the completion of the Human Genome Project. In this school of nursing, knowledge of medical genetics did improve as the students progressed toward graduation. These results support the general assumption that knowledge about health topics should increase as students progress within the nursing program.

Even though an increase in knowledge among the groups was shown in this study, additional research needs to be performed to assess the curriculum in order to determine where genetics information is covered. This study did not look at the placement of

genetic information within the curriculum; however, it would be interesting to see how certain placement of genetic content in the curriculum influences the knowledge of medical genetics among the students.

Also future research should be conducted on the actual knowledge of genetics among nursing students. This survey only assessed the perceived knowledge of nursing students. Research conducted on the actual knowledge of genetics among nursing would pinpoint areas for additional instruction of certain genetic material that may be deficient among nursing.

In summary, this study revealed that pre-licensure nursing students have an increased level of knowledge as the nursing program advances. Unfortunately, this study does not indicate the areas of curriculum in the school of nursing that enhances the knowledge of medical genetics among the nursing students. Thus, nursing education should be examined to identify gaps in medical genetics curriculum within all aspects of nursing instruction.

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APPENDIX A

IRB APPROVAL

THE UNIVERSITY of NORTH CAROLINA
GREENSBORO
Office of Research Compliance

January 25, 2008

Dr. Lynne Lewallen
Nursing
419 Moore Building
Refer to: IRBNo.078208

Dear Dr. Lewallen,

As required by University policy a member of the UNCG IRB has given your research protocol entitled “Undergraduate Nursing Student’s Genetic Needs Assessment” (IRB No. 078208) an exempt review as permitted under UNCG’s Federal Wide Assurance (FWA 00000216). Your minimal’ risk protocol has been deemed exempt under section B 1 of 45 CFR 46.101.

You should be aware that any changes in your protocol must be approved by the IRB prior to being implemented. Likewise, any problems, complaints or injuries that arise during the course of your project which involves human participants must be reported promptly to the Office of Research Compliance. The approved informed consent form is attached. This version must be used when obtaining informed consent as outlined in this protocol but the stamp does not need to appear on the form. Obtaining documentation of informed consent has been waived in accordance with 45CFR46. 117 C-2.

This research protocol is valid for five years unless changes are made which remove the exempt status. You will receive a continuing review form prior to the fifth anniversary to keep this protocol active. Conversely you are responsible for notifying the ORC when your study is completed and all work is published. Thank you for your cooperation on this matter and best wishes on your project.

Sincerely,

Eric Allen, Director
Office of Research Compliance

Cc:

APPENDIX B

COVER LETTER

Dear Nursing Student:

I am a Graduate nursing student under the direction of Dr. Lynne Lewallen. I am conducting a research study on the genetic knowledge of undergraduate nursing students. The results of this study will be used to help assess the need for additional genetic information in school of nursing curricula.

I am requesting your participation in this study, which will involve completing the attached questionnaire, which should take about 10 minutes. Once you complete and turn in the questionnaire, your part in the study is over. Your participation in this study is voluntary. If you choose not to participate or to withdraw from the study at any time, there will be no penalty and it will not affect your grade in this course. There are no risks to you involved in participating in this study. Although there are no direct benefits to you, the results from this study may help to provide better instruction for nursing students in the future.

The attached questionnaire is anonymous. Please do NOT put your name on the questionnaire. Your course number is written on the questionnaire for my collection purposes only. The results of the study may be published in the nursing literature, but individual answers to the questionnaire will not be reported in the article. The article will only report on the results as a group. The questionnaires will be kept locked up for five years, or three years after publication in a journal, which ever is longer, and then they will be shredded.

If you have any questions concerning the research study, please call me at (336) 552-6490 or e-mail me at chdodson@uncg.edu, or Dr. Lynne Lewallen Associate Professor of Nursing, Parent-Child Department at (336) 334-5170 or lynne_lewallen@uncg.edu. If you have any questions about your rights as a research participant, you may contact Eric Allen, Office of Research Compliance at (336) 256-1482 or eric_allen@uncg.edu.

Please keep this letter in case you have questions about the study in the future.

If you complete and return this questionnaire, that means you consent to participate in this study. Please return the questionnaire to the envelope provided at the front of the class today. If you are unable to complete the questionnaire today, you may return it to my folder in the MSN student drawer in the Student Lounge, room 422 Moore building by _____.

APPENDIX C

INSTRUMENT

Course Number: 110 220 310 320 340 360 430

GENETICS NEEDS ASSESSMENT SURVEY

The **Genetics Needs Assessment** is designed to provide insight on the knowledge base, experiences, and comfort level within the field of medical genetics among undergraduate students. The information you provide on this survey will be kept confidential.

Please complete this survey with a pen or pencil. Return the survey to the provided envelope provided at the front of the classroom by the end of the class. If you are unable to complete the test by the end of the class period, you may return the completed survey to a return envelope labeled "Genetics Needs Assessment Survey" located in the student lounge (Room 422). The deadline for returning the survey is _____.

Please complete this survey without the help of others. You will not be penalized for any incorrect answers. Your survey will be kept confidential. Please do not write your name on the survey.

Thank you for your assistance!

I. Demographics.

Directions: Please fill in blank or place a check mark in the appropriate slot.

Age: ____

Gender: Male ___ Female ___

Educational Background:

Do you have a previous degree? Yes ____ No ____ If so what in? _____

II. Background Assessment.

Directions: Check the box that most accurately represents your current knowledge/comfort with the following topics in genetics. Note: If you have already been formally trained in an area (e.g. course or workshop), please indicate this by marking the last column.

Topic:	**No knowledge of this topic**	**Minimal knowledge of this topic**	**Some knowledge of this topic**	**High level of knowledge of this topic**	**Extremely comfortable explaining this topic to others**	**Have previous formal training**
DNA Structure/Function						
RNA Structure/Function						
DNA Replication						
Mitosis						
Meiosis						
Transcription						
Translation						
Protein Synthesis						
Mutations						
Autosomal Dominant Inheritance Patterns						
Autosomal Recessive Inheritance Patterns						
X-Linked Inheritance Patterns						
Mitochondrial Inheritance Patterns						
Genograms						
Tay Sachs						
Cystic Fibrosis						
Breast/Ovarian Cancer						
Colon Cancer						
Hemochromatosis						
Sickle Cell Disease						
Thalassemias						
Fragile X						

Topic:	**No knowledge of this topic**	**Minimal knowledge of this topic**	**Some knowledge of this topic**	**High level of knowledge of this topic**	**Extremely comfortable explaining this topic to others**	**Have previous formal training**
Phenylketonuria (PKU)						
Huntington's Disease						
Gaucher Disease						
Myotonic Dystrophy						
Familial Hypercholesterolemia						
Neurofibromatosis						
Duchenne's Muscular Dystrophy						
Hardy-Weinberg Equilibrium						
Polymerase Chain Reaction (PCR)						
Trisomy 21						
Trisomy 18						
Trisomy 13						
Turner Syndrome						
Klinefelter Syndrome						
Osteogenesis Imperfecta						
Gene Therapy						
Pharmacogenetics						

2. Please check the box that most accurately represents your response.

I can define the following terms:	**Yes**	**No**
Gene		
Locus		
Allele		
Genotype		
Phenotype		
Homozygote		
Heterozygote		
Dominant		
Recessive		
Missense Mutation		
Nonsense Mutation		
Frameshift Mutation		
Karyotype		

3. Please check the box that most accurately represents your response.

I would feel comfortable:	**Definitely Not**	**Probably Not**	**Probably Yes**	**Definitely Yes**
Finding information on a specific genetic disease on the Internet				
Using OMIM				
Recommending a specific support group to a patient with a genetic disease				
Making a specific referral for a patient with genetic questions				
Speaking to a patient about his/her family history				
Speaking to a family about a diagnosis of a specific genetic disease				
Drawing a patient's pedigree				
Given a pedigree, predicting the chances that an unborn child would have a genetic disease				
Speaking with a family about customizing medications based on genetic make-up				

4. Please check the box that most accurately represents your response.

The following educational/conference activities would improve my knowledge/understanding of genetics:	**No**	**Probably Not**	**Probably Yes**	**Definitely Yes**
Lectures				
Small Group Discussion				
Role Play				
Practice with Standardized Patients				
Readings				
Problem Sets				

Thank you for completing this survey!

APPENDIX D

PERMISSION FOR USE OF INSTRUMENT

Dear Crystal,

Let me locate the information and I will get back to you soon so you can use the tool.

Ann

Ann Maradiegue PhD, CFNP, RN
Assistant Professor

Research Interests: Central American Adolescent Health Risk, Genetics, Family History, Depression