KNOWLEDGE AND ATTITUDES OF CERTIFIED DIABETES EDUCATORS REGARDING GENETIC TESTING FOR TYPE TWO DIABETES MELLITUS

By

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Submitted in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice

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Abstract

With increased longevity and an aging population, type 2 diabetes mellitus is at the forefront of adult onset chronic disease globally. In the United States the ability to respond to this crisis hinges upon the American Diabetes Association’s (ADA) proactive approach of identifying individuals who are pre-diabetic and educating them in behavior modification to prevent or delay the disease. Genetic testing could be an important piece of this endeavor. Certified diabetic nurse educations (CDE) are at the front line of this endeavor. The purpose of this study was to examine CDEs perceived knowledge and favorable and reserved attitudes of genetic testing as well as observe for any significant relationships between this perceived knowledge and attitudes toward genetic testing. Questionnaires were mailed to a nationwide sample of certified diabetes educators (n = 2,000); the response rate was 16% (n = 320).

The mean perceived knowledge score was 7.24 (SD = 4.98) on a scale of 0 to 22. The favourable attitudes mean score was 25.3 (SD = 3.67) on a scale of 6 to 30; the reserved attitudes mean score was 20.7 (SD = 3.51) on a scale of 7 to 35. No significant relationships were found between perceived knowledge and attitudes.

Conclusions: The results identified that there is a need for education programs related to genetic testing for T2DM for CDEs as well as a need to include information
regarding genetic testing for chronic diseases in all undergraduate nursing programs.

Recommendations for further research are provided.
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Dedication

I dedicate this thesis to my late sister, Gerri L. Moore, who was my friend, alibi, study buddy, and biggest cheerleader. I wish you could have been here to finish this with me as I’m not sure I would have started it without you. I love and miss you every day.

I also dedicate this thesis to my husband, Bradley, who has always been the object of my affection and source of inspiration.

Lastly, I dedicate this thesis to Mary Ellen Good, RN, CDE, who walked onto an oncology floor in 1997 and turned a staff nurse into a certified diabetes educator.
Acknowledgements

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Chapter 1

Introduction

With increased longevity and an aging population, chronic disease is becoming pandemic. Specifically, type 2 diabetes mellitus is at the forefront of adult onset chronic disease and is even more commonly found in pediatric populations. The ability to respond to the proliferation of new diagnoses of type 2 diabetes mellitus hinges upon the American Diabetes Association’s (ADA) proactive approach. The ADA’s self-reported central goal for type 2 diabetes mellitus is to find individuals who have a pre-diabetic status and educate them in behavior modification, thereby preventing or delaying the onset of disease. This important goal is currently only partially met through ADA credentialed programs that use certified diabetes educators and the Diabetes Risk Assessment Tool for educational endeavors.

The Diabetes Risk Assessment Tool is an instrument with points assigned to age, gender, presence of diabetes during pregnancy, hypertension, physical activity, weight, and family history of diabetes mellitus. Total scores for this instrument measure from 0 to 11, with higher scores indicating a greater risk for development of diabetes mellitus. The risk survey question regarding the presence of a family history of diabetes is a “yes” or “no” question, with 0 scored for “no” and 1 point scored for “yes.” This assignment of a score for family history of diabetes increases the overall score, thereby indicating an increased risk of developing diabetes mellitus as well as suggesting a genetic link to type 2 diabetes mellitus.

Background

The World Health Organization (2014) estimates that almost 347 million people
worldwide have diabetes and that the chronic disease potentiated by hyperglycemia has caused more than a million deaths worldwide, with a projected increase by two thirds between 2008 and 2030. The Centers for Disease Control and Prevention ([CDC], 2013) approximates that 32.8% of males and 38.5% of females will develop diabetes mellitus in their lifetime. Further, the CDC suggests that health care professionals can prevent or delay the onset of type 2 diabetes by increasing understanding of behavior modifications and stressing primary prevention of diabetes as an important priority for the nation.

The authors of the National Institutes of Health’s (NIH) premiere study (2002), Diabetes Prevention Program (DPP), suggested that millions of high-risk adults who modify their diet and exercise to lose a small amount of weight effectively delay or prevent the development of type 2 diabetes mellitus. In the NIH follow-up study, Diabetes Prevention Program Outcomes Study (2013), 88% of the surviving Diabetes Prevention Program participants who were eligible to join were reassessed. It was found that the effects of the DPP had persisted for years and reduced the incidence of diabetes mellitus by 43% among the participants in the lifestyle arm.

In looking at children at risk for type 2 diabetes mellitus, Foster et al. (2010) reported lower obesity rates in eighth grade students. These were students who were initially found to be overweight or obese in sixth grade. In the schools that received nutritional modification interventions through the school cafeteria and increased physical activity, behavioral knowledge and skills, and social support, the obesity rates for sixth grade students were lowered. There were no significant differences in weight in the children from the schools that did not implement the program.
While genetic testing for some cancers has been extensive and is flourishing as a mode of primary prevention, genetic testing for type 2 diabetes mellitus is lacking.

**Purpose**

The purpose of this study was to identify the perceived knowledge and attitudes of certified diabetes educators (CDEs) relevant to genetic testing for type 2 diabetes mellitus.

**Theoretical Framework**

Ajzen and Fishbein’s Theory of Reasoned Action (TRA) was the theoretical underpinning for this study. The TRA purports that action toward a behavior is based on intention. Intention is described (Ajzen 2001, 2002; Ajzen & Manstead, 2007) as an attitude toward the behavior and what is accepted as normal. Ajzen and colleagues believe intention to follow through with the behavior is controlled by attitudes, personal beliefs, and perceived control.

In the TRA, Ajzen (2001, 2002) states that only specific attitudes can be expected to predict the behavior. The theory further describes the importance of individuals’ personal beliefs and perceived control and explains that knowing these beliefs can predict intention. To be parsimonious, more favorable attitudes, more positive personal beliefs, and greater perceived control correlate with stronger intention to perform the behavior.

In this study perceived knowledge and attitudes were investigated in an effort to assess their relationship to each other. To predict the certified diabetes educators’ intentions regarding genetic testing, one must first know their beliefs and attitudes. As genetic testing was not available, intention could not be studied directly, but as action and intention are closely related, a positive relationship between knowledge and attitude
may indicate that certified diabetes educators may be more likely to actively use genetic testing.

**Theoretical Definitions of the Main Study Variables**

In this study, the two main variables are perceived knowledge and attitudes. Perceived knowledge is the knowledge individuals believe they have and is subjective (Calsbeek et al. 2007 and Morren et al. 2006). Attitudes are the opinions an individual has and are subjective. (Calsbeek et al. 2007 and Morren et al. 2006).

**Significance to Nursing**

In order to decrease the pandemic of type 2 diabetes, it is important to educate those with type 2 diabetes and their families about the genetics of diabetes. Certified diabetes educators are on the front lines in the education of individuals with type 2 diabetes mellitus and their families. While the CDE title is a multidisciplinary certification shared by exercise physiologists, pharmacists, doctors, dieticians, and registered nurses, nursing is a holistic profession and most likely to consider genetic testing as a prevention practice. Registered nurses who desire the certification for diabetes education enter into practice not only through testing but also through a mandatory apprenticeship with a senior educator. Having such a narrow focus, these CDE registered nurses need to have obtained genetic knowledge prior to their apprenticeship. Unfortunately, there is little literature regarding the integration of genetic information into basic nursing education programs. L. Ward (personal communication, November 8, 2014) and S. Daack-Hirsch (personal communication, November 8, 2014) state that genetics knowledge in students primarily focuses on Mendelian concepts of genetics, rather than on chronic disease, despite a consensus
guideline (Greco, Tinley, & Seibert, 2012). This study examined the knowledge of nurse CDEs and their attitudes regarding genetic testing. The results may be used to supplement educational requirements for CDEs and offer genetic education programs for current CDEs as continuing educations offerings.

**Research Questions**

1. What perceived knowledge do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

2. What favorable attitudes do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

3. What reserved attitudes do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

4. What is the relationship between certified diabetes educators’ perceived knowledge of genetic testing and favorable attitudes towards genetic testing?

5. What is the relationship between certified diabetes educators’ perceived knowledge of genetic testing and reserved attitudes towards genetic testing?
Chapter 2

Literature Review

Using steps suggested by Garrard (2011), a comprehensive literature review was completed using the Matrix Model. This assisted in narrowing the topics of interest and identifying the research variables. The review of the literature covered an 11-year period, from 2003 to 2014. An initial search of healthcare bibliographic databases CINAHL and MEDLINE returned a small number of articles significant to the topic area. The search was then expanded to include the business and sociology databases PsychInfo and SocIndex. Search terms included the use of the key word “genetics” paired with “testing,” “type 2 diabetes,” “attitudes,” “perceived knowledge,” “registered nurses,” and “health care provider.” Additional searches were completed using Google Scholar and PubMed. After completion of a key word search, additional articles were identified by reviewing the reference lists of research studies that pertained to the topic of interest. Last, a search by author name was done in order to find any other work authors may have been written on the topic.

The studies were organized into two major subject areas: perceived knowledge and attitudes toward genetic testing and genetic testing with type 2 diabetes mellitus. Within each subject area, the studies were arranged by research type.

Perceived Knowledge and Attitudes Toward Genetic Testing

In the Netherlands, Morren, Rijken, Baanders, and Bensing (2006) and Calsbeek, Morren, Bensing and Rijken (2007) studied a sample of patients with chronic diseases. Patients with asthma, diabetes mellitus type 2, and several cardiovascular diseases were selected based upon their primary diagnosis as entered by their primary
physician. Two surveys were mailed: the Perceived Knowledge of Genetic Testing Scale and Attitudes towards Genetic Testing Instrument.

The Perceived knowledge of Genetic Testing Scale is comprised of two subscales. The medical possibilities of genetic testing subscale (range 0 to 10) has a reliability reported as 0.88; the social consequences subscale (range 0 to 12) has a reliability reported as 0.86 for a total of 11 items. Total scores range from 0 to 22 with a reported Cronbach’s alpha of 0.91 (Calsbeek et al., 2007).

The Attitudes Toward Genetic Testing Instrument measures attitudes toward genetic testing using 13 statements scored on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). The instrument is comprised of two subscales that measure favorable attitudes which reported a reliability of 0.82 and reserved attitudes with reported reliability of 0.70. A total genetic attitude scale has not been developed as these 2 subscales measure two different concepts.

In April 2002, a total of 577 patients responded to the first survey (Calsbeek et al., 2007). The survey was repeated in April 2004 with 113 patients from the 2002 group unavailable due to a variety of reasons. Results for both studies revealed that on genetic perceived knowledge, “the best-known items of genes and heredity relate to statements on the associations between genes and diseases such as ‘onset of certain diseases are due to genes, environment and lifestyle’ was correctly answered by more than 70% in all diagnostic groups” Lesser known items dealt with associations between genes. Calsbeek et al. identified that factors influencing the level of perceived knowledge included younger individuals with a higher education level and perception of the inherited nature of their illness.
Morren et al. (2006) and Calsbeek et al. (2007) found for genetic perceived knowledge that patients with diabetes mellitus in particular reported having no perceived knowledge on the several statements measuring the medical possibilities and social consequences of genetic testing. Most patients had no perceived knowledge about the consequences of DNA testing in the social sphere; the consequences of DNA testing for work were the least known. With regard to medical possibilities, the least known subject related to the possibilities and risks of gene therapy. The best known subject concerned the possibility of early detection of disease.

Attitudes regarding genetic testing were also reported by Morren et al. (2006) and Calsbeek et al. (2007), with patients with diabetes agreeing on several statements indicating a favorable view toward DNA testing. Findings of 78% to 86% were found associated with more broadly formulated statements regarding “hopefulness of treatment” and “early detection,” with opinions on specific statements not changing between the studies. However, Calsbeek et al. (2007) noted that the diabetes mellitus group scored lower in their study, which was attributed to “a less favorable attitude towards genetic testing”; 28% of the patients identified the idea of DNA tests as frightening and worried about the consequences of DNA testing for taking out insurance policies. Further, Calsbeek et al. found that fewer patients with diabetes mellitus reported that in the case of a DNA test, their family need not know about the results and fewer thought that a DNA test could change one’s future than did participants with diabetes mellitus in the Morren et al. (2006) study. Still, Calsbeek et al. found there appeared to be a positive relationship between favorable attitudes toward genetic testing and the belief that the illness has a hereditary component.
Maradiegue, Edwards, Seibert, Macri, and Sitzer (2005) studied perceived knowledge of genetic testing in nursing students. Their study was performed with a sample of 46 advanced practice nursing (APN) students enrolled in family (24), adult (6), adult/geriatric nurse practitioner (1), and nurse anesthetist (15) programs. Twenty-one students were from a state university; 25 students were from a federally funded university. Demographic data were obtained for the students. All the students had a minimum of a baccalaureate (BSN) degree and were attending graduate education classes toward a master’s degree in nursing in an area of advanced practice nursing. Seventy percent of the students were women; the most frequent age range was 30 to 39 years. None of the students were in their clinical advanced practice nursing courses but had completed their basic core courses. The survey consisted of multiple-choice questions that assessed the students’ personal evaluation of their knowledge of medical genetics principles and their awareness and understanding of various human genetics topics, concepts, tests, and disorders.

According to Maradiegue et al. (2005), most of the students were familiar with common genetic terms such as meiosis, mitosis, and mutation and responded that they had “minimal” to “some” perceived knowledge of these terms. In addition, the majority of students noted “some” to “minimal” perceived knowledge of Mendelian inheritance and terms such as autosomal dominant trait and recessive trait; however, very few students reported perceived knowledge of mitochondrial inheritance. Over 56% of the students noted “none” or “minimal” perceived knowledge of the genogram, and most students (54%) reported “none” to the question on perceived knowledge of the polymerase chain reaction (PCR) test.
To assess perceived knowledge of human genetics disorders, Maradiegue et al. (2005) presented the APN students with a survey that included a wide range of disorders, including such conditions as sickle cell anemia, Tay Sachs, and cystic fibrosis, which conform to Mendelian inheritance principles, along with multifactorial genetics conditions and genetics conditions appearing in adulthood. Perceptions of perceived knowledge of these conditions varied with a few students noting a “high” perceived knowledge level on some of the genetic conditions. Dichotomous responses (e.g., yes/no) were used to gather information regarding whether the students thought they could define common genetics concepts. While 71% felt they could define genotype and 81% felt they could define phenotype, only 39% felt they could identify allele and 20% felt they could define loci. Additionally, while all the students stated they could define the genetics terms dominant and recessive, only one student (2%) felt confident defining missense mutation, nonsense mutation, or frame shift mutation.

Further study included a survey on students’ perceptions about comfort level with regard to drawing a pedigree, speaking with a family diagnosed with a genetics condition, and discussing genetics with clients. While 57% of the students noted “probably yes” or “definitely yes” with regard to feeling comfortable speaking on the topic of medical genetics, only 34% stated they felt comfortable speaking with a family diagnosed with a genetics condition; only 22% stated “probably yes” or “definitely yes” with regard to feeling comfortable drawing a “pedigree.”

Maradiegue et al. (2005) also inquired about previous undergraduate training on selected human genetics conditions; 21 students responded. Consistent responses of no previous undergraduate educational training occurred on all items regarding previous
training on human genetics conditions; more than 95% of the students reported no prior training during their undergraduate programs on most of these conditions.

**Genetic Testing and Type Two Diabetes Mellitus**

Philippa et al. (2010) reported on a study begun in 1985 of civil servants aged 35 to 55 years to assess the presence of genetic markers in the development of type 2 diabetes. Basic physiologic measures were recorded and diabetes status was determined through a variety of blood tests. DNA was extracted from blood samples to determine specific single nucleotide polymorphisms (SNPs), chosen because of their associations with diabetes risk. With 73% participation, the cohort included 10,308 participants at entry to the study. During 1991 to 1993, participants were rescreened for diabetes (85.5% of the original sample). Two sample $t$-tests compared variable mean scores in people who developed diabetes and those who did not. The association of each genotype with risk of diabetes by logistic was calculated using regression analysis. Of the 5,135 participants studied for an average of 11.7 years, only 302 had developed type 2 diabetes mellitus. The 20 SNPs typed, together with risk estimates for type 2 diabetes, were in line with previous reports (Philippa et al., 2010).

Lyssenko et al. (2008) also studied diabetes risk and genetics by following two prospective cohorts from the Malmo Preventive Project and the Botnia study in Finland, consisting of 18,831 persons, for a median period of 23.5 years. Among these subjects, diabetes developed in 2,201 participants. Lyssenko et al. measured weight, height, waist and hip circumference, and blood pressure. Blood samples were drawn at designated intervals after a 75-g oral glucose challenge for measurement of serum glucose and serum insulin levels. Also, blood testing was performed for SNPs in 16 genes associated
with type 2 diabetes mellitus. Lyssenko et al. postulated that the predictive ability of clinical factors and the specific polymorphisms were risk factors for future type 2 diabetes. They used a number of clinical models in their analysis and found common variants in 11 genes significantly associated with the risk of future of type 2 diabetes. Interestingly, Lyssenko & Laakso (2013) found that prediction of type 2 diabetes mellitus in high-risk individuals is of little value in current clinical practice due to the limitations of genetic risk models, low discriminative ability of the genetic test, questionable clinical relevance of some genetic variants in disease prediction, and the lack of appropriate models for studies of gene-gene and gene-environment interaction.

**Summary and Conclusion**

This chapter focused on perceived knowledge and attitudes as well as genetic testing and type 2 diabetes mellitus. Calsbeek et al. (2007) found that the more medical perceived knowledge patients with diabetes displayed, the lower their reserved attitude score, while higher social perceived knowledge scores were associated with higher reserved attitude scores. In APN students (Maradiegue et al., 2005), perceived knowledge was more closely identified with traditional genetic terms, and the majority of students did not report previous genetic training. The literature supports a genetic risk for the development of type 2 diabetes mellitus but does not advocate the use of genetic testing on a routine basis.
Chapter 3

Methods

In this chapter there is a description of the research design, setting, and sample. Operational definitions, instruments, and procedures are also detailed. Data management, statistical analyses, and protection of human subjects are described.

Research Design

A cross-sectional level II descriptive correlational design was used to explore the relationships between perceived knowledge and attitudes regarding genetic testing for type 2 diabetes mellitus in certified diabetes educators. Data were collected at one point in time.

Setting

The data were collected using a mailed survey distributed through the United States Postal Service. A mailing list of 6,675 registered nurses (RNs) who were also currently certified diabetes educators was obtained from the National Certification Board of Diabetes Educators (NCBDE) and represented all 50 states. The NCBDE was established in 1986 as an independent organization to promote the interests of diabetes educators and the public at large by granting certification to multidisciplinary professionals involved in teaching persons with diabetes through the establishment of eligibility requirements and the development of a written examination. Since it was first awarded in 1986, the CDE credential has become a standard of excellence for the delivery of quality diabetes education.

Sample

A random sample of 2,000 RN CDEs from across the United States was invited to
participate in this study. The researcher corresponded via email with the research
department of the NCBDE, which provided mailing addresses of all RNs who were
CDEs in the United States; 6,675 names and addresses appeared on the list provided by
the NCBDE. The entire list was entered into Random.org for randomization. To be
eligible for the study, subjects had to be employed in diabetes education a minimum of
50% of the time, use English as their primary language, and deny having had previous
genetic testing done previously.

Power analysis was conducted for this study via G*Power.org. A two-tail normal
bivariate correlational model with an established alpha of 0.05 and power of 0.95
determined that the sample size needed would be 115 subjects. Considering a possible
low return rate for mailed surveys and the potential for missing data and also to increase
reliability, the sample size was expanded to a randomized 2,000 subjects.

Operational Definitions of the Main Variables

The main variables in this study were perceived knowledge and attitudes.
Calsbeek et al. (2007) and Morren et al. (2006) operationally defined perceived
knowledge of genetic testing as the total mean score on the Perceived Knowledge of
Genetic Testing Questionnaire. They operationally defined attitude toward genetic
testing as the total mean favorable and total mean reserved attitudes subscale scores on
the Attitudes toward Genetic Testing Instrument. As these subscales measure separate
concepts, there is not a total mean score.

Instruments

The instruments used for this study were a Demographics and Background Data
Sheet, the Perceived Knowledge of Genetic Testing Scale, and the Attitudes towards
Genetic Testing Instrument.

**Demographic and Background Data Sheet**

Data were collected using a Demographic and Background Data Sheet with had 8 items: 1) percent of time spent in diabetes education, 2) language, 3) gender, 4) age, 5) highest level of nursing education, 6) years in practice as a certified diabetes educator, 7) previous genetic testing, and 8) genetic education/training.

**Perceived Knowledge of Genetic Testing Scale**

The Perceived Knowledge of Genetic Testing Scale was developed by Calsbeek et al. (2007). This scale is comprised of two subscales. The medical possibilities of genetic testing subscale consists of five questions (range 0 to 10) with reliability reported as 0.88; the social consequences of genetic testing subscale includes six questions (range 0 to 12) with reliability reported as 0.86. A 3-point scale determines perceived knowledge (0 = nothing to 2 = sufficient perceived knowledge). Total scores range from 0 to 22 with a reported Cronbach’s alpha of 0.91 (Calsbeek et al.). These items require approximately 2 minutes to complete. Email permission to use the Perceived Knowledge of Genetic Testing Scale was received from Calsbeek.

**Attitudes Toward Genetic Testing Instrument**

The Attitudes Toward Genetic Testing Instrument developed by Calsbeek et al. (2007) measures attitudes toward genetic testing using 13 statements scored on a 5-point Likert scale; scores range from 1 (strongly disagree) to 5 (strongly agree). The instrument is comprised of two subscales. Six statements measure favorable attitudes with a reported a reliability of 0.82; seven statements measure reserved attitudes with a reported reliability of 0.70. Scores for the favorable attitude subscale range from 6 to 30
and scores from the reserved attitudes subscale range from 10 to 35. A total genetic attitude scale has not been developed as these two subscales measure two different concepts. Email permission to use this tool was obtained from Calsbeek.

**Procedure**

Prior to recruitment and data collection, approval for the study was obtained from the Case Western Reserve University Institutional Review Board (IRB). The potential participants were mailed the consent form containing information on the study and all elements required: the Demographic and Background Data Sheet, the Perceived Knowledge of Genetic Testing Scale, and the Attitudes Toward Genetic Testing Instrument. A self-addressed stamped envelope was included for the return of responses. Participants were given the option to self-disclose personal email addresses if they wished to receive aggregate results at the end of the study. No reminders were sent.

**Data Management**

Prior to data collection, a data code book for all data was prepared. All coding was promptly performed once the completed surveys were returned and performed solely by the researcher to minimize error. Data were entered into the computer by the researcher daily. All distractions were avoided to ensure correct data entry. Each data file was printed and compared with data entry for accuracy. Two independent researchers reviewed 10% of the data entry for error. Any errors were corrected on the original as well as on the backed-up data copies. All calculations were performed using Version 22 of SPSS. Missing data were minimal and given the designation of 99 within the codebook and in SPSS.

**Statistical Analysis**
Version 22 of the SPSS program was used to analyze the data. Research question 1 addressed the mean score on the Perceived Knowledge of Genetic Testing Scale. Research questions 2 and 3 addressed the mean score of the favorable attitudes and the mean score of the reserved attitudes subscales of the Attitudes Toward Genetic Testing Instrument. Pearson’s correlation coefficient was used to analyze the data for questions 4 and 5 to determine if a correlation existed between the perceived knowledge mean score, favorable attitudes mean score, and reserved attitudes mean score. The alpha was set at 0.05, two tailed.

**Protection of Human Subjects**

Approval for this study was obtained from the Case Western University Institutional Review Board. The President of Rhodes State College (employer of the researcher) validated that the researcher/employee did not have to obtain approval from Rhodes State College Institutional Review Board as the study was not using students or employees of the college. Likewise, the National Board of Certified Diabetes Educators also verified that approval was not needed to utilize their listing of certified diabetes educators. This was a minimal risk study.

All data are password protected on a password-protected computer and were backed up on a password-protected thumb drive that is stored in a locked file cabinet. The consent forms and survey hard copies are stored separately in a locked file cabinet in the researcher’s home. The participants were informed that the thesis committee chair as well as the IRB of Case Western Reserve University could have access to the data. The findings will be presented in aggregate form to the six participants who provided personal email addresses. No incentives were given for participation. All data
will be destroyed in three years.
Chapter 4

Results

In this chapter, response rate and description of the sample are detailed. Reliability is provided for the instruments. Results are also detailed for each of the research questions.

Response Rate

A total of 2,000 surveys were sent through the United States Postal Service. Approximately 25%, or 546 surveys, were returned. Of these, 320 met inclusion criteria, making the response rate 16%. No surveys were discarded due to missing data.

Description of the Sample

The participants in the study included males \((n = 13, 4.1\%)\) and females \((n = 307, 95.9\%)\). They were predominantly older with age 50+ years the largest category \((n = 253, 79\%)\). Participants had predominantly a bachelor’s degree in nursing \((n = 142, 44.4\%)\) followed by a master’s degree \((n = 122, 38.1\%)\). Years as a certified diabetes educator were variable and are presented in Table 1. Participants were also predominantly employed in diabetes education 75% to 100% of the time \((n = 244, 76.3\%)\). Most participants reported having no previous genetic training \((n = 269, 84.1\%)\). Demographic characteristics of the sample are listed in Table 1.
Table 1.
*Characteristics of the sample*

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</tr>
<tr>
<td>Female</td>
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<td>41</td>
<td>12.80%</td>
</tr>
<tr>
<td>Bachelor Degree</td>
<td>142</td>
<td>44.40%</td>
</tr>
<tr>
<td>Master Degree</td>
<td>122</td>
<td>38.10%</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>10</td>
<td>3.10%</td>
</tr>
<tr>
<td>Years as a Certified Diabetes Educator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 to 5 years</td>
<td>49</td>
<td>15.30%</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>80</td>
<td>25%</td>
</tr>
<tr>
<td>11-15 years</td>
<td>67</td>
<td>20.90%</td>
</tr>
<tr>
<td>16-20 years</td>
<td>43</td>
<td>14.40%</td>
</tr>
<tr>
<td>21-25 years</td>
<td>43</td>
<td>13.40%</td>
</tr>
<tr>
<td>26-30 years</td>
<td>26</td>
<td>8.10%</td>
</tr>
<tr>
<td>Over 30 years</td>
<td>8</td>
<td>2.50%</td>
</tr>
<tr>
<td>Time Spent in Diabetes Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 25% up to 50%</td>
<td>76</td>
<td>23.80%</td>
</tr>
<tr>
<td>More than 50% up to 75%</td>
<td>100</td>
<td>31.30%</td>
</tr>
<tr>
<td>More than 75% up to 100%</td>
<td>144</td>
<td>45%</td>
</tr>
<tr>
<td>Previous genetic training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>50</td>
<td>15.60%</td>
</tr>
<tr>
<td>No</td>
<td>269</td>
<td>84.10%</td>
</tr>
<tr>
<td>Previous genetic testing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>319</td>
<td>99.70%</td>
</tr>
</tbody>
</table>
Reliability of the Instruments

For this study, the total Perceived Knowledge of Genetic Testing Scale had a Cronbach’s alpha of .71. For the medical possibilities of genetic testing subscale, the Cronbach’s alpha was .63. For the social consequences subscale, the Cronbach’s alpha was .66. Compared with Calsbeek et al. (2007), these subscale reliabilities are low. Independent factor analysis was performed in an effort to understand the possible reasons behind these findings.

For this study, the Cronbach’s alpha of the Attitudes toward Genetic Testing Instrument subscales were .89 for the favorable attitudes subscale and .53 for the reserved attitudes subscale.

Analysis of Research Questions

Research question 1. What perceived knowledge do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

The mean total perceived knowledge of genetic testing was 7.24 (SD = 4.98) on a scale of 0 to 22. Perceived knowledge on the medical subscale was 2.35 (SD = 2.39) on a scale of 0 to 10, while perceived knowledge on the social subscale was 4.88 (SD = 3.61) on a scale of 0 to 12. The highest percentages of those reporting no knowledge were evident in the items relating to medical knowledge of genetic testing. The least known of those statements was related to the possibilities and risks of gene therapy (69.7%, n = 221). The participants were perceived to have more sufficient knowledge about the social consequences of genetic testing. The most sufficient knowledge of all statements was related to the rights of third parties to inquire about the results of DNA testing (48.7%, n = 155). CDEs’ perceived knowledge scores for specific items are
shown in Table 2.

<table>
<thead>
<tr>
<th>Table 2</th>
<th>Perceived knowledge of certified diabetes educators regarding genetic testing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All*</td>
</tr>
<tr>
<td>Medical Possibilities</td>
<td></td>
</tr>
<tr>
<td>The possibility and risks of gene therapy</td>
<td>317</td>
</tr>
<tr>
<td>The significance of DNA-testing for my relatives</td>
<td>317</td>
</tr>
<tr>
<td>The significance of DNA-testing for my offspring</td>
<td>317</td>
</tr>
<tr>
<td>The possibility to use genetic testing to prevent or treat a disorder</td>
<td>317</td>
</tr>
<tr>
<td>The possibility of early detection of certain disorders using DNA-testing</td>
<td>317</td>
</tr>
<tr>
<td>Missing*</td>
<td>3</td>
</tr>
<tr>
<td>Social consequences</td>
<td></td>
</tr>
<tr>
<td>The consequences of DNA-testing for my work</td>
<td>318</td>
</tr>
<tr>
<td>The consequences of DNA-testing for taking out insurance</td>
<td>318</td>
</tr>
<tr>
<td>The rights of third parties to inquire about the results of DNA-testing</td>
<td>318</td>
</tr>
<tr>
<td>The consequences of DNA-testing for my daily life</td>
<td>318</td>
</tr>
<tr>
<td>Your rights to refuse DNA-testing</td>
<td>318</td>
</tr>
<tr>
<td>Your own possibilities to apply for DNA-testing</td>
<td>318</td>
</tr>
<tr>
<td>Missing*</td>
<td>2</td>
</tr>
</tbody>
</table>

Research question 2. What favorable attitudes do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

For the favorable attitudes subscale on the Attitudes Toward Genetic Testing Instrument, the mean score was 25.3 (SD = 3.67) on a scale of 6 to 30. Interestingly, participants favored the item regarding the development of DNA research as a positive medical progression, 176 (57%) agreed and 105 (34%) strongly agreed and the item regarding wanting to know if the disease is inherited had 147 (48%) in agreement and 133 (43%) in strong agreement equally. Participants least favored the item related to approving the use of DNA testing for early detection of diseases with 175 (57%) agreeing and 83 (27%) strongly agreeing. Favorable attitudes are shown in Table 3.
### Table 3

**Attitudes of certified diabetes educators regarding genetic testing for type 2 diabetes mellitus**

<table>
<thead>
<tr>
<th>Attitude</th>
<th>All*</th>
<th>Strongly Disagree</th>
<th>Strongly Disagree</th>
<th>Don't know/no opinion</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Favorable</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I think the development of DNA research is hopeful in the treatment of diseases.</td>
<td>308</td>
<td>6 (2%)</td>
<td>7 (2%)</td>
<td>18 (6%)</td>
<td>169 (55%)</td>
<td>108 (36%)</td>
</tr>
<tr>
<td>I think that the development of DNA research is a positive medical progress.</td>
<td>308</td>
<td>5 (2%)</td>
<td>4 (1%)</td>
<td>18 (6%)</td>
<td>176 (57%)</td>
<td>105 (34%)</td>
</tr>
<tr>
<td>I approve of using DNA-testing for early detection of diseases.</td>
<td>308</td>
<td>5 (1%)</td>
<td>3 (&lt;1%)</td>
<td>42 (14%)</td>
<td>175 (57%)</td>
<td>83 (27%)</td>
</tr>
<tr>
<td>I would inform my siblings about the results of a DNA-test for a specific disease.</td>
<td>308</td>
<td>4 (1%)</td>
<td>3 (&lt;1%)</td>
<td>22 (7%)</td>
<td>150 (49%)</td>
<td>129 (42%)</td>
</tr>
<tr>
<td>I would inform my children about the results of DNA-testing for a specific disease.</td>
<td>308</td>
<td>4 (1%)</td>
<td>2 (&lt;1%)</td>
<td>32 (10%)</td>
<td>133 (43%)</td>
<td>137 (44%)</td>
</tr>
<tr>
<td>I want to know whether my disease is hereditary.</td>
<td>308</td>
<td>3 (&lt;1%)</td>
<td>4 (1%)</td>
<td>21 (7%)</td>
<td>147 (48%)</td>
<td>133 (43%)</td>
</tr>
<tr>
<td>Missing*</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Reserved</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The possibility of a DNA-test will change one's future.</td>
<td>308</td>
<td>1 (&lt;1%)</td>
<td>8 (3%)</td>
<td>73 (24%)</td>
<td>162 (53%)</td>
<td>64 (21%)</td>
</tr>
<tr>
<td>I worry about the consequences of DNA-testing for being able to take out insurance.</td>
<td>308</td>
<td>1 (&lt;1%)</td>
<td>21 (7%)</td>
<td>81 (26%)</td>
<td>127 (41%)</td>
<td>77 (27%)</td>
</tr>
<tr>
<td>As long as a disease cannot be treated, I don't want a DNA-test.</td>
<td>308</td>
<td>29 (9%)</td>
<td>106 (34%)</td>
<td>104 (34%)</td>
<td>52 (17%)</td>
<td>17 (6%)</td>
</tr>
<tr>
<td>If I had a DNA-test done, my family need not know about the result.</td>
<td>308</td>
<td>28 (9%)</td>
<td>111 (36%)</td>
<td>87 (28%)</td>
<td>71 (23%)</td>
<td>11 (4%)</td>
</tr>
<tr>
<td>I worry about the consequences of DNA-testing for the chances of finding a job.</td>
<td>308</td>
<td>17 (6%)</td>
<td>89 (29%)</td>
<td>107 (35%)</td>
<td>73 (23%)</td>
<td>22 (7%)</td>
</tr>
<tr>
<td>I don't want a DNA-test to tell me that I am at risk for a certain disease.</td>
<td>308</td>
<td>50 (16%)</td>
<td>172 (55%)</td>
<td>59 (19%)</td>
<td>24 (8%)</td>
<td>3 (&lt;1%)</td>
</tr>
<tr>
<td>The idea of a DNA-test frightens me.</td>
<td>308</td>
<td>60 (19%)</td>
<td>157 (51%)</td>
<td>50 (16%)</td>
<td>35 (11%)</td>
<td>6 (2%)</td>
</tr>
<tr>
<td>Missing*</td>
<td>12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Research question 3.** What reserved attitudes do certified diabetes educators have regarding genetic testing for type 2 diabetes mellitus?

For the reserved attitudes subscale on the Attitudes towards Genetic Testing scale, the mean score was 20.7 ($SD = 3.51$) on a scale of 7 to 35. Participants were most reserved about the possibility of a DNA test changing one’s future, with agreement at 162 (53%) and strongly agreeing at 64 (21%). In comparison, the least reserved item was not wanting a DNA test to tell if one is at risk for a certain disease, with only 27 (8%) agreeing or strongly agreeing. Reserved attitudes are shown in Table 3.

**Research question 4.** What is the relationship between certified diabetes educators’ perceived knowledge of genetic testing and favorable attitudes toward genetic testing?

Pearson’s correlation was computed using the total perceived knowledge mean score and the favorable attitudes subscale mean score. There was no significant correlation found.

**Research question 5.** What is the relationship between certified diabetes educators’ perceived knowledge of genetic testing and reserved attitudes toward genetic testing?

Pearson’s correlation was computed using the total perceived knowledge mean score and the reserved attitudes subscale mean score. There was no significant correlation found.
Chapter 5

Discussion

In this chapter, the findings for the research questions are discussed and compared with previous research. Implications for education and practice are detailed, and recommendations for further research are expounded upon.

Response Rate

Two thousand surveys were mailed through the United States Postal Service. A total of 546 surveys were returned. Of these, 320 met inclusion criteria making the response rate 16%. No surveys were discarded due to missing data. For their study, Calsbeek et al. (2007) sent out two mailings of the Perceived Knowledge of Genetic Testing Scale and the Attitudes Toward Genetic Testing Scale; they had a return rate of 82.3% from patients with diabetes for the survey sent in 2002 and a return rate of 87.9% when the survey was repeated in 2004. CDEs have not been previously questioned regarding perceived knowledge of genetic testing or attitudes toward genetic testing.

Since Calsbeek et al. (2007) sent the Perceived Knowledge of Genetic Testing Scale and the Attitudes toward Genetic Testing Instrument to patients with chronic disease rather than to health care professionals treating the disease, one could postulate that the low return rate in the current study is attributable to CDEs not viewing the topic of genetic testing for type 2 diabetes mellitus as an important part of their practice.

Performance of the Instruments

Calsbeek et al. (2007) had a Chronbach’s alpha of 0.91 for perceived knowledge while this study had a Chronbach’s alpha of 0.80 for perceived knowledge. The subscales for medical and social considerations, .76 and .77, respectively, were lower when compared to
Calsbeek et al.’s alphas, .88 for medical consequences and .86 for social consequences. Burns & Grove (2001) consider a Chronbach’s alpha from $0.6 < 0.7$ as acceptable while $0.7 < 0.8$ is considered good. In the Calsbeek et al. study, alphas were .82 for the favorable attitudes regarding genetic testing subscale and .70 for reserved attitudes. This study had alphas of .89 for favorable attitudes, which was consistent with Calsbeek et al., and .59 for reserved attitudes, which is significantly lower. Burns & Grove (2001) consider Chronbach’s alphas from $0.7 < 0.8$ good but $0.5 < 0.6$ poor.

In independent analysis of each statement on the reserved attitudes subscale, the alpha could be increased to .66 if statement number 7 were discarded from analysis. Interestingly, statement number 7 considers attitude toward the possibility of a DNA test changing the future. With this in mind, this lower alpha could be attributed to the nature of this study’s participants. Examination of the study participants shows a homogenous group in gender, age, language, time spent in diabetes education, and lack of previous genetic training. While Calsbeek et al. (2007) questioned 398 individuals with asthma, diabetes, and cardiovascular disease, this study questioned 320 CDEs. Possibly individuals with diabetes would be more vested into finding an alternate cause for their disease than the educators who treat diabetes. Another possibility could be that this reserved attitude statement falls as the first question on the reserved attitudes subscale. While patients with diabetes may have been reading Calsbeek’s instrument carefully and applying it to their own personal experience with diabetes, the CDEs completing the questionnaire could have been answering automatically from previous questions, rather than analyzing each statement.

**Characteristics of the Sample**
In this descriptive study, data were collected from a sample of 320 CDEs with a nationally mailed survey. Participants were predominantly females aged 50 and older with a bachelor’s or a master’s degree. Years as a CDE were evenly spread from 1 to 30 years. Participants were also predominantly employed in diabetes education 75% to 100% of the time. Most participants reported having had no previous genetic training.

In comparing this sample with findings about the national RN workforce reported by Budden, Zhong, Moulton, & Cimiotti (2013), it is clear that the sample from the current study is similar to the national workforce, although nationally, the prevalence of male nurses is increasing. Budden et al. reported that 53% of RNs working today are over 50 years old and 55% have bachelor’s degrees or higher, consistent with the findings of this study. Budden et al. did not report on RNs working within the specialty of diabetes education.

**Discussion of the Research Questions**

Research question 1 dealt with the mean of the perceived knowledge scale. This mean score, was 7.24 ($SD = 4.98$) on a scale of 0 to 22. This finding seems to indicate that CDEs overall have a low perceived knowledge of genetic testing. Looking at the sample characteristics again, this is not surprising as 99.7% indicated that they had not received any previous genetic training. Likewise, given the mean age of the sample, their nursing education likely took place prior to the era of genomic sequencing. The mean score, on the medical consequences subscale 2.35 ($SD = 2.39$) on a scale of 0 to 10, seems to contribute to this overall lower score. Given the results of the Maradiegue et al. (2005) study, which showed advanced practice nursing students had only a basic knowledge of Mendelian genetic terms, this is not a surprising finding. In 2005, less
than one third of all baccalaureate nursing programs in the United States had curricula that included genetics and genomics content, which demonstrates that the nursing profession is not yet fully competent in this area (Jenkins & Calzone, 2007). However, while there are now well-developed competencies with specific recommendations that genetics and genomics content be included at all levels of professional nursing education, there is a scarcity of literature describing specific strategies for incorporating such content into nursing curricula (Garcia, 2010).

Research question 2 dealt with the mean score of the favorable attitudes subscale on the Attitudes toward Genetic Testing Instrument. The mean score was 25.3 ($SD = 3.67$) on a scale of 6 to 30. With a mean higher than the average mean of 18 for this subscale, this finding would seem to indicate that CDEs had more favorable attitudes regarding genetic testing. A few of the more favored items on the subscale concerned the development of DNA research as a positive medical progression, wanting to know if the disease is inherited, and approval of using DNA testing for early detection of diseases. In light of their decreased level of perceived knowledge, having increased favorable attitudes is suspect. Looking back to the characteristics of the sample, no questions were asked about practice setting, whether participants’ personal practice area was rural or urban or research based. If this question had been asked, perhaps there would have been different findings per practice area. Likewise, if the study participants had been asked about the type of genetic training they had received in their nursing programs, rather than simply presence or absence, there may have been a different finding. While 99.7% acknowledged not having had previous training, asking the question in a different way, with the assumption that they had such training, could have
made participants think in greater depth about what constitutes the concept of genetic training.

Research question 3 dealt with the mean score of the reserved attitudes subscale on the Attitudes toward Genetic Testing Instrument. The mean score was 20.7 ($SD = 3.51$) on a scale of 7 to 35. This finding would seem to indicate that CDEs agreed or strongly agreed with the statement that a DNA test changes one’s future. This does correlate with the favorable attitudes statement approving the use of DNA testing for early detection of diseases. Interestingly, there is an inference that 73% would want a DNA test to tell them if they are at risk, which correlates with the favorable attitudes statement of using DNA testing for early detection of disease. Again, in light of their decreased level of perceived knowledge, having increased reserved attitudes is suspect. Looking back to the characteristics of the sample, there were no areas of qualitative inquiry. Perhaps, if there were an open area for the participants to write in their attitudes regarding genetic testing and diabetes, a theme might emerge that would show more personal analysis.

Question 4 correlated the mean of the complete perceived knowledge tool and the mean of the favorable attitudes subscale. While there were no significant correlations found in this study, it is interesting to consider that the amount of perceived knowledge did not impact favorable attitudes. In comparison, Calsbeek et al. (2007) and Morren et al. (2006) had a significant finding between perceived knowledge and favorable attitudes. The current study included CDEs within the boundaries of the United States. Calsbeek et al. and Morren et al. used the same participants in each of their studies within the Netherlands. For this study, the majority of participants were bachelor’s prepared or master’s prepared RNs. Their education level is higher than that of the
majority of the Calsbeek et al. and Morren et al. participants, whose educational levels were listed as basic (no education) to intermediate vocational education. In the earlier studies, higher perceived knowledge correlated with more favorable attitudes, which was not the case in this study. Inquiry into how much and types of education is not shared in studies performed in the Netherlands, suggesting that perhaps the education in that country integrates genetics more readily into basic education programs than in the United States, where genetics is not broadly studied.

Question 5 correlated the mean of the complete perceived knowledge tool and the mean of the reserved attitudes subscale. There were no significant correlations found in this study, as in the Calsbeek et al. (2007) and Morren et al. (2006) studies. Thus, the amount of perceived knowledge does not seem to influence reserved attitudes regardless of educational level or nationality. However, considering that Calsbeek et al. and Morren et al. questioned patients with chronic disease and this study questioned RNs who had not been asked these questions before, this finding is not surprising.

Limitations

The study used a cross-sectional descriptive design. Cross-sectional designs by nature are limited in that they study only one moment in time with a specific set of guidelines. The fact that this was a mailed survey is another limitation; no reminders to complete the survey were sent. The listing of the names and addresses of the CDEs provided by the NBCDE could not be validated as current. A further limitation could be the lack of inquiry into how much genetic training was provided in the participants’ nursing programs. This information, with a question about the type of genetic training received in the post-genetic-sequencing era, could have strengthened the study.
Widening the professional discipline might also have strengthened the study. As the CDE credential is a multidisciplinary credential, surveying physicians might have yielded significant results.

**Implications for Education and Practice**

With the increasing scientific inquiry into genetics and chronic disease, certified diabetes educators may be called upon to provide education not only in diabetes self-management but also the genetics of type 2 diabetes. While little is known regarding the types and amounts of genetic training provided in nursing education programs, Jenkins and Calzone (2007) suggested that introduction of genetic content into curricula may help increase health care providers’ understanding of this topic and the education provided to patients diagnosed with genetic-related chronic diseases. The results of this study could be used in the development of continuing education courses related to patient care with regard to the items that scored lower on the tools used in this study. Particular attention could be paid to item number 7 on the Attitudes toward Genetic Testing Instrument, possibly adding a qualitative portion to this statement to further evaluate the differences between RNs and patients regarding this item.

With regard to practice, the knowledge that type 2 diabetes mellitus has a genetic linkage could inspire certified diabetes nurse educators to at least begin the discussion of genetic testing with their CDE colleagues from other disciplines, perhaps for the identification of specific diabetes medication responsiveness. Personalized medicine is cutting edge, and one can speculate that it will have a positive impact on quality of life in the future. Interdisciplinary teamwork not only would support positive outcomes for patients, but also could grow the specialty of diabetes education by adding a new
recognized discipline to the credential of CDE.

**Recommendations for Future Research**

As no significant correlations were found, recommendations for future research involves further investigation into nursing education regarding the types, amounts, and specifics of genetic training that nurses receive. Other recommendations would be for more longitudinal studies, qualitative studies, or mixed-method studies of certified diabetes educators’ knowledge and attitudes as genetics information regarding the multifactorial processes involving chronic disease increases. Also, further examination of the independent study variable may be warranted to examine what types of relationships exist between the statements. Once these relationships are identified, continuing education programs for CDEs regarding genetic testing could perhaps be created.

**Conclusions**

With increased longevity and an aging population, type 2 diabetes mellitus is at the forefront of adult onset chronic disease globally. In the United States, the ability to respond to this crisis hinges upon the American Diabetes Association’s proactive approach of identifying individuals who are pre-diabetic and educating them in behavior modification to prevent or delay the disease. Genetic testing could be an important piece of this endeavor. Certified diabetic nurse educators are at the front line of this endeavor. The purpose of this study is to examine certified diabetes nurse educators’ perceived knowledge and favorable and reserved attitudes toward genetic testing while also observing for any significant relationships between perceived knowledge and attitudes toward genetic testing for type 2 diabetes mellitus. Questionnaires were mailed
to a nationwide sample of 2,000 certified diabetes educators. The response rate was 16% ($n = 320$). The mean perceived knowledge score was low at 7.24 ($SD = 4.98$) on a scale of 0 to 22. The favorable attitudes mean score was high at 25.3 ($SD = 3.67$) on a scale of 6 to 30. The reserved attitudes mean score was neutral at 20.7 ($SD = 3.51$) on a scale of 7 to 35. No significant correlations were found between perceived knowledge and attitudes. The results identified that genetic testing information for chronic disease is needed for certified diabetes educators, along with information regarding genetic testing for chronic diseases in all undergraduate nursing programs.
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