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Third-Degree Family Health History and Perception of Disease Risk

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This is to certify that the doctoral dissertation by

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Walden University
2015

Abstract

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by

Liana F. Romero

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health Epidemiology

Walden University

May 2015

Abstract

Chronic diseases are a significant cause of illness and mortality in the United States. Hereditary predisposition to chronic diseases is a useful indicator for identifying people at risk for disease development. An ideal tool for determining this predisposition is the CDC, NIH, and AAFP recommended third-degree family health history (FHH). The aim of this quantitative, cross-sectional study, based on the theoretical frameworks of social constructivism and the health belief model, was to assess the possible influence between the completed third-degree FHH and the participant's perception of disease risk. Two-hundred seventy-three participants were recruited from health care facilities and from the general population using convenience sampling. Bivariate and multivariate tests were applied to analyze the obtained data. Binary regression indicated a statistically significant association between the presence of heart disease, stroke, breast cancer, ovarian/cervical cancer, prostate cancer, colon cancer, and diabetes, and the perception of risk for the particular disease as noted in the FHH. A familial history of stroke appeared to be the strongest predictor of perception of disease risk. Moreover, increasing age, particularly within the age range of 40 to 57, was associated with increasing levels of perception of disease risk for heart disease, stroke, and prostate cancer. Individuals from the general population significantly indicated higher-than-average risk for colon cancer compared to those from health care facilities. Social change implication of this study may be the widespread implementation of a familial health history questionnaire that leads to an impactful, higher degree of disease risk awareness, prompting preventive action on the part of the individual, and leading to improved individual and population health.

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Dedication

During the 5 years of my doctoral journey, so many people have touched my life and given me the motivation to move forward. Thank you to my parents and step-parents, my Miami family, friends Melanie Erickson and Judy Stellini as well as other family, friends, and co-workers for all their support and encouragement. Much gratitude to my cousin Liza Roig for all of her help, and a special thank you to Mike Farrell for his humorous enthusiasm during the final stages. To my husband, Oscar, and our children Kevin, Michael, Angela, and Monica, thank you for your infinite patience, but more important for always believing in me and inspiring me to find the resilience to follow my destiny and make my dreams come true.

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Chapter 1: Introduction to the Study

The escalating burden of chronic diseases necessitates a change in management of the United States health care system from the traditional reactive/curative based approach to algorithms focused on risk assessment and disease prevention (Fineberg, 2013; O'Neill et al., 2009; van Baal, Feenstra, Hoogenveen, Ardine de Wit, & Brouwer, 2007). Prevention begins with recognizing the potential for disease susceptibility due to heredity risk (Hanson, Novilla, Barnes, De La Cruz, & Meacham, 2007). However, without open communication of health issues among family members, people may fail to gain awareness of the possible risk for disease that may exist across generations of their family. A family's health history may play a significant role in behavior modification and subsequent disease risk reduction (Hanson et al., 2007). Therefore, an important area of research in the development and implementation of chronic disease preventive care plans is the association between the family health history (FHH) and the perception of disease risk.

In Chapter 1, I present background on why the FHH is important in the identification of risk for chronic diseases. As explained through the problem statement, purpose of the study, and significance of the study, I also present the rationale for exploring the possible associations between the knowledge of the third-degree FHH and the perception of disease risk as well as the association between the demographics of the participants and the perception of disease risk.

Background

Chronic diseases in the United States currently account for an estimated 107 million cases of illness and greater than 1.7 million deaths annually (Center for Disease Control and Prevention [CDC], 2012; HealthyPeople.gov, 2011; Kung, Hoyert, Xu, & Murphy, 2008). Cardiovascular disease (CVD), stroke, cancers (breast, gynecological cancers, colon and prostate), and diabetes are highly prevalent chronic diseases for which early identification of risk for the disease and implementation of preventive care measures may reduce disease onset and improve quality of life (Claassen et al., 2010; Hanson et al. 2007; O'Donnell, 2004). Risk assessment of chronic disease begins with a patient knowing his or her risk level due to hereditary predisposition (Acheson et al., 2010; Debruyne et al., 2006; Scheuner, Whitworth, McGruder, Yoon, & Khoury, 2006; Sesso et al., 2001; Valdez, Yoon, Qureshi, Green, & Khoury, 2010; Walter & Emery, 2005; Walter et al., 2013). The FHH questionnaire is an established instrument in health care practice used for the collection of a patient's medical information. It may also be applicable as a useful tool for assessment of chronic disease risk from hereditary predisposition (Acheson et al., 2010; Claassen et al., 2010; Hanson et al., 2007; Scheuner et al., 2006; Walter & Emery, 2005; Walter et al., 2013).

The health history of a family is an assessment of risk for disease based on the cumulative influences of physiological predispositions, behavior/lifestyle practices, and environmental exposures of the individual family members (Annis, Caulder, Cook, & Duquette, 2005; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wilson et al., 2009; Yoon, Scheuner, Jorgensen, & Khoury, 2009). A history of chronic illness

among family members is a strong indicator of risk for CVD, stroke, cancer (breast, ovarian, colon, or prostate), and diabetes (Annis et al., 2005; Debruyne et al., 2006; O'Neill et al., 2009; Powell et al., 2013; Scheuner et al., 2006; Valdez et al., 2010; Wilson et al., 2009; Yoon, Scheuner, & Khoury, 2003; Yoon et al., 2009). Risk for a chronic disease has been shown to double if a person has at least one first-degree or first generation relative (parent, sibling, or children) who develops the disease by middle age (O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010). Risk may even triple if more than one first-degree relative is diagnosed with a disease. This has been demonstrated among women with a familial history of breast cancer and among families with colorectal cancer or CVD histories (Fuchs et al., 1994; Hunt, Williams, & Barlow, 1986; Lloyd-Jones et al., 2004; O'Neill et al., 2009; Powell et al., 2013; Sesso et al., 2001; Scheuner et al., 2006; Valdez et al., 2010).

The FHH questionnaire commonly completed by most patients is focused on first-degree relatives. However, the recommendation from the American Academy of Family Physicians (AAFP), American Medical Association (AMA), CDC, the U.S Department of Health and Human Services (HHS), and National Institute of Health (NIH) is to use a questionnaire that gathers information on three degrees or generations of family (AAFP, 2012; AMA, 2014; Berg et al., 2009; CDC, 2013b; HHS, n.d.; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010). The three degrees of relatives are comprised of first-degree as described above, second-degree that include maternal/paternal grandparents, aunts/uncles, nieces/nephews and half-siblings, and third-degree that include first cousins (AAFP, 2012; AMA, 2014; Berg et al., 2009; CDC, 2013b; HHS,

n.d.; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010). The utilities of using the third-degree FHH in health care practice include providing the physician with an understanding of the patient's current condition and assisting in the development of an intervention or preventive care protocol (Bickley & Szilagyi, 2012; Mai et al., 2011). The third-degree FHH may also aid patients in appraising and recognizing their individual level of risk for developing a given chronic disease as well as motivating patients to implement behavioral changes to delay disease onset or improve disease outcomes (Cegala, 2011; Claassen et al., 2010; Ko, Turner, Jones, & Hill, 2010; Valdez et al., 2010). As important are the public health applications. In public health, a comprehensive FHH is a tool for gathering data for disease epidemiology, risk stratification of chronic diseases, and the subsequent development and implementation of targeted health promotions and education initiatives (Audrain-McGovern, Hughes, & Patterson, 2003; Bickley & Szilagyi, 2012; Dearborn & McCullough, 2009; Harrison et al, 2003; Valdez et al., 2010).

In spite of the recommendations from AAFP, AMA, CDC, HHS, and NIH, the third-degree FHH is not routinely used in medical practice (Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013). Stated barriers for routine use of the third-degree FHH include the availability of time during a medical consultation, training for health care employees collecting the FHH, and patient's knowledge for their family's health history (Annis et al., 2005; Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Cegala, 2011; Claassen et al., 2010; Flynn et al., 2010; Janssens et al., 2012; O'Neill et al., 2009; Parmar, 2003; Powell et al., 2013; Qureshi et al., 2011; Rich et al.,

2004; Ruffin et al., 2011; Valdez et al., 2010; Wattendorf & Hadley, 2005; Wilson et al., 2009; Yoon et al., 2003; Yoon et al., 2009). Specifically, a patient's extent of knowledge of FHH appears to be associated with gender and age, with women and older patients having greater degree of knowledge versus men and younger patients (Archer et al., 2011; Beier & Ackerman, 2003; Cegala, 2011; Janssens et al., 2012; O'Neill et al., 2009; Qureshi et al., 2011; Rich et al., 2004). A limited number of studies have shown a relationship between cultural practices and how families communicate on health issues, which may also influence the patient's knowledge of FHH and the perception of disease risk (Chow et al., 2009; Elder et al., 2009; Mai et al., 2011; Nam et al., 2011; Shaw et al., 2009). However, studies investigating the association between ethnicity and a patient's knowledge of FHH are few due to limited representation of ethnic groups or lack of inclusion of ethnic groups as mediating variables (Janssens et al., 2012; Kayser, Acquati, & Tran, 2012; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Yoon et al., 2003). Consequently, this quantitative study aimed to address these gaps in information and explore the possible associations between the participant's third-degree FHH and his or her perception of disease risk as well as the FHH controlled for the demographics of the participants and the perception of disease risk.

Problem Statement

The health care burden of chronic diseases in the United States is evident by the estimated 107 million cases of disease and 1.7 million deaths occurring annually (CDC, 2012; HealthyPeople.gov, 2011; Kung et al., 2008). Identification of risk for the diseases accompanied by early preventive care may delay or prevent disease onset, improve an

individual's quality of life, and progressively minimize the burden of chronic diseases on health care (Claassen et al., 2010; O'Donnell, 2004). A third-degree FHH may serve as a tool to assess an individual's risk level for chronic disease and prompt a call to action to implement health-related changes based on the individual's perceived level of risk (Bickley & Szilagyi, 2012; Cegala, 2011; Claassen et al., 2010; Ko et al., 2010; Mai et al., 2011; Valdez et al., 2010; Wang et al., 2009). Consequently, further investigation may aid in understanding the possible associations between completing the third-degree FHH and the perception of disease risk as well as the influence of the FHH, controlled for demographics, and the perception of disease risk.

Purpose of the Study

The third-degree FHH is the recommended questionnaire for collecting information on the history of family health. The third-degree FHH may be an effective tool to assess the risk for chronic diseases and to motivate the patient to implement behavioral changes to delay disease onset or improve disease outcomes (Bickley & Szilagyi, 2012; Cegala, 2011; Claassen et al., 2010; Ko et al., 2010; Mai et al., 2011; Valdez et al., 2010). The accuracy and thoroughness with which a person completes the third-degree FHH is based on the knowledge the person has of their FHH, which may be influenced by the demographics of the patient and communication among family members. Therefore, in this research study I examined the possible associations between completing the third-degree FHH and the participant's perception of disease risk as well as the influence of the FHH, controlled for demographics, on the FHH and the perception of disease risk.

Research Questions and Hypotheses

The research questions for this study were developed to investigate the possible associations between completing the third-degree FHH and the participant's perception of disease risk in addition to the influence of the participant's demographics on the FHH and the perception of disease risk.

Research Question 1 (RQ1): How does completing the third-degree FHH influence the participant's perception of disease risk?

$H1_0$: Completing the third-degree FHH does not influence the participant's perception of disease risk, as measured by the survey instrument.

$H1_a$: Completing the third-degree FHH does influence the participant's perception of disease risk, as measured by the survey instrument.

Research Question 2 (RQ2): How does the participant's third-degree FHH, controlled for demographics (gender, age, race, ethnicity, and place of recruitment [physician office versus general community locations]), influence the perception of disease risk?

$H2_0$: The participant's third-degree FHH, controlled for demographics, does not influence the perception of disease risk.

$H2_a$: The participant's third-degree FHH, controlled for demographics, does influence the perception of disease risk.

Theoretical Framework

The theoretical frameworks applied to this study included social constructivism and the health belief model (HBM). The foundation of social constructivism or

socioculturalism is the work of psychologist Lev Vygotsky. In his work on social constructivism, Vygotsky focused on the ability of individuals to learn through personal experiences and participation in a given culture (as cited in Wertsch, 1997). Through his theory, Vygotsky emphasized the importance of learning information through interactions with well-informed and educated members of their social circle (as cited in Wertsch, 1997). Vygotsky also considered the relevancy of background and culture in developing the degree and breadth of knowledge acquired by the learner (as cited in Wertsch, 1997). Social constructivism was applied to this study in the context of a participant's learned knowledge of FHH as influenced by the background, culture, and/or ethnicity to which the participant has been exposed over his or her lifetime.

The HBM was developed in the 1950s by social psychologists Hochbaum, Rosenstock, and Kegels who suggested that various elements play a role in a person's perception of his or her likelihood of acquiring a disease. These elements included perceptions of risk and severity of the diseases, perceptions of the benefits of an interaction or treatment, and perceptions of obstacles in carrying out the interactions or treatment (as cited in Cerkoney & Hart, 1980; Janz & Becker, 1984; Rosenstock, 1974). Additional facets of the HBM included the cues that prompt an individual to adopt an interaction or treatment as well as the individual's level of confidence in effectively completing the interaction or treatment (Rosenstock, Strecher, & Becker, 1988). The theoretical application of the HBM was tested in this study by the use of the third-degree FHH and the influence of the FHH on the participant's level of perceived disease risk.

Nature of the Study

The nature of this study was a quantitative, cross-sectional design that aimed to assess the possible influence between the completed third-degree FHH and the participant's perception of disease risk. The study participants were recruited from health care facilities and from the general population using convenience sampling. Each participant completed a questionnaire consisting of three sections: a continuous/categorical questionnaire to gather demographic information (gender, age, race, ethnicity, professional experience related to health care, and place of recruitment [health care facility versus general locations]); the comprehensive third-degree FHH; and the 5-point Likert scale questionnaire to assess the perception of disease risk of the third-degree FHH. The study questionnaire was developed and offered online through Survey Gizmo (www.surveygizmo.com). A hardcopy version of the same questionnaire was also available to individuals recruited at the health care facilities. The completeness factor, centered on the participant's knowledge of his or her third-degree FHH, was calculated individually for each participant based on whether or not the participant knew if each family member identified had any of the chronic conditions listed. The sample size was calculated using statistical power analysis, alpha level application for Type 1 error, and effect size.

Definition of Terms

Chronic diseases: In the context of this study, chronic diseases are a group of health conditions identified by the CDC as having highest prevalence, morbidity, and mortality. Chronic diseases are also highly preventable disease conditions (CDC, 2012).

This disease category is inclusive of CVD, stroke, cancers (breast, ovarian and cervical, colon and prostate), and diabetes (CDC, 2012).

Familial health history: The FHH is a questionnaire designed to gather the medical history of family members to identify risk of disease based on shared genetics, culture, behavior/lifestyle practices, and environmental exposures (Annis et al., 2005; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wilson et al., 2009; Yoon et al., 2009).

Knowledge of family health history: The knowledge of FHH is the actual information that a given individual may have of the health history of the family, both maternal and paternal, as influenced by social constructivism, culture, practices and family interaction.

Medical consultation: In the context of this study, the medical consultation is the type or nature of the health care visit (annual physical, illness/treatment, or monitoring/follow-up).

Perceived level of risk: In the context of this study, the perceived level of risk is the degree to which a study participant is concerned about the probability of having a hereditary predisposition for a chronic disease based on the information documented on the FHH.

Third-degree FHH: The third-degree FHH is comprised of questions that gather the medical histories of the first-degree relatives (parent, sibling, or child), second-degree relatives (maternal/paternal grandparents, aunts/uncles, nieces/nephews, and half-

siblings), and first cousins or third-degree relatives (AAFP, 2012; Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010).

Assumptions

A key assumption of the study was that the study participants had knowledge of their family's health history as needed to complete a third-degree FHH. Further, it was assumed that the participants' self-reported information was accurate, truthful, and thorough, and that the participants did not withhold information. Another assumption was that the validated third-degree FHH questionnaire used in the study, which was based on the recommendations of AAFP, CDC, HHS, and NIH, appropriately captured the participant's FHH (AAFP, 2012; Berg et al., 2009; CDC, 2013b; HHS, n.d.; O'Neill et al., 2009; Powell et al., 2013). A final assumption of the study was that volunteer participants were representative of a diverse population, thus leading to statistically meaningful results from the study.

Scope and Delimitations

The study was delimited to assessing whether completion of the third-degree FHH influenced the participant's perceived level of disease risk. The study included male or female participants, 18 years of age or older, of any race or ethnicity who could read and understand English. Individuals who indicated they were adopted or did not know if they were adopted were excluded from the study, as it was assumed they did not have FHH knowledge of their biological family.

Nonrandom convenience sampling was used to recruit participants. Participants were recruited from health care facilities and from the general community. Recruitment

information was posted at various locations throughout the cities of Newark and Wilmington and surrounding areas in Delaware within New Castle County, Delaware as well as through a Facebook page created specifically for the study. Because the participant pool was limited to those individuals who volunteered to complete the survey, the study findings may not be generalizable to a larger population.

It was not within the scope of this study to develop mitigations such as training information or tutorials to overcome possible knowledge barriers for completing the third-degree FHH. It was also not within the scope of the study to provide medical care, preventive interventions for chronic diseases, or tools to enhance the perception of risk among the study participants.

Limitations

Several limitations to the study research are noted. The study participants from the health care facilities were recruited from within a specific geographical area due to logistical management. Therefore, this portion of the study population was limited to the individuals who volunteered for the study within the geographical areas of the health care facilities (Scheuner et al., 2006). This may have led to selection bias and limited generalizability of the findings from the study. The study participants may have also been a source of recall bias since the data were self-reported.

The online survey format has its own limitations, which may include difficulty in completing or reluctance by participants to complete due to technological challenges, lack of computer access, and concerns around privacy (Shannon, Johnson, Searcy, & Lott, 2002). Additionally, the electronic survey format can lend itself to misinterpretation

and mistakes by the survey participant (Shannon et al., 2002). Another limitation is that the study did not provide a process for validating the FHH information entered by study participants. Therefore, true lack of knowledge of FHH or accuracy of information reported in the FHH cannot be proven. Consequently, inaccuracies in the information reported may have altered the results of the data.

An additional source of bias may have resulted due to the Hawthorn effect (Delgado-Rodríguez & Llorca, 2004). Since a sample of the study participants were recruited from health care facilities, these individuals may have had an enhanced level of disease risk perception, which may have contributed to inaccurate information, overstatement of disease risk, and biased result outcomes. Conversely, the study participants recruited from the general community may have had less concern about disease risk at the point in time of their participation in the study.

The use of a cross-sectional design also had limitations such as the study design only being able to infer correlations and not causal relationships and the requirement of a larger sample size to attain a significant power (Creswell, 2009). The cross-sectional study design may have also been subject to selection bias, information bias, and potential for confounding due to factors such as educational level and health care experience or training (Cooper, 2000; Delgado-Rodríguez & Llorca, 2004; LaMonte, 2013).

Measures to address the limitations included ensuring that recruitment took place at health care facilities that were known to serve a widely diverse population. Recruitment flyers for the participants from the general population were posted at locations with high traffic of individuals from widely diverse populations. To minimize

confounding, educational level and health care experience or training was controlled. Other measures to control the study limitations included providing participants with very clear directions for how to complete the study in addition to emphasizing the importance of providing as thorough and accurate information as feasible based on their knowledge levels of FHH.

Significance of the Study

The study was a distinctive opportunity to address a gap in research relative to the influence of completing the third-degree FHH on the participant's perception of personal risk for chronic disease(s). The information obtained through this study may aid in the development of a comprehensive, third-degree FHH that is aligned with AAFP, CDC, and NIH recommendations and useful for assessing chronic disease risk (AAFP, 2012; Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013). Additionally, the information may aid in the development of health promotions and education initiatives that effectively convey a sense of personal disease risk.

An accurate and complete FHH increases its usefulness as a primary tool for chronic disease risk assessment at a time when chronic diseases use the bulk of health care resources, and the applications for genetic testing based on risk assessment are significantly expanding (Khoury, Feero, & Valdez, 2010; Powell et al., 2013; Rich et al., 2004; Valdez et al., 2010). Herein lay the opportunities for social change that may result from the study: widespread implementation of a familial health history questionnaire that leads to an impactful, higher degree of disease risk awareness, prompting preventive

action on the part of the individual, and leading to improved individual and population health.

Summary

Chronic diseases are a significant cause of illness and mortality in the United States. Hereditary predisposition to chronic diseases is a useful indicator for identifying people at risk for disease development. With knowledge of disease risk, an individual, in consultation with health care professionals, may implement behavioral changes that could aid in delaying disease onset or improving disease outcomes. An ideal tool for determining hereditary predisposition is the familial health history, and in particular, the CDC, NIH, and AAFP recommended third-degree FHH (AAFP, 2012; Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010). However, the influences of the third-degree FHH questionnaire and participant demographics on the level of perceived risk of disease are not fully understood. The goal of the study outlined in this chapter was to investigate these gaps in the knowledge base, as supported by the review of the literature presented in Chapter 2.

Chapter 2: Literature Review

Introduction

Although extensive research has been devoted to the significance of the FHH as an indicator of disease risk, limited information is available on the influence of a completed third degree FHH questionnaire on the patient's perception of disease risk. The purpose of this research study was to contribute to the body of work on FHH by examining the possible association of the completed third-degree FHH on the participant's perceived level of disease risk as well as the influence of the participant's demographics on the FHH and the perception of disease risk. The conclusions of this study may contribute to increasing awareness of the importance of an accurate and complete FHH, the usefulness of the third-degree FHH as primary tool for chronic disease risk assessment, and the value of the FHH in creating or increasing awareness of disease risk. The contributions of this study to the existing knowledge base may lead to social changes in public health and health care. These social changes may include the widespread implementation of a comprehensive FHH that can be used by physicians to aid in disease risk assessment and promoting greater disease risk perception among people, which may contribute to improved individual and population health.

In this chapter, I present the theoretical constructs that form the basis for the study as well as the relevant associations between the theories and the supporting literature. An analysis of recent peer-reviewed literature is summarized, including a review of the FHH as a tool of disease risk assessment, the influence of the FHH on the perception of disease risk, and the influence of participant demographics on the perception of disease risk.

Literature Search Strategies

The literature search strategies used in this review included accessing research databases relevant to the subject matter of this study. The databases included MEDLINE with Full Text, PubMed Central, Elsevier, Science Direct, EBSCO, BioMed Central, ProQuest Health & Medical Complete, Dissertations & Theses at Walden University, and the Internet search engine Google Scholar. Additionally, the websites for the CDC, NIH, HHS, and AAFP were searched for applicable literature and guidelines. Keywords and terminology used in the execution of the search included the following, either individually or in combination: *family health history, familial health history, third degree family health history, chronic disease risk assessment, chronic disease risk assessment from family health history, disease perception from family health history, patient perception of chronic disease risk, patient perception of disease risk, hereditary risk for chronic disease, knowledge of family health history, ethnicity and family health history, demographics and family health history, demographics and perception of chronic disease risk, demographics and knowledge of family health history, learning through family, family as the source of learning, learning and ethnicity, age and learning, gender and learning, social constructivism and constructivism, Vygotsky and social formation, culture and constructivism,* and *health belief model*. The literature review was primarily focused on articles published over a 5-year period from 2009 to 2013. The exceptions to the literature review timeline were seminal articles and book chapters focused on the theoretical foundations in addition to key journal articles that support the evolution of

concepts such as the utility of the FHH, its applications to chronic diseases, and the factors influencing knowledge of the FHH.

Theoretical Foundation

The theoretical and conceptual frameworks for the study are based on the theory of social constructivism or socioculturalism conceptualized by Vygotsky and Rosenstock's HBM. The examination of the effects of the demographical characteristics (age, gender, race, and ethnicity) on the patient's extent of knowledge of the FHH and the assessment of the perception of disease risk ascertained from the third-degree FHH are guided by the theoretical foundations of social constructivism and the HBM.

Social Constructivism or Socioculturalism

Through the theory of social constructivism or socioculturalism, Vygotsky (1986) considered how people learn, gain, and share information by being a part of and interacting within their social and cultural spheres (Corden, 2001; Wertsch, 1985). According to Vygotsky (1978), biology alone was not responsible for how an individual developed, but rather he emphasized that social factors were just as critical in the formation of the individual's knowledge and foundation. Vygotsky (1978, 1986) argued that culture directly affected the way children learn, and he emphasized that knowledge was built through the continued interactions within social entities and with individuals who had greater levels of experience and knowledge, such as family members. Further, Vygotsky's idea that the learning process aligned with inner values acquired from upbringing spoke to the influence of culture in determining what individuals would and

would not learn from their family members and other social entities (as cited in Daveydov & Kerr, 1995).

Supporting Vygotsky's theories of socioculturalism, substantial research exists on the role of the family as the primary entity of learning and behavioral development (Audrain-McGovern et al., 2003; Bandura & McClelland, 1978; Lau, Quadrel, & Hartman, 1990; Parsons & Fox, 1952). Gender, culture, and ethnicity further shape how an individual constructs knowledge and meaning from the information he or she has gathered through the learning process (Rich et al., 2004; Wu & Schimmele, 2005). This includes what individuals learn about their own health, their family's heath, health-related lifestyles and behaviors, and perceived healthiness (Claassen et al., 2010; Lau et al., 1990; Parsons & Fox, 1952; Ruffin et al., 2011).

Kleinman, Eisenberg, and Good (1978) expanded on the concept of social constructivism or socioculturalism by theorizing that knowledge gained from family members was constructed from information influenced by their cultural practices and beliefs. Therefore, if cultural practices within a family were not conducive to discussions of health or illness, or the concepts or conditions of illness were miscommunicated, members of the family would lack knowledge or knowledge accuracy of their health history (Kleinman et al., 1978; Lau et al., 1990). Conversely, Valach, Young, and Lynam (1996) proposed that the family unit could serve as the center of health promotion for its members if the concepts of healthy lifestyle and disease prevention were shared goals within the family.

Beyond considering the family unit, Alegria, Atkins, Farmer, Slaton, and Stelk (2010) described how constructivism also occurred through the interactions an individual had with the community including educators, health care providers, and other members of the same cultural makeup. Common sets of beliefs, practices, and principles that created alignment among the members of the community emerged through this process of knowledge-building (Alegria et al., 2010). Thus, Alegria et al. (2010) demonstrated that social constructivism influenced the health beliefs of individuals through their social/cultural interactions and knowledge building processes.

Further expanding on the influence of culture in health matters, Alegria et al. (2010) indicated conditions of disease, illness, and treatment varied among different cultures. Additionally, Alegria et al. noted that culture could affect how an individual recognized or coped with illness in addition to how an individual accepted the ability of a health care intervention to resolve a health problem. Consequently, culture could enhance an individual's health literacy and potentially make the individual more perceptive of disease susceptibility and risk as well as more knowledgeable of the benefits of screening and intervention (McBride, Koehly, Sanderson, & Kaphingst, 2010).

Health Belief Model

The HBM was developed in an effort to aid public health officials in understanding why individuals were reluctant to accept the screening programs for determining the presence of disease or disease risk and the preventive measures to deter disease (Janz & Becker, 1984; Rosenstock et al., 1988). The premise of the HBM was formed from the behavioral theories focused on perceived value and goal attainment

(Janz & Becker, 1984). Hochbaum, Rosenstock, and Kegels suggested that the perceptions of susceptibility, severity, benefits, and obstacles all conveyed a message of the perceived likelihood of acquiring a disease and triggered a call to action relative to seeking treatment for a disease (as cited in Cerkoney & Hart, 1980; Janz & Becker, 1984; Rosenstock, 1974).

Janz and Becker (1984) pointed to demographical diversity including gender, age, and ethnicity and differences in social and environmental structures as variables influencing a given individual's beliefs and perceptions about health and illness. Vance (1995) made the connection between the principles of social constructivism and the development of gender-specific health-related behaviors. Together with Courtenay (2000), Vance considered how genders differed in their beliefs and behaviors related to health. Studies showed that in contrast to women, men appeared to have a decreased perception of susceptibility exhibited through their engagement in unhealthy and higher risk behaviors such as smoking and excessive alcohol consumption (Courtenay, 2000; Mahalik, Burns, & Syzdeck 2007; Pinkhasov et al., 2010; Wang et al., 2008).

The cultural and social concepts of femininity and masculinity are significant in the formation of gender-based health beliefs and health-related behaviors (Evans, Frank, Oliffe, & Gregory, 2011; Mahalik et al., 2007). In many cultures, women are seen as nurturers or caretakers. Women are also considered more cognoscente of health issues and matters of illness and more willing to adopt healthy lifestyles (Moore, 2010). In contrast, men are more highly associated with strength, virility, endurance, and healthiness, which are attributes aligned with the cultural perceptions of masculinity

(Courtenay, 2000; Evans et al., 2011; Moore, 2010). Thus, the theory of social constructivism or socioculturalism has fostered an awareness of differences in knowledge and behaviors between the genders and among cultures, which may influence health beliefs and the perceptions of disease risk.

Literature Review

Chronic Diseases

The prevention, diagnosis, and treatment of chronic diseases have become key focus areas for public health and health care as a whole (Chronic Disease Prevention and Management, 2010). One significant reason for this focus is the widespread prevalence of chronic diseases. As of 2008, 107 million or almost 50% of all adults in the United States have at least one chronic disease condition (HealthyPeople.gov, 2011). Additionally, many individuals may suffer from multiple chronic diseases simultaneously leading to complicated procedures, costly treatments, and less favorable outcomes (Lochner & Cox, 2013; Schneider, O'Donnell, & Dean, 2009).

Another important reason to focus on chronic diseases is the cost associated with their treatment and management. In the United States, the treatment and management of chronic diseases accounts for 75% of the $2 trillion annual health care expenditure (CDC, 2013a; Cory et al., 2010). On a global scale, the pace of expenditure due to chronic diseases is highly related to the growing older population and the behavioral/lifestyle choices that are directly associated with chronic disease risk, disease onset, and disease severity (CDC, 2012; Yach, Hawkes, Gould, & Hofman, 2004). Four behavioral practices are directly attributed to the rise in patients with chronic diseases: obesity, lack of

physical activity, tobacco use, and excessive alcohol consumption (CDC, 2012; Claassen et al., 2010; Cory et al., 2010; Shuval et al., 2013; Yach et al., 2004). These are considered modifiable behaviors. Unchanged, however, these behaviors are responsible for exacerbating the incidence of CVD, stroke, cancers, arthritis, and diabetes (CDC, 2012; Cory et al., 2010; Yoon et al., 2009).

Nevertheless, behavioral practices are not the only contributors to chronic diseases. Environmental factors such as workplace exposures and life-stressors can also lead to risk for and development of chronic diseases (Feil & Fraga, 2012; Garrido, Hash-Converse, Leventhal, & Leventhal, 2011; Rappaport & Smith, 2010). Most important is the inherited risk of disease that an individual may possess because of a positive FHH of chronic diseases.

Family Health History

The health history of a family is an important profile of the health status of the family members and their possible predisposition to disease risk due to hereditary conditions, culture, lifestyle/behavioral practices, and environmental exposures (Annis et al., 2005; Claassen et al., 2010; de Hoog, Portegijs, & Stoffers, 2013; Doerr & Teng, 2012; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wilson et al., 2009; Yoon et al., 2009). According to Emery and Rose (1999), "the family history in primary care should be seen as a multidimensional tool that allows us to examine patient's concerns and explore the role of both nature and nurture in the aetiology and prevention of disease" (p. 261). The advent of genomic testing for predetermining risk or presence of disease has led to the use of the comprehensive FHH questionnaire as an essential first

step for patient screening (AAFP, 2012; Annis et al., 2005; Christianson et al., 2012; Claassen et al., 2010; Janssens et al., 2012; Khoury & Mensah, 2005; Khoury et al., 2010; Mai et al., 2011; Maradiegue & Edwards, 2005; Powell et al., 2013; Ramsey, Yoon, Moonesinghe, & Khoury, 2006; Rich et al., 2004; Valdez et al., 2010; Walter et al., 2013; Wu et al., 2013). Relative to chronic diseases, the FHH questionnaire is used to guide modifications to lifestyle and behavior in order to prevent or delay onset of disease, or if disease is present, to reduce the severity and/or complications of disease (Annis et al., 2005; Claassen et al., 2010; de Hoog et al., 2013; Mai et al., 2011; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wilson et al., 2009; Yoon et al., 2009). Other important outcomes of gathering a FHH include establishing a rapport with the physician, assessment by the physician of the well-being of the patient (including mental status), and potentially, legal protection for both the physician and the patient (Kornusky, 2012).

A number of studies have addressed the association of the FHH to the risk of chronic diseases in a given patient. Type 2 diabetes has garnered significant focus due to the high prevalence of disease and associated comorbidities (Harrison et al., 2003). Results from one study showed that individuals with a family history of type 2 diabetes had a 2 to 6 fold greater chance of developing the disease than individuals with no family history of diabetes (Annis et al., 2005). Annis et al. (2005) focused on the 10,283 participants of the National Health and Nutrition Examination Survey conducted from 1999 to 2002 and looked at the first-degree relatives of the participants. Of those individuals with a family history of type 2 diabetes, the prevalence of the disease was 4 fold versus individuals with no family history. An additional study involving a review of

five cohort studies, one case-control study, and five cross-sectional studies involving thousands of participants in the United States, Europe, South Africa, and Taiwan confirmed increased prevalence of type 2 diabetes among people with first-degree relatives who had the disease (Harrison et al., 2003). Further studies have shown that the familial risk for diabetes among the general population was 29%, and the chances of a person developing diabetes were 2 to 4 times greater if both parents had diabetes (Wang et al., 2012; Zolt et al., 2009). These researchers independently confirmed the importance of using the FHH as a tool for risk assessment, disease prevention, and behavioral modification as well as pointing to the beneficial applications for combating the growing public health epidemic of diabetes.

As part of a multifactorial approach similar to the diabetes example, the FHH has been shown to be an important screening tool for identifying family members at risk for coronary heart disease (CHD) and CVD (Qureshi et al., 2012). Morales, Cowan, D'agua, and Hershberger (2008) emphasized the importance of obtaining a comprehensive FHH from patients presenting with cardiomyopathies, which as a disease class have been highly associated with genetic mutations. In the study, the FHH was considered of high importance in the identification of family members affected by the disease or at risk for the disease (Morales et al., 2008). Additionally, the FHH was found to aid in understanding how the causative genes behaved as they were inherited among the family members (Maradiegue & Edwards, 2005; Morales et al., 2008).

Similar to Morales et al. (2008), O'Donnell (2004) stated that a positive FHH was present in most cases of early onset coronary heart disease (CHD) and atherosclerotic

CVD. With early onset CHD, for example, disease among siblings versus parents was shown to impart a stronger effect on disease risk (Nasir et al., 2004). In other studies, a positive association was observed between number of first-degree relatives with CHD and the probability of disease risk for a given individual (Scheuner et al., 2006; Shuval et al., 2013; Valdez et al. 2010). Noteworthy is that these studies all emphasized the importance of considering the FHH for wide-spread screening and identification of families at risk for CVD and/or CHD disease (Morales et al., 2008; Nasir et al., 2004; O'Donnell, 2004; Scheuner et al., 2006; Valdez et al., 2010).

Notable emphasis has been placed on researching the utility of the FHH in understanding hereditary patterns of cancer and the justification for genomic screening of patients at risk for cancer (Christianson et al., 2010; Ginsburg & Willard, 2009; Kardia, Modell, & Peyser, 2003; Murff, Greevy, & Syngal, 2007; Wang et al., 2012). Genetic mutations and gene variants associated with specific types of cancers have been successfully mapped through gene sequencing; this in turn has facilitated patient screening for known mutations and variants (Ginsburg & Willard, 2009; Hopper, Bishop, & Easton, 2005). However, due to cost associated with wide spread screening, the FHH is recommended as a practical first step in determining relative disease risk (Flynn et al., 2010; Hopper et al., 2005; Wu et al., 2013).

The benefits of utilizing a FHH for assessing cancer risk have been repeatedly suggested in studies. Fuchs et al. (1994) pointed to 12 studies conducted over several decades that indicated the likelihood of developing colorectal cancer increased as much as 8 fold among individuals who had a first-degree relative with the disease. The risk also

increased if the individual was younger and had a first-degree relative who already had the disease and or if the individual had multiple first-degree relatives with the disease (Fuchs et al., 1994). Further research by Scheuner, McNeel, and Freedman (2010) confirmed that a positive FHH was associated with a 2 to 5 time increase in disease risk for a member of the family. Family history of colorectal, prostate, ovarian, or breast cancer among first-degree and second-degree relatives was shown to pose a higher disease risk among members of the family (Murff, Spigel, & Syngal, 2004; Scheuner et al., 2010; Wideroff et al., 2010). The recommendation from the research was the collection of an accurate FHH that encompassed more than first-degree relatives in order to establish hereditary disease risk and justification for genetic screening, testing, counseling, and appropriate intervention measures (Flynn et al., 2010; Murff et al., 2007; Ramsey et al., 2006; Scheuner et al., 2010; Wideroff et al., 2010).

Early identification provides an opportunity for early interventions that could prevent disease development or delay disease onset (Morales et al., 2008; Nasir et al., 2004; O'Donnell, 2004; Scheuner et al., 2006; Valdez et al., 2010; Zolt et al., 2009; Zolt, Cox, Silvey, & Leman, 2012). As suggested by Qureshi et al. (2012), greater than 60% of individuals at risk for CHD could be identified through a FHH profile and subsequently benefit from a preventive care regimen. Zolt et al. (2009) also noted that early identification of individuals with risk of developing type 2 diabetes followed by implementation of lifestyle changes could delay disease onset by 58%.

However, another body of research exists challenging the evidence supporting the routine use of the FHH as a risk assessment tool as well as evaluating the financial

feasibility of wide spread screening for complex diseases in primary care. According to Khoury et al. (2010), the NIH concluded there was insufficient evidence to support the routine use of the FHH as a stand-alone screening tool for complex diseases in primary care practice. Another study of 16,970 men and women in the United Kingdom concluded that a universal screening program utilizing a patient-completed questionnaire did not demonstrate high effectiveness in preventing cardiac events; however, the study also concluded that a family history of diabetes, smoking, and obesity could provide information for preventive strategies (Chamnan, Simmons, Khaw, Wareham, & Griffin, 2010). Yet Frezzo, Rubinstein, Dunham, and Ormond (2003) observed in their study that 79.5% of patients were at risk for a chronic disease as ascertained from the collection and review of FHH in a primary health care setting.

Routine implementation of a comprehensive FHH has received support from health care providers and public health agencies and associations. The CDC launched the Family History Public Health Initiative in 2002, and the HHS United States Surgeon General's Family History Initiative was launched in 2004. Both programs aimed to establish awareness and acceptance for routine FHH collection to aid in risk assessment, health care, and preventive measures (Khoury et al., 2010; Orlando et al., 2011; Wang, Gallo, Fleisher, & Miller, 2011; Winderoff et al., 2010). The National Health Interview Survey (NHIS) was also launched as a public health initiative to collect population-wide FHH in order to understand the burden of risk and disease (Ramsey et al., 2006; Scheuner et al., 2010; Wideroff et al., 2010). At the state level, the California Health Interview Survey, the Family Health Study, and the Behavioral Risk Factor Surveillance System

aimed to collect FHH to understand the prevalence of disease within families (Mai et al., 2011; Scheuner et al., 2010; Wideroff et al., 2010). Further, governmental agencies such as the United States Preventive Services Task force (USPSTF) issued guidance statements on the increased cancer risk among individuals with a family history of disease (Flynn et al., 2010).

As previously noted, the CDC, NIH, HHS, AAFP, American Medical Association (AMA), and the National Cancer Institute (NCI) established recommendations on the use of the comprehensive FHH questionnaire. These agencies were involved in the development of computer-based FHH questionnaires such as Family Healthware, MeTree, Health Heritage®, My Family Health Portrait, the Myriad hereditary cancer quiz, and the NCI Risk Assessment Tool. These questionnaires and tools were created to facilitate the collection process and standardize the questionnaire (AAFP, 2012; Berg et al., 2009; CDC, 2013b; de Hoog et al., 2013; Cohn et al., 2010; Doerr & Teng, 2012; HHS, n.d.; Khoury & Mensah, 2005; Mai et al., 2011; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wang et al., 2012; Wu et al., 2013; Yoon et al., 2009; Zimmerman, Patel, & Chen, 2008).

The primary care physician's office is recognized as the ideal location to facilitate the collection of a comprehensive FHH (Kemper et al., 2010; Plat, Kroon, Van Schayck, De Leeuw, & Stoffers, 2009; Qureshi et al., 2011; Valdez et al., 2010). However, numerous studies noted that the primary care visit did not allow sufficient time for completion of a comprehensive FHH (Annis et al., 2005; Archer et al., 2011; Cegala, 2011; Christianson et al., 2012; Claassen et al., 2010; Doerr & Teng, 2012; Flynn et al.,

2010; Greendale & Pyeritz, 2001; Guttmacher, Collins, & Carmona, 2004; Hinton, 2008; Janssens et al., 2012; Mathers et al., 2010; O'Neill et al., 2009; Parmar, 2003; Powell et al., 2013; Qureshi et al., 2011; Reid, Walter, Brisbane, & Emery, 2009; Rich et al., 2004; Ruffin et al., 2011; Valdez et al., 2010; Wattendorf & Hadley, 2005; Wilson et al., 2009; Yoon et al., 2003; Yoon et al., 2009). Additionally, Christianson et al. (2012) and Doerr and Teng (2012) pointed to concerns around reimbursement for the time the physician or the physician's office personnel spent on completing a comprehensive FHH, interpreting the findings, and managing disease risk interventions.

The nature of the medical visit such as routine visit or emergency and patient's agenda for the visit have also been noted as possible barriers for obtaining a comprehensive FHH (Christianson et al., 2012; Doerr & Teng, 2012; Langlands, Prentice, & Ravine, 2010; Qureshi et al., 2012). Langlands et al. (2010) investigated the opportunity for obtaining a comprehensive FHH during a hospital admission for an acute illness since for some patients an emergency might be the only medical care received. It was concluded that an emergency hospital visit or in-patient stay was a viable opportunity to obtain a FHH from the patient (Langlands et al., 2010). Studies also identified the physician's interpretation of the FHH and the physician's lack of knowledge of genetics and hereditary conditions of diseases as` additional barriers to routine implementation of the FHH for disease risk assessment (Doerr & Teng, 2012; Greendale & Pyeritz, 2001; Guttmacher et al., 2004; Hinton, 2008; Mathers et al., 2010; Murff et al., 2007). Nevertheless, the most significant barrier in attaining an accurate and complete FHH is the person's level of knowledge of the health history of the family.

Knowledge of Family Health History

The most frequently administered FHH questionnaires gather information on the first-degree relatives (parent, sibling, and children) only. This is in in spite of the recommendation from the AAFP, CDC, HHS, and NIH to use the third-degree FHH (AAFP, 2012; Berg et al., 2009; CDC, 2013b; HHS, n.d.; Maradiegue & Edwards, 2005; Morales et al., 2008; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010). While information on first-degree relatives tends to have a greater degree of accuracy, a number of studies have shown that information on the FHH tends to become less accurate for second-degree relatives and more so for third-degree relatives (Doerr & Teng, 2012; Facio et al., 2010; Langlands et al., 2010; Wideroff et al., 2010; Ziogas & Anton-Culverl, 2003). For example, the study conducted by Ziogas and Anton-Culverl (2003) showed that among patients with first-degree relatives who had cancer, the reliability of FHH was 75% to 90%. However, the reliability declined to 50% to 80% for second degree relatives and dropped even further for third-degree relatives. Wideroff et al. (2010) and Yoon et al. (2009) obtained similar results. Frezzo et al. (2003) also noted that FHH questionnaires lacked information on the diseases and age of onset of diseases of second-degree relatives. Several factors were cited as potentially influencing the lack of information relative to the FHH. These included the patient's ability to recall information, patient's experience of illness, withholding of information due to fear of receiving negative medical diagnosis, and cultural practices barring discussion of sensitive medical issues (Emery & Rose, 1999; Frezzo et al., 2003; Walter & Emery, 2005; Wu et al., 2013).

Important to note is that the potential consequences of an incomplete FHH relative to second or third-degree relatives are failure to identify individuals who have familial risk for chronic disease and failure to provide early interventions that can prevent or delay disease onset (Koehly et al., 2009; Murff et al., 2007; Roth et al., 2009). Koehly et al. (2009) proposed a possible solution by suggesting that families identify family health information "gatherers" and "disseminators" (p. 2205) who would facilitate the process of compiling a comprehensive FHH and sharing it among the family members.

The authors of a limited number of other studies, however, pointed to demographics such as gender and age as influencing the level of knowledge a person may have of the health history of the family. Annis et al. (2005) demonstrated that a greater number of women had an awareness of their FHH of diabetes as compared to men. Other researchers noted that women appeared to be more involved with or aware of family illnesses probably due to their more frequent role as nurtures and care takers (Acheson et al., 2010; Annis et al., 2005; Beier & Ackerman, 2003; CDC, 2004; Courtenay, 2000; Koehly et al., 2009; O'Neill et al., 2009; Ramsey et al., 2006). Specifically related to cancer, Scheuner et al. (2010) showed that women had a greater awareness of cancer related illness among relatives and were more 1.4 times more likely to report a familial risk for cancer as compared to men. This dynamic may result from greater public awareness of such diseases as breast and ovarian cancer as compared to other diseases, even though women may be at higher risk for other conditions such as diabetes, CHD and CVD (Annis et al., 2005; Doerr & Teng, 2012; Wang et al., 2009).

Men were more likely to refrain from conversations related to cancer such as prostate cancer, possibly to protect their image of strength, masculinity and/or virility (Courtenay, 2000; Evans et al., 2011; Mai et al., 2011; Wideroff et al., 2010). Cultural practices and beliefs could influence the type of health-related discussion men were more likely to participate in beginning at a young age and therefore affect how men gained and constructed knowledge about family health matters (Courtenay, 2000). Consequently, older men appeared to have a greater awareness of familial risk for heart disease as compared to younger men (King, Tong, Pack, Spencer, & Amos, 2002; Scheuner et al., 2010; Wang et al., 2009).

Age is also relevant to an individual's level of knowledge of the FHH. Young et al. (2001) noted the wide acceptance that the family structure was the primary source of learning and information of health behaviors, lifestyle practices, and knowledge. The members of a family that discussed health matters openly were more likely to have greater awareness of family health starting at a younger age (Young et al., 2001). However, Watt, McConnachie, Upton, Emslie, and Hunt (2000) observed that sons and daughters from 1,477 families in Scotland had more knowledge of their FHH if the relatives had died at a younger age. This pointed to the possibility that greater awareness of the FHH was brought about by the trauma of the premature death of a family member. The few studies that have considered age in the context of FHH knowledge indicated more expansive knowledge of health history among older individuals as compared to younger members of the family (Acheson et al., 2010; O'Neill et al., 2009). O'Neill et al. (2009) considered this might be due to the likelihood of older individuals having more

family members affected by chronic disease conditions. Yet Murff et al. (2004) suggested that older individuals lacked knowledge of certain diseases and thus provided erroneous information. However, Koehly et al. (2009) encouraged the engagement of older family members as an ideal source of information of the health history of older, deceased, or more distant members of the family.

While several studies have incorporated gender and age as independent variables when considering knowledge of FHH, no study has specifically looked at gender and age as it relates to the third-degree FHH questionnaire. Perhaps this results from the limited use of the third-degree FHH in primary care or internal medicine. Additionally, limited information is available on the influence of ethnicity and cultural practices on the knowledge level of FHH regardless of the type of FHH questionnaire used. One explanation for this gap in the literature is the limited representation of ethnic groups or lack of inclusion of ethnic groups as an independent variable (Janssens et al., 2012; Kayser et al., 2012; O'Neill et al., 2009; Powell et al., 2013; Valdez et al., 2010; Wideroff et al., 2010; Yoon et al., 2003). Wang et al. (2010) noted the lower levels of health literacy among minority groups and among members of ethnic groups with limited command of the English language. Such conditions could limit participation of ethnically diverse individuals in studies related to FHH, or they could also result in incomplete or inaccurate information on the health history questionnaire due to misinterpretation of the information requested.

Wideroff et al. (2010) conducted one of the few studies available on ethnicity and self-reported disease conditions. He observed lack of information about the FHH and

lower reported levels of cancer among a small sample size of African-Americans. This was partly attributed to cultural practices limiting information sharing among family members and lack of knowledge of paternal family history (Kupfer, McCaffrey, & Kim, 2006; Wideroff et al., 2010). Desai, Bruce, Desai, and Druss (2001) also noted an under-reporting of cancer among nonwhite patients, but the number of nonwhite participants was considerably smaller as compared to White participants. In another study, researchers pointed to the possibility that members of certain cultures perceived reporting of health issues as an opportunity to increase reliance on and support from family members or their community, although no other literature reviewed substantiated this assumption (Wu & Schimmele, 2005).

As has been demonstrated by the Human Genome Project, cultural diversity transcends chronic disease illness, and this is apparent in the growing number of culturally diverse individuals with diabetes, cancer, CHD/CVD, and or other chronic diseases (Kayser et al., 2012; Maradiegue & Edwards, 2006). However, certain ethnic groups have higher prevalence for chronic diseases as compared to other groups. For example, prostate cancer is twice as prevalent among African American men as compared to White men, and Native Americans have three times the prevalence of diabetes as compared to White Americans (Maradiegue & Edwards, 2006). Additionally, ethnic groups in lower socioeconomic statuses (SES) may have greater prevalence of certain chronic disease conditions such as colorectal, breast, and prostate cancers (Chu, Miller, & Springfield, 2007). Consequently, accounting for culture and ethnicity in the FHH questionnaire may aid in reducing health disparities through the recognition of

disease risk and implementation of preventive measures against disease conditions (Maradiegue & Edwards, 2006).

Knowledge of FHH, like the health of the individual family member, will change over time, and physicians and patients should account for these changes through routine updates of the FHH (Benson, Baer, Breco and Kaelber, 2010; Hinton, 2008: Mathers et al., 2010; Powell et al., 2013). This is particularly true for the pediatric patient whose parents or guardians complete the health history, and whose family members may potentially develop chronic disease conditions that may pose risk to the child at a future point in time (Benson et al., 2010). Hinton (2008) pointed to the public health recommendation that patients maintain an up-to-date FHH similar to an immunization record. The benefits of maintaining a current FHH are vigilance of disease risk and opportunity for prevention and behavioral changes.

Perception of Disease Risk

Health care and public health professionals aim to improve individual and population health of chronic diseases through risk stratification, prevention, and intervention (Audrian-McGovern et al., 2003). A comprehensive FHH is recommended as the first step in identifying risk for disease. Consequently, the role of the FHH in creating awareness of disease risk is frequently considered in researching chronic disease prevention (Audrian-McGovern, 2003; Chamnan et al., 2010; Claassen et al., 2010; Kreuter & Strecher, 1995; O'Neill et al., 2009; Qureshi et al., 2000; Walter et al., 2004; Wang et al., 2008; Wang et al., 2012; Yoon et al., 2003; Zlot et al., 2009; Zlot et al., 2012). In the area of breast cancer, research showed that women may over or

underestimate the risk of disease based on a family history of breast cancer; however, personalized counseling for women with a positive family history of breast cancer may lead to improvements in health behaviors (Audrian-McGovern, 2003). Modeling studies on the influence of the FHH on the perception of CVD also pointed to possible benefits in targeting interventions to individuals identified as having risk of disease (Chamnan et al., 2010). Nevertheless, the authors noted that the positive FHH alone was not sufficient to prevent development of CVD (Chamnan et al., 2010). Claassen et al. (2010) also concluded that a positive FHH could be used to develop personalized interventions if the patient perceived increased risk of disease.

A study of 1,317 adults was conducted to assess the perception of risk relative to several chronic diseases including heart disease, cancer, and stroke; the study showed that "patients have optimistic biases about their risks of heart attack and stroke, but pessimistic biases about cancer" (Kreuter & Strecher, 1995, p. 63). The authors noted a reduction in the biases when patients were provided with an accurate health risk assessment (Kreuter & Strecher, 1995). A similar study Wang et al. (2009) reviewed the FHH of 2,362 patients collected during the Family Healthware Impact Trial and noted patients had greater perception of disease risk related to cancer as compared to heart disease, stroke, or diabetes. This phenomenon appeared to be linked to patient's perception that cancer could not be controlled but the other diseases could be controlled (Wang et al., 2009). Zlot et al. (2009) analyzed the perception of diabetes risk from data collected by the 2005 Oregon Behavioral Risk Factor Surveillance System. Researchers showed that patients with a positive family history of disease perceived much greater risk

of developing the disease as compared to patients who had a negative family history of diabetes (Zlot et al., 2009). The CDC's 2004 HealthStyles Survey noted greater perception of disease risk for diabetes among participants if their mother or siblings had diabetes as compared to their father having diabetes. One other randomized study by Pijl et al. (2009) showed patients perceived greater risk of developing diabetes if they had a positive FHH of the disease, and they were more likely to implement control measures after completing a FHH.

Summary and Conclusions

The literature review presented in this chapter summarized data on the impact of chronic diseases on health care and public health, the potential utility of the FHH for disease risk assessment by clinicians, and the efficacy of the FHH as a first-line tool for screening individuals requiring further testing, intervention, and behavioral modifications. However, the FHH is only as accurate as the information provided by patients. Limited studies have shown that gender, age, race, ethnicity, and culture may influence the amount of knowledge an individual has of the health history of the family. A number of researchers noted that an accurate FHH might aid in modifying the perception of disease risk while providing clinicians with an opportunity to develop personalized programs for behavior modification of individuals with high disease risk. However, these studies did not specifically focus on the perception of disease risk after completing a comprehensive third-degree FHH. Thus, the aim of this research study was to address the literature gaps by assessing the perception of disease risk and the possible

influence of demographics on the perception of disease risk, as ascertained through completing the third-degree FHH.

In the following section, Chapter 3, the methodology and research design of the study are presented as well as the criteria for the selecting the study population, sampling method, recruitment protocol, instruments, data collection, and data analysis. Additionally, the ethical considerations and threats to validity, as applicable, are summarized.

Chapter 3: Research Method

Introduction

The purpose of this research study was to contribute to the knowledge base of the FHH by assessing the possible associations between completing the third-degree FHH and the participant's perception of disease risk as well as the demographics of the participants and the perception of disease risk, as ascertained by completing the third-degree FHH. I conducted a cross-sectional, quantitative study on a convenience sample of the target population using a three-part survey questionnaire, which included an instrument for gathering demographics, the third-degree FHH, and the perception of disease risk instrument. The knowledge of FHH was determined for each participant by calculating a completion factor based on whether the participant knew the status of disease for each relative indicated. The completion factor was used to assess the possible association between the knowledge of FHH and perception of disease risk. Furthermore, I investigated the possible association between the demographics of the participants and the perception of disease risk, since the participant's knowledge about the FHH may be influenced by demographics.

In this chapter, I also present the study variables and describe the research design and rationale. The methodology is explained in detail, including a description of the study population, the sampling procedures used in the study, and the procedures for recruitment, participation, and data collection. The constructs of the instruments used for the third-degree FHH questionnaire and risk perception survey are detailed along with the plan for data analysis. Threats to validity are described and specifics on the ethical

procedures applicable to the study are provided. A summary of the key points of the chapter is also provided.

Research Design and Rationale

The cross-sectional study design has been shown to be well suited for studying the theoretical framework of the HBM (Fulton et al., 1991; Kiviniemi, Bennett, Zaiter, & Marshall, 2011; Shui et al., 2012). Consequently, this study was designed as a cross-sectional survey to assess the perception of disease risk based on completing the self-administered third-degree FHH questionnaire. The FHH is routinely collected as a questionnaire; therefore, the survey questionnaire format was the appropriate instrument for this study (Acheson et al., 2010; Claassen et al., 2010; Hanson et al., 2007; Scheuner et al., 2006; Walter & Emery, 2005; Walter et al., 2013). The level of risk perceived by the study participant can also be graded and quantitatively analyzed using data gathered via a survey questionnaire. Hence, I used a validated perception of disease risk questionnaire delivered as 10 questions using a 5-point Likert scale. The demographics of participant were collected using nine questions designed to capture age, gender, race, ethnicity, educational level, experience in health care, health status, and location of recruitment for the study.

The three-part survey questionnaire was created as a self-administered online survey using the web-based survey program offered through Survey Gizmo (www.surveygizmo.com). The web-based questionnaire also offered ease of use, an economical method of deployment, ability to access a large and diverse participant pool, and an expedited data gathering process (Creswell, 2009). A paper version of the exact

same survey was made available to participants recruited at health care facilities as an opportunity for those participants to complete the questionnaire while waiting at the facility for their appointment.

Research Questions

The research questions developed for this study aimed to meet the key objectives of investigating the possible influence of completing the third-degree FHH on the risk of disease perceived by the study participant and the possible association between the demographics of the participants and the perception of disease risk, as ascertained by completing the third-degree FHH.

RQ1: How does completing the third-degree FHH influence the participant's perception of disease risk?

$H1_0$: Completing the third-degree FHH does not influence the participant's perception of disease risk, as measured by the survey instrument.

$H1_a$: Completing the third-degree FHH does influence the participant's perception of disease risk, as measured by the survey instrument.

RQ2: How does the participant's third-degree FHH, controlled for demographics (gender, age, race, ethnicity, and place of recruitment [physician office versus general community locations]), influence the perception of disease risk?

$H2_0$: The participant's third-degree FHH, controlled for demographics, does not influence the perception of disease risk.

$H2_a$: The participant's third-degree FHH, controlled for demographics, does influence the perception of disease risk.

Study Variables

The perception of disease risk was the dependent variable (DV) for both RQ1 and RQ2. The knowledge of the third-degree FHH factor was the independent variable (IV) for RQ1 and RQ2 with the demographic characteristics as the mediating variables for RQ2. The demographic variables included age, gender, race, ethnicity, education level, experience in health care, health status, and location of recruitment for the study.

Methodology

Population

The population for this study included male or female participants inclusive of any race and ethnicity, 18 years of age or older who were able to read and understand English. In addition, all potential participants who indicated on the questionnaire that they are adopted were excluded from the study, as they were likely unaware of the FHH of their biological family. Participants were recruited from the cities of Newark and Wilmington and surrounding areas within New Castle County, Delaware. Additionally, a page was created on Facebook to recruit participants. The Facebook page provided a link to the online survey accessible through a private domain Universal Resource Locator (URL) at www.yourfhh.com.

According to the United States Census Bureau (2014), the estimated population 18 years of age or older within the cities of Newark and Wilmington and surrounding areas within New Castle County area was 108,146 of which 51.5% are women and 48.5% are men. Race and ethnicity are categorized by the United States Census Bureau according to the standards set forth by the Office of Management and Budgets (OMB,

2003). Applying these categories, the population of Newark, Wilmington and surrounding areas within New Castle County, Delaware is estimated to be 60.5% White, 23.1% Black, 4.6% Asian, 9.1% Hispanic or Latino, and 2.7% two or more races (United States Census Bureau, 2014).

The target geographical area has a diverse population due to the presence of institutions of higher education such as University of Delaware, Widener University, and Delaware Technical College; international banking such as Bank of America, Citibank, Discover Card, and Chase; investment companies such as ING and BP Group; and technology companies such as Dupont, Siemens, Hologic, and Hewlett Packer. Additionally, there is a large population of individuals in the service industry primarily in the areas of the farming, hospitality, construction, and landscaping industries. Consequently, the population visiting the health care facilities within this geographical were representative of both genders and a wide variety of ages, races, ethnicities, and educational and professional levels.

Sampling Procedures

The sampling method for this study was a convenience method in which the participants were recruited based on ease, such as proximity or accessibility, or they self-selected themselves through their willingness to volunteer as participants in the study (Web Center for Social Research Methods, 2008). The inclusion criteria for the sample population were male or female participants inclusive of any race and ethnicity, 18 years of age or older, and able to read and understand English. Participants younger than 18 years of age, individuals who were unable to read or understand English, or those who

indicated on the questionnaire that they were adopted were excluded from the study. The adoption exclusion was based on the assumption that adopted individuals would not have knowledge of the health history of their biological family.

Because convenience sampling is a nonprobability, nonrandom method, the recommended sample was estimated using a power analysis. The power analysis generated a value appropriate to demonstrate a true, statistically significant difference that would allow the rejection of the null hypothesis and avoidance of Type I and Type II errors (MEERA, n.d.). The G*Power Calculator version 3.1.9 (2014) was used to calculate the sample size based on performing chi-square test of association and binary logistic regression. As the sample size was calculated during the design phase of study, a priori power analysis was executed (Miles, n.d.). The calculation generated a minimum sample size of 269 participants when applying an alpha level of 0.05, a medium effect size convention, and the generally accepted power value of 0.80 or 80% probability of finding a real effect of the independent variables, knowledge of FHH and demographics, on the dependent variable of perception of disease risk (Sainani, n.d.).

The accuracy of the sample size was triangulated by performing another calculation using confidence level and confidence interval. Several studies noted a confidence level of 95% with an average confidence interval of 6 or less for the reliability of the reported FHH versus actual medical records (Acheson et al., 2010; Janssens et al., 2012; Mai et al., 2011; Murff, Byrne, & Syngal, 2004; Ziogas & Anton-Culver, 2003). The web-based Sample Size Calculator from Creative Research Systems (2012) was used to calculate the sample size based on a confidence level of 95%, confidence interval of 6,

and population size of 108,146. A sample size of 266 individuals was generated using this calculation (Creative Research Systems, 2012).

Procedures for Recruitment and Participation

The study participants were recruited from both health care facilities and the general community in order to assess if there is a difference in the level of perception of disease risk between the two groups. The goal was to obtain half of the study population, or 135 participants, from each group. Based on a search conducted on the Healthgrades (2013) website, a leading online resource to choose and research physicians and hospitals, the cities of Newark and Wilmington and surrounding area within New Castle County, Delaware have approximately 365 primary care or family medicine doctors and 419 internal medicine doctors meeting the needs of the population. Consequently, recruitment was carried out over a 6-week period by posting informational flyers at six health care facilities, which were accessible geographically in Newark, Wilmington, and Centreville, Delaware. These locations were selected based on having a large patient volume representing a wide range of demographic profiles. The number of health care facilities engaged was expanded at Week 3 in order to ensure that the participants from the health care facilities would be adequately represented in the sample.

The recruitment from the general community locations involved posting the informational flyer at the public libraries in Newark and Wilmington, 10 supermarket community boards, and community boards at the cafes, restaurants, and shops along Newark's Main Street. Additionally, flyers were posted at the employee cafeterias and coffee lounges at five large businesses spanning banking, investment, education, and

technology. Finally, the flyers were posted and distributed at seven churches within Newark and Wilmington, Delaware. A Facebook page was also created specifically for the study. The page was titled "Your FHH" and provided information on the purpose of the study along with the URL for the online survey (www.yourfhh.com). The Facebook page proved to be the best source of recruitment, as it was an efficient way to disseminate information for participation in the survey among a much larger and diverse group of individuals. To avoid biasing the participants prior to completing the surveys, no specific information was provided in the flyer on the perception of disease risk portion of the survey.

Participants recruited at the health care facilities had the option of completing the survey online or using a paper copy of the exact same questionnaire as available through the URL. Participants from the general community only had access to the online survey. Only 13 participants completed the paper copy of the survey. The paper copy of the questionnaire was provided in a packet with the consent form, instructions, and a postage paid envelope with both return and send to information addressed to me. Once the questionnaire was received, the information gathered on the paper questionnaire was entered onto the online survey at www.yourfhh.com, and the online survey number was cross-referenced on the paper questionnaire for traceability.

Whether completing the survey online at www.yourfhh.com or using the paper copy, each participant was provided with comprehensive instructions for completing the survey and with a consent form, which needed to be acknowledged before proceeding to the survey. The consent form provided information on the purpose of the study, the

voluntary and anonymous participation in the survey, and the option to withdraw from participation at any point in the survey (see Appendix B). Completion and submission of the online survey questionnaire or mailing of the paper copy of the questionnaire served as the implied consent to participate in the study. Information protected by the Health Insurance Portability and Accountability Act (HIPAA), participant identifiers, or Internet Protocol (IP) addresses were not obtained; therefore, anonymity for the participants was ensured. The survey questionnaires each had a unique number to account for the number of surveys completed, but the unique numbers did not trace back to any personal information.

Instrumentation

The survey instrument consisted of three sections (see Appendix C and Appendix D). The first section comprised of nine questions captured demographics on the participants including gender, age, race, ethnicity, adoption status, education, health care training, current health status, and location of recruitment. Question 10 was the third-degree FHH designed to capture presence of disease among three degrees of family members on both the maternal and paternal side. The third-degree FHH questionnaire was created by combining the FHH sections of the established questionnaires from AMA's Adult Family History Form (2014), the HHS's My Family's Health Portrait (2013b), the Mount Sinai Beth Israel Family History Questionnaire for Cancer Genetic Evaluation (2013), and the University of Utah School of Medicine Health Family Tree (2005; see Appendix C). These questionnaires have been evaluated in previous studies, and the researchers have demonstrated the reliability of the questionnaires in effectively

gathering an individual's FHH (de Hoog et al., 2013; Mai et al., 2011; Plat et al., 2009; Reid et al., 2009; Wang et al., 2011). The individuals participating in these studies were either recruited from primary care facilities or chose to complete the questionnaire based on physician request, genetic screening, or a desire to learn about disease risk (de Hoog et al., 2013; Mai et al., 2011; Plat et al., 2009; Reid et al., 2009; Wang et al., 2011).

The questionnaire for perception of disease risk consisted of the 10 questions from the original posttest perception of disease risk questionnaire developed by Acheson et al. (2010; see Appendix D). The survey used a 5-point Likert scale to measure each question of perceived risk. Acheson et al. (2010) administered the perception of disease risk questionnaire to 2,330 participants before and after completing the Family Healthware FHH. The results of the study demonstrated that immediately following completion of the Family Healthware questionnaire, patients perceived disease risk based on a positive family history of disease. In a subsequent study, Wang et al. (2012) administered the perception of disease risk questionnaire to 3,786 patients participating in a trial to assess the utility of the Family Healthware FHH. The results of this study also showed an increased perception of risk after completing the FHH (Wang et al., 2012). The required permission to use the risk perception questionnaire was received from Dr. Acheson, lead author or coauthor of the published papers (see Appendix E).

The FHH questionnaires from AMA, HHS, and University of Utah are open-source documents that do require permission for use. The questionnaires are available to anyone and may be accessed via the following websites:

- AMA: http://www.ama-assn.org//ama/pub/physician-resources/medical-science/genetics-molecular-medicine/family-history.page
- HHS: https://familyhistory.hhs.gov/ffh-web/home.action
- Mount Sinai Beth Israel: http://www.wehealny.org/services/bi_breastcenter/GeneticProgram.html
- University of Utah School of Medicine: http://healthfamilytree.utah.edu/

The third-degree FHH included a series of questions relative to the presence of CVD, stroke, cancers (breast, ovarian, cervical, colon, and prostate), and diabetes among the first, second, and third-degree relatives of the participant. The risk perception questions evaluated the study participant's perception of risk based on completing the third-degree FHH for the same disease conditions recorded in the third-degree FHH. The risk perception questions were placed after the third-degree FHH in order to minimize biasing the participant prior to completing the third-degree FHH.

While the third-degree FHH was based on validated instruments used in prior studies, and the perception of risk questionnaire was also validated by Acheson et al. (2010) prior studies, the slight modifications made to the questionnaires required checking the validity and reliability of the survey instruments. After receiving Institutional Review Board (IRB) approval, the survey was provided to three individuals in the health care field and three individuals from the general population who are former work colleagues. Based on their review of the survey, two minor modifications were made to the third-degree FHH to clarify "None of These Diseases" instead of "No Disease" and "Do Not Know About Diseases" instead of "Do Not Know".

To further assess the utility of the survey, the first 30 survey responses were evaluated as part of a pilot study. This initial group of responses included participants who were recruited from both the health care facilities and the general community. The participants were given access to the online survey questionnaire following approval from Walden's Institutional Review Board (IRB). The participants were required to complete the questionnaire in the same manner as any survey participant. This initial group of participants were able to successfully complete the questionnaire, demonstrating that the instrument was both valid and reliable for the study (see Chapter 4).

The three sections of the survey questionnaire took approximately 10 to 20 minutes to complete depending on how many relatives the participant actually had. Once the participant had completed the third-degree FHH and the risk perception survey, the participant also concluded involvement in the study. Since the study was anonymous, there was no mechanism to provide individualized survey results to the participant.

Operationalization Constructs

The dependent variable (DV) for this study was the perception of disease risk. Perception of disease risk was ascertained by completing the perception of disease risk questionnaire following the third-degree FHH. To complete the third-degree FHH, the study participant had to have knowledge of the family's health history. The knowledge of FHH was determined by calculating a completeness score from the information entered on the FHH for the following factors: first -degree relatives, second-degree relatives, and third-degree relatives, and knowledge of the presence of CVD, stroke, cancers (breast, ovarian, cervical, prostate, or colon), and/or diabetes for each identified relative.

- First-degree relatives were defined as the parents, sibling or children of the participant.
- Second-degree relatives were defined as the maternal/paternal grandparents, aunts/uncles, nieces/nephews and half-siblings.
- Third-degree relatives were defined as first-cousins.
- Knowledge of the presence of disease of each identified-relative was defined in the context of the chronic disease conditions of CVD, stroke, cancers (breast, ovarian, cervical, prostate, or colon), and/or diabetes and whether the identified relative had one or more of these conditions.

The DV of perception of disease risk was measure through the following variables: perceived level of risk for CVD, perceived level of risk for stroke, perceived level of risk for breast cancer (women), perceived level of risk for ovarian and/or cervical cancer (women), perceived level of risk for colon cancer, perceived level of risk for prostate cancer (men), perceived level of risk for diabetes, and overall perceived level of developing a chronic disease following completion of FHH.

- Perceived level of risk for CVD was defined as the participant's concern of developing CVD based on the documented history of CVD in the family.
- Perceived level of risk for stroke was defined as the participant's concern of having a stroke based on the documented history of stroke in the family.
- Perceived level of risk for breast cancer was defined as the female participant's concern of developing breast cancer based on the documented history of breast cancer in the family.

- Perceived level of risk for gynecological caner was defined as the female participant's concern of developing ovarian and/or cervical cancer (CDC, 2014) based on the documented history of gynecological cancer in the family.
- Perceived level of risk for colon cancer was defined as the participant's concern of developing colon cancer based on the documented history of colon cancer in the family.
- Perceived level of risk for prostate cancer was defined as the male participant's concern of developing prostate cancer based on the documented history of prostate cancer in the family.
- Perceived level of risk for diabetes was defined as the participant's concern of developing diabetes based on the documented history of diabetes in the family.

Variables

The variables for the study are presented in Table 1 along with the appropriate level of measurement, relevant research question, and specific survey item related to the variable.

Table 1

Variable, Level of Measurement, Research Question, Item on Survey

Variable	Level of measurement	Research question(s)	Item on survey
Age: years	Continuous	RQ1, RQ2	1
Gender: male/female	Categorical/Binary		2
Race: varying	Nominal		3
Ethnicity: varying	Nominal		4
Adoption status	Nominal		5
Education: varying	Ordinal		6
Experience/training	Nominal		7
Place of recruitment:	Categorical/Binary		9
Knowledge of Third-degree FHH	Ordinal for health status Continuous for age Nominal for disease presence, absence, or "Don't know" Continuous for Completeness Score	RQ1, RQ2	8 9 10 10
Perception of disease risk Prior collection of FHH	Ordinal or Categorical Nominal	RQ1, RQ2	11, 12, 13, 14, 15, 16, 17, 18, 19 20

Research Questions

Research Questions

The research questions developed for this study aimed to meet the key objectives of investigating the possible influence of the knowledge of the third-degree FHH on the risk of disease perceived by the study participant and the possible association between the demographics of the participants and the perception of disease risk, as ascertained by completing the third-degree FHH.

RQ1: How does completing the third-degree FHH influence the participant's perception of disease risk?

RQ2: How does the participant's third-degree FHH, controlled for demographics [gender, age, race, ethnicity, and place of recruitment (physician office versus general community locations)], influence the perception of disease risk?

Hypotheses

$H1_0$: Completing the third-degree FHH does not influence the participant's perception of disease risk, as measured by the survey instrument.

$H1_a$: Completing the third-degree FHH does influence the participant's perception of disease risk, as measured by the survey instrument.

$H2_0$: The participant's third-degree FHH, controlled for demographics, does not influence the perception of disease risk.

$H2_a$: The participant's third-degree FHH, controlled for demographics, does influence the perception of disease risk.

Data Collection and Analysis

The data were collected by recruiting participants from health care facilities and the general community, which included participants recruited via Facebook. On-site recruitment was conducted in the areas of Newark, Wilmington, and surrounding areas of Delaware. The questionnaire for the survey consisted of three sections. The first section of the survey was comprised of nine questions to collect the demographic information of the study participant. The age was entered by the study participant. Gender, race, ethnicity, education, adoption status, experience/training, and place of recruitment were presented as multiple choice questions, as were the selection of chronic diseases for each relative. The actual third-degree FHH question allowed the participants to enter all of

their relatives on both their maternal and paternal side. The perception of disease risk questionnaire consisted of 10 questions measured on 5-point Likert scale.

The third-degree FHH portion of the questionnaire was reviewed and scored to determine the knowledge of FHH factor. The knowledge of FHH factor was based on whether the participant knew and documented the health history for each relative indicated by the participants (Truell, Bartlett, & Alexander, 2002). However, each study participant had a different number of relatives and a different number of possible "Do Not Know About Diseases" selections requiring that each third-degree FHH be evaluated individually (Truell et al., 2002). A questionnaire was considered complete if the study participant was able to fill in information on all first, second, and third-degree relatives listed on the questionnaire by the patient.

Data were exported from Survey Gizmo onto the Statistical Package for the Social Sciences (SPSS) version 21, which was used in executing the data analysis (2012) as described in Table 2. For RQ1 in which the DV was the perception of disease risk and IV was the knowledge of FHH, the statistical test used initially was chi-square applied to the variables recoded as categorical variables. Spearman's *rho* correlation was also used to evaluate the strength of the relationship between the continuous variable knowledge of FHH completion factor and the perception of disease risk for each disease (Likert scale) as ordinal variables. For RQ2 the DV was the perception of disease risk, IV was the knowledge of FHH, and mediating variables were the demographics of the participants. Descriptive statistics were generated on the demographics. Additionally, chi-square test was used to assess the potential relationship between categorical variables. For the

inferential statistics, binary logistic regression was performed. The outcome variable was the perceived risk for each disease recoded in SPSS into categorical variables according to the binary classification of Wang et al. (2012). For example, the responses of the question "Compared to most people of your age and sex, what would you say your chances are for developing diabetes? (much higher than average, higher than average, about the same as average, lower than average, much lower than average)" were recoded into Low Risk (including about the same as average, lower than average, much lower than average) and High Risk (including much higher than average, higher than average). In addition, for the regression model the main predictor of interest was the knowledge of FHH completeness factor scored between 0 and 1.00. Knowledge of FHH was also controlled for the demographics of the participants in the regression model.

Table 2

Research Questions/Hypotheses and Appropriate Statistical Procedures

Research question	Hypothesis (H_a)	Variables	Statistical procedure/analysis
RQ1: How does completing the third-degree FHH influence the participant's perception of disease risk?	Completing the third-degree FHH does influence the participant's perception of disease risk.	IV: Third-degree FHH DV: Perception of disease risk	Chi-square Pearson's *r* if DV normally distributed. If DV not normally distribute: Spearman's *rho* Correlation Binary logistic regression DV versus IV and mediating variables
RQ2: How does the participant's third-degree FHH, controlled for demographics, influence the perception of disease risk?	The participant's third-degree FHH, controlled for demographics, does influence the perception of disease risk.	IV: Third-degree FHH and demographics DV: Perception of disease risk	Descriptive statistics Chi-Square Binary logistic regression- DV versus IV and mediating variables

Data cleaning and screening were performed as surveys were submitted to ensure that errors were identified, and the incomplete surveys were deleted prior to conducting the data analyses. Possible sources of errors included missed responses and incorrectly entered or coded data. Careful review of the data prior to analyses also ensured that obvious errors such as a female responding to the male only question on perceived risk for prostate cancer were quickly identified.

Threats to Validity

Threats to internal validity in a cross-sectional study included selection bias, recall bias, and reporting bias (Cooper, 2000; Delgado-Rodríguez & Llorca, 2004; LaMonte, 2013). The geographical limitation of the study and self-selection process may

have resulted in limited demographical diversity; therefore, the study design may have impeded the ability to generalize to a larger population. The study did not provide a process for validation of information provided by study participants. True lack of knowledge of familial health histories or inaccurate information about familial health histories could not be proven. Inaccuracies in the information reported on the study instruments may have led to reporting bias, which could have altered the results of the data. Testing reactivity or the Hawthorn effect may have been an additional source of bias, as the study participants' perceived level of disease risk could be in influenced by their environment (Delgado-Rodríguez & Llorca, 2004). The study participants recruited from health care facilities may have had an enhanced level of disease risk perception, which could have contributed to inaccurate information and biased results (Delgado-Rodríguez & Llorca, 2004).

Measures to address the limitations included recruiting participants at various locations to ensure a demographically diverse population, which should ideally have varying levels of knowledge of the family's health history. Other measures included conducting the pilot study to confirm the directions were clear and participants were able to follow the directions for completing the questionnaires. Construct validity was addressed by utilizing validated instruments that were shown to accurately capture the information to be measured. Statistical conclusion validity was addressed by having the appropriate sample size for both patients and controls. The sample size was calculated using the recommended statistical power, alpha level, and effect size (García-Pérez, 2012).

Ethical Procedures

Prior to commencing any data collection for this study, the Walden's Institutional Review Board (IRB) reviewed and approved the study (approval #10-14-14-0237638). Each participant had access to the consent form either through the online survey or in paper format. The consent form explained that voluntary nature of participation, ability to withdraw from the study at any time, and the minor risks associated with the study including eyestrain and possible stress. The participants provided consent to be included in the study by accessing and completing the survey on line or mailing the paper copy of the survey. In alignment with the IRB approval, no identifying or HIPAA protected information was collected from the participants. Additionally, no IPA addresses were accessed or stored. The online surveys were stored securely in a password protected file, and the paper copies of the surveys were kept stored in a locked file cabinet only accessible to me as the researcher. These files will be deleted or destroyed after a period of five years or in February 2020.

Summary

This purpose of this cross-sectional study was to contribute to the current body of work on FHH by examining the possible associations of completing the third-degree FHH on a person's perception of disease risk and the influence of the FHH and a person's demographics on the perception of disease risk. The target population for the study included individuals from Newark, Wilmington, and surrounding areas of Delaware and individuals recruited through the Your FHH Facebook page. Two methods for power

analysis were employed to determine that the appropriate sample size for the study consisted of a minimum of 269 participants.

The instruments for the study consisted of nine questions to gather demographics on the participant, the third-degree FHH, and 10 questions for assessing the perception of disease risk measured on a 5-point Likert scale. The questionnaire was based on established instruments with only slight modifications. Upon receipt of approval from Walden's IRB, a pilot study was executed to ensure the integrity of the modified questionnaires. The quantitative analyses focused on examining the possible associations between the third-degree FHH and the participant's demographics (age, gender, race, ethnicity, education, experience/training in health care, and place of recruitment) as independent/mediating variables and the participant's perception of disease risk. Threats to validity considered included selection bias, reporting bias, recall bias, and testing reactivity. Appropriate ethical procedures for this study were addressed including the importance of participant consent, anonymity, consent, and file/information security. SPSS version 21 (2012) was used to execute the data analyses, and the results of the study are presented in Chapter 4.

Chapter 4: Results

Introduction

The cross-sectional study and research questions aimed to assess the possible association of completing the third-degree FHH on a person's perception of disease risk and the influence of the FHH as well as the person's demographics on the perception of disease risk, as ascertained through knowledge of FHH.

RQ1: How does completing the third-degree FHH influence the participant's perception of disease risk?

$H1_0$: Completing the third-degree FHH does not influence the participant's perception of disease risk, as measured by the survey instrument.

$H1_a$: Completing the third-degree FHH does influence the participant's perception of disease risk, as measured by the survey instrument.

RQ2*:* How does the participant's third-degree FHH, controlled for demographics (gender, age, race, ethnicity, and place of recruitment [physician office versus general community locations]), influence the perception of disease risk?

$H2_0$: The participant's third-degree FHH, controlled for demographics, does not influence the perception of disease risk.

$H2_a$: The participant's third-degree FHH, controlled for demographics, does influence the perception of disease risk.

The pilot study findings, data collection methods, statistical analysis performed for the study, and the results of the analyses are presented in this chapter. SPSS software version 21 was used to perform the data analyses.

Pilot Study

The demographic section of the survey instrument was comprised of standard multiple-choice questions designed to gather data from the participants. The third-degree FHH was portion of the questionnaire was based on validated instruments used in prior studies. This is also true of the perception of risk portion of the questionnaire, which was validated by Acheson et al. (2010) in prior studies. However, the slight modifications made to the FHH portion of the questionnaire required checking the validity of the entire survey instruments. After receiving IRB approval, the entire survey instrument was provided to three individuals in the health care field and three individuals from the general population, who are former work colleagues. These individuals were instructed to review the survey for clarity of instructions, flow of the survey, complexity of completing the survey, and potential areas of confusion. Based on their review of the survey, two minor modifications were made to the third-degree FHH to clarify "None of These Diseases" instead of "No Disease" and "Do Not Know About Diseases" instead of "Do Not Know." Once these modifications were made, the www.yourfhh.com link was published to access the actual survey available at the Survey Gizmo website.

Further assessing the validity of the survey, the first 30 survey responses were evaluated as part of the pilot study. This initial group of respondents included participants who were recruited from both the health care facilities and the general community. The scope of this portion of the pilot was to ensure that the participants could complete the entire survey correctly with the instructions provided. These participants were indeed able to complete the questionnaire. Further, I was able to calculate the completeness

score consistently based on the information provided by the participants in the third-degree FHH. Based on the ability of the participants to follow the instructions for the survey, fill out the FHH portion of the survey, fully complete the three sections of the survey, it was concluded that the survey instrument was valid for collecting the data needed to execute the study.

Data Collection

The data for the study were collected through a survey instrument completed by participants recruited from health care facilities and the general community inclusive of participants recruited via Facebook. Recruitment was conducted in Newark, Wilmington, and surrounding areas of Delaware. The questionnaire for the survey instrumented consisted of three sections. The first section of the survey was comprised of nine multiple-choice questions to collect the demographic information of the study participant including age, gender, race, ethnicity, education, adoption status, experience/training, and place of recruitment. The actual third-degree FHH question allowed the participants to enter all of their relatives on both their maternal and paternal side. The perception of disease risk questionnaire consisted of 10 questions measured on a 5-point Likert scale. The perception of disease risk questionnaire was developed and validated by Acheson et al. (2010). Dr. Acheson provided approval to use the questionnaire in the study (see Appendix E).

The third-degree FHH portion of the questionnaire was scored based on whether the participant knew and documented the health history for each relative indicated (Truell et al., 2002). However, each study participant had a different number of relatives and a

different number of possible "Do Not Know About Diseases" selections requiring each third-degree FHH be reviewed individually (Truell et al., 2002). A questionnaire was considered complete if the study participant was able to fill in information on the first, second, and third-degree relatives listed on the questionnaire by the participant.

The FHH questionnaire starting score was 100% or 1.000 based on the total number of relatives listed by the participant. If the study participant listed a relative and selected the "Do Not Know About Diseases" checkbox, this was considered an indication of lack of knowledge of the presence or absence of the specific disease conditions listed in the survey. The "Do Not Know About Diseases" responses reduced the 1.000 score by a proportional amount. For example, if a participant listed a total of 15 relatives and checked "Do Not Know About Diseases" responses for four relatives, the participant had knowledge on 11 of the 15 relatives, which was equal to 11/15 or a completeness score of 0.73. Consequently, the completeness score of the questionnaire was equated to the knowledge the participant had of his or her specific FHH.

Since there was no way of verifying the information on the study participant's relatives, several criteria were uniformly applied in evaluating the FHH and calculating the completeness scores. If the participant listed a relative and indicated "None of These Diseases," it was indicative that the relative did not have any of the disease conditions listed. If the participant listed no relatives beyond the parents and grandparents, it was assumed that the individual had no siblings, children, aunts, uncles, or cousins. If the participant did not check any boxes for one or both parents and/or grandparents, it was counted as a "Do Not Know About Diseases" and lack of knowledge about that relative.

This assumption took into consideration that adopted individuals were excluded from the study, and thus each individual would have had biological parents and grandparents on both the maternal and paternal side.

The first two questions from perception of disease risk questionnaire (Questions 11 and 12) focused on general assessments on the importance of disease risk in families. Question 11, "It is important for my own health to know if diseases like cancer, diabetes, stroke or heart disease run in my family," and Question 12, "A person's family health history can make him/her more likely to get diseases like cancer, diabetes, stroke or heart disease were first coded in SPSS from lowest to highest with 1 coded as "*strongly disagree*" to 5 coded as "*strongly agree*". Questions 13 to 19 on the perception of disease risk for heart disease, stroke, breast cancer, ovarian/cervical cancer, prostate cancer, colon cancer, and diabetes were coded as ordinal variables and ranked from lowest to highest in SPSS with 1 equal to "*much lower than average*" to 5 equal to "*much higher than average*".

Additionally, Questions 11 through 19 were recoded into the binary classification of Wang et al. (2012) to create categorical variables. For example, the responses of the question "Compared to most people of your age and sex, what would you say your chances are for developing diabetes? (Much higher than average, higher than average, about the same as average, lower than average, much lower than average)" were recoded into low risk (including about the same as average, lower than average, much lower than average) and high risk (including much higher than average, higher than average). These

new variables were labeled with a 2 added to the name of the original variable, such as COLONRISK for original variable and COLONRISK2 for the new variable.

Question 8 assessed the current health status of the participants. The 5-point Likert scale for health status was recoded in SPSS into three new health status variables comprised of 1 equal to the variables excellent, very good, or good health ratings, 2 as the variables fair and poor and 3 as the variable not sure/do not know. Age was also recoded into age brackets in order to manage the number of categories in the frequency tables. Age was coded into seven age brackets beginning with 18 to 25 years old and ending with 76 to 85 years old.

Data collection for the survey took place during a period of 42 days beginning on October 15, 2014 through November 26, 2014. The total number of participants who attempted to complete the survey using either the online survey or the paper copy of the questionnaire equaled 370. However, 94 surveys were incomplete. These were missing all information on the FHH and/or the perception of disease risk. All incomplete surveys were deleted from the data set, resulting in a total of 276 complete surveys or a response rate of 74.6%. Additionally, as noted in the previous paragraph, Question 5 specifically asked if the participant was adopted. Only three out of the total number of individuals who accessed the survey indicated they were adopted. These three questionnaires were omitted from the data set resulting in a final data set comprised of 273 surveys. Access to the online survey was closed after verifying that the 273 surveys were complete.

Data cleaning and screening were performed as surveys were submitted ensuring that errors were identified and incomplete surveys were deleted prior to downloading the

data to SPSS. Errors included missed responses and incorrectly entered or coded data. Data were then exported from Survey Gizmo onto the SPSS version 21 program, which was used in executing the data analysis as described in Table 2. Careful review of the data prior to analyses also ensured that obvious errors presenting as outliers or anomalies were quickly identified. The explore function of SPSS was used to ensure that no outliers were present in the data.

Descriptive and Demographic Statistics

The sample size calculated for the study was 269 participants to achieve adequate statistical power. The number of individuals who attempted to complete the survey equaled 370, but only 273 surveys were complete or not from individuals who were adopted. The descriptive statistics to generate frequencies and percent were run on the data set using SPSS. The study participants were comprised of 95 males (34.8%) and 178 females (65.2%). Of the participants, 125 (45.8%) were recruited from health care facilities, while 148 (54.2%) were recruited from the general population locations and Facebook. Additionally, 129 participants (47.3%) had training in health care while 155 participants (52.7%) did not have health care training. The frequencies of age, race, ethnicity, and educational level of the participants are listed in Table 3.

Table 3

Descriptive Statistics – Demographic Variables

Demographic	Frequency (*f*)	Percent (%)
Gender		
Male	95	34.8
Female	178	65.2
Age		
18-25	17	6.2
26-35	56	20.5
36-45	54	19.8
46-55	82	30.0
56-65	42	15.4
66-75	17	6.2
76-85	5	1.8
Race		
White	195	71.4
Black	41	15.0
Asian	20	7.3
Native Hawaiian / Pacific Islander	1	0.4
American Indian / Alaska Native	2	0.7
Multiple races	14	5.1
Ethnicity		
African	5	1.8
African American	29	10.6
Afro-Caribbean	12	4.4
Canadian	6	2.2
East Asian	10	3.7
European	85	31.1
Hispanic/Latino	77	28.2
Japanese	3	1.1
Middle Eastern/Arab	5	1.8
South Asian	6	2.2
Other	35	12.8
Educational Level		
Grades 1 - 8	2	0.7
Grades 9 - 11	3	1.1
Grade 12 or GED	33	12.1
College 1 – 3 years	57	20.9
College 4 years	80	29.3
Graduate school or advanced degree	98	35.9

Prior to completing the FHH and the perception of disease risk questions, the participants were also asked to rate their health status. The majority of the participants, 240 (87.9%) rated their health as "Excellent," "Very Good," or "Good." Only 34 participants (12.1%) rated their health as "Fair" or "Poor." None of the participants indicated "Not Sure/Do Not Know." Since there were no individuals who indicated they did not know about their health status, the other variables were recoded into two new variables including 1 equal to "*excellent, very good,* and *good*" and 2 equal to "*fair* and p*oor*." The recoded health status variable was used in running a chi-square test of association in order to analyze whether there was a relationship between the location of recruitment and the health status rating, as this would be an initial indicator that individuals were being biased by testing reactivity or the Hawthorn effect (Delgado-Rodríguez & Llorca, 2004). The analysis indicated X^2 (1, N = 273) = 1.16, p = .281 or no statistical significance between the location of recruitment and the health status rating of the participants.

Test for Normality

A Shapiro-Wilk's test was performed with each independent variable (age, gender, race, ethnicity, education, experience in health care, and knowledge of health history) and the dependent variables of perception of disease risk. The assumption of normality for the perception of disease risk was not satisfied for any of the independent variables, as assessed by the Shapiro-Wilk's test (p > .05), inspection of the histograms, and calculation of the z-scores. Consequently, Spearman's *rho* was conducted for the nonnormally distributed independent variables to assess the measure of the strength and

direction of the association between the dependent perception of disease risk variables coded as ordinal variables and the knowledge of FHH (independent variable) for RQ1.

Research Question 1 Results

The aim of RQ1 was to investigate if the participant's knowledge of the third-degree FHH influenced the participant's perception of disease risk. The null hypothesis for this research question was that completing the third-degree FHH did not influence the participant's perception of disease risk, while the alternate hypothesis was that completing the third-degree FHH did influence the participant's perception of disease risk.

For each FHH submitted to the study, a completion factor was calculated based on the number of relatives indicated by the participant. Each "Do Not Know About Diseases" checked by the participant reduced the 1.000 starting factor by an amount proportional to the total number of relatives indicated. Each completion factor was calculated and manually added into SPSS under the variable KNWLGFHH. The mean of the completion factors was .776 and the median was .800 with a standard deviation of .199. A total of 33 participants or 12.1% had completion factors of .500 or lower. A total of 240 participants or 87.9% had completion factors greater than .500 to 1.000. Only 62 participants or 22.7% had fully completed FHH, as ascertained by the information submitted, thus achieving a 1.000 completion score. These descriptive statistics are indicative that the vast majority of participants had knowledge of the FHH of at least half of their relatives and nearly a quarter of participants (22.7%) had knowledge of the FHH of all of their relatives. Looking specifically at the "Do Not Know About Diseases"

responses, these entries were primarily associated with lack of FHH knowledge of uncles, aunts, and cousins or the second and third-degree relatives. This is consistent with the body of knowledge available, which indicates that knowledge of FHH is an obstacle for routine implementation of a third-degree FHH.

To investigate the possible association between completing the third-degree FHH and the perception of disease risk, chi-square test for association was conducted between the knowledge of FHH completeness factors and each perception of disease risk variables. The knowledge of FHH completeness factor is a continuous variable, and the perception of disease risk questions are ordinal variables measured on a 5-point Likert scale. Therefore, in order to execute the chi-square analysis, the two variables were transformed into nominal or categorical variables. The knowledge of FHH completeness factors were transformed into a new variable designated KNWLDGE3 comprised of 1 for low knowledge scores between .200 to .500, 2 for medium knowledge scores between .501 and .799, and 3 for high knowledge scores between .800 and 1.000. The rationale for creating these variables stemmed from the need to reduce the number of categories within the continuous variable knowledge of FHH completeness factor. The cutoffs for the variables were modeled after Wang et al. (2012) in which familial risk for disease was categorized as weak, moderate, or strong.

As previously described, the perception of disease risk variables were recoded as 1 representing low risk (including about the same as average, lower than average, and much lower than average) and 2 representing high risk (including much higher than average and higher than average).

Five out of the seven chi-square analyses conducted had one (25%) or more cells with expected count less than five, while two of the analyses had counts greater than five. There was no statistically significant association between any of the disease-specific questions and knowledge of FHH. The results of the chi-square tests are summarized in Table 4 by disease condition.

Table 4

Chi-square Test of Association - Perception of Disease Risk to Knowledge of FHH

Disease risk	*df*	*N*	χ^2 Value	*p*
Heart disease	2	273	3.731	.155
Stroke	2	273	3.944[a]	.139
Breast cancer	2	178	1.266[a]	.531
Ovarian/Cervical cancer	2	178	.926 [a]	.630
Prostate cancer	2	95	.563 [b]	.754
Colon cancer	2	273	.495 [a]	.781
Diabetes	2	273	3.181	.204

Note. a. 1 cell or more with expected count less than 5.
b. 3 cells with expected count less than 5

However, since the knowledge of FHH completeness factor was originally calculated as a continuous variable (KNWLGFHH) and the perception of disease risk questions were measured as ordinal variables, I wanted to assess the strength and direction of the association between the two variables by performing a Spearman's *rho* correlation. Prior to performing this analysis, a Shapiro-Wilk's test was performed for the independent variable knowledge of health history and the dependent variables of

perception of disease risk. The assumption of normality for the perception of disease risk was not satisfied for any of the independent variables, as assessed by the Shapiro-Wilk's test (p >.05), inspection of the histograms, and calculation of the z-scores. The results of the Spearman's *rho* analyses performed between the perception of disease risk factors and the knowledge of FHH are presented in Table 5.

Table 5

Spearman Correlation - Perception of Disease Risk to Knowledge of FHH

Disease Risk	*N-2*	r_s	*p*
Heart disease	271	-.086	.158
Stroke	271	-.177	.053
Breast cancer	176	-.058	.440
Ovarian /cervical cancer	176	-.015	.847
Prostate cancer	93	-.144	.163
Colon cancer	271	-.103	.089
Diabetes	271	.020	.742

The results of the Spearman correlation showed that there was no strong association between the knowledge of FHH completeness factor and the various perception of disease risk. There was a negative, weak correlation between the knowledge of FHH and perception of risk for stroke, $r_s(271) = -.177$, $p <.053$, as well as between the knowledge of FHH and perception of risk for colon cancer, $r_s(271) = -.103$, $p <.089$ (Laerd Statistics, 2013). However, the analyses was indicative of statistical significant results for the association between knowledge of FHH and perceived risk of

stroke (p <.053) and perceived risk of colon cancer (p<.089) based on using a p value of < 0.1 (Stoddard, 2013).

Binary logistic regression was performed in order to assess if participants who documented specific diseases among family members in the FHH did perceive a risk for the disease or diseases indicated. Each of the 273 health histories were reviewed and each disease indicated by the participant was coded as a 1 for presence of disease in the family or a 0 for no presence of disease in the family. New nominal variables were created for each disease condition being investigated: HHRTD for history of heart disease; HSTRK for history of stroke, HBRST for history of breast cancer, HCROV for history of cervical/ovarian cancer, HPRST for history of prostate cancer, HCOLON for history of colon cancer, and HDIAB for history of diabetes. As stated, the FHH for each participant was individually reviewed and a 1 was indicated for the disease if a family member was listed as having the disease. The number 0 was indicated for any disease not listed by the participant.

Once the data were entered for the new variables, a binary logistic regression was performed between each of the new variables and the corresponding perception of disease risk response. As shown in Table 6, the results of these binary regressions indicated there was a statistical association between the presence of the disease in the family and the perception of risk for the particular disease as noted in the FHH with heart disease (p <.003), stroke (p <.001), breast cancer (p <.001), ovarian/cervical cancer (p <.027), prostate cancer (p <.001), colon cancer (p <.001), and diabetes (p <.001).

A history of stroke in the family appeared to be the strongest predictor of perception of disease risk with an odds ratio of 5.84 (95% CI [2.89, 11.78]), indicating that those individuals who had family members who had experienced a stroke where more than five times more likely to perceive a risk for stroke. Presence of heart disease in the family was another predictor of perception of disease risk with an odds ratio of 2.38 (95% CI [1.343, 4.215]), indicating that individuals with a history of heart disease also perceived greater risk for developing heart disease .

Table 6

Binary Logistic Regression Between Presence of Disease History (Independent Variable) and Perception of Disease Risk (Dependent Variable)

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Heart disease	-.867	.292	8.821	1	.003	2.379	1.343	4.215
Stroke	1.764	.358	24.238	1	.000	5.835	2.891	11.778
Breast cancer	-3.031	.563	28.943	1	.000	.048	.016	.146
Ovarian /cervical cancer	-1.308	.591	4.892	1	.027	.279	.085	.862
Prostate cancer	-2.970	.799	13.834	1	.000	.051	.011	.245
Colon cancer	-2.039	.459	19.782	1	.000	.130	.053	320
Diabetes	-2.140	.303	49.798	1	.000	.118	.065	.214

Note: *B* = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

For RQ1, the statistical analyses included chi-square test of association between the knowledge of FHH completeness factors and each perception of disease risk variables; Spearman's *rho* analysis to assess the measure of the strength and direction of the association between the perception of disease risk factors and the knowledge of FHH; and binary logistic regression between the presence of disease variable and the corresponding perception of disease risk response. The results of the chi-square analysis indicated there was no statistical significance between completing the third-degree FHH

and the participant's perception of disease risk, and consequently, the null hypothesis is accepted. However, the Spearman's *rho* demonstrated indicative statistical significance between knowledge of FHH and perceived risk of stroke (p <.053) and perceived risk of colon cancer (p < .089) based on using a p value of < 0.1 (Stoddard, 2013), and the binary logistic regression demonstrated statistical significance between the presence of disease in a family and the perceived risk for acquiring the disease.

Research Question 2 Results

The aim of RQ2 was to assess how the third-degree FHH, controlling for demographics, influenced the perception of disease risk. For the null hypothesis I proposed that a person's demographics did not influence the perception of disease risk, and for the alternate hypothesis I proposed that a person's demographics do influence the perception of disease risk. As previously explained, the 5-point Likert scale for perception of disease risk was transformed into two new variables representing low risk and high risk groups. Chi-square test of association was conducted between each demographic characteristic and each perception of disease question.

The KNWLGFHH variable (completion factor) was assessed relative to the demographics of the study participants to determine if the demographics influenced the knowledge of FHH. The frequencies of KNWLGFHH specific for each demographic characteristic were calculated by utilizing the Data Split file function, and these are presented in Table 7.

Table 7

Knowledge of FHH by Demographic Variable

Demographic	Mean	Median	SD	Minimum	Maximum
Place of recruitment					
Health care facility	.716	.789	.173	.273	1.000
Community	.790	.815	.212	.200	1.000
Gender					
Male	.717	.750	.205	.200	1.000
Female	.809	.833	.184	.273	1.000
Age					
18-25	.840	.857	.186	.429	1.000
26-35	.778	.800	.193	.273	1.000
36-45	.814	.825	.157	.476	1.000
46-55	.790	.800	.186	.400	1.000
56-65	.723	.788	.237	.200	1.000
66-75	.734	.769	.213	.333	1.000
76-85	.525	.550	.163	.364	.769
Race					
White	.798	.818	.186	.200	1.000
Black	.677	.667	.216	.200	1.000
Asian	.778	.814	.218	.273	1.000
Native Hawaiian / Pacific Islander	.750	.750	-	.750	.750
American Indian / Alaska Native	.876	.876	.122	.789	.962
Multiple Races	.762	.811	.185	.500	1.000
Ethnicity					
African	.729	.812	.310	.200	1.000
African American	.679	.643	.226	.250	1.000
Afro-Caribbean	.717	.732	.168	.429	1.000
Canadian	.699	.697	.125	.571	.842
East Asian	.781	.809	.212	.400	1.000
European	.792	.800	.181	.364	1.000
Hispanic/Latino	.808	.833	.189	.200	1.000
Japanese	.765	.833	.275	.462	1.000
Mid Eastern/Arab	.797	.788	.137	.625	1.000
South Asian	.785	.833	.263	.273	1.000
Other	.788	.800	.198	.250	1.000
Educational Level					
Grades 1 - 8	.654	.654	.163	.538	.769
Grades 9 - 11	.665	.750	.192	.444	.800
Grade 12 or GED	.683	.625	.237	.200	1.000
College 1 – 3 years	.762	.786	.190	.250	1.000
College 4 years	.786	.809	.191	.273	1.000
Graduate school or advanced degree	.816	.842	.180	.200	1.000
Healthcare Training					
Yes (n =129)	.810	.833	.181	.200	1.000
No (n=144)	.747	.786	.204	.200	1.000

The analysis of the influence of demographic characteristics on the knowledge of FHH indicated participants recruited from the health care facilities had lower knowledge of FHH as compared to the participants from the general population. In alignment with published data, women scored higher than men did on FHH. Analyses of age demonstrated that participants in the age range of 18 to 55 scored higher overall than participants in the age range of 56 to 85. Specifically, participants in the age range of 36 to 55 had the highest mean scores. Noteworthy is that younger participants scored higher versus older participants. The analyses of knowledge of FHH factors by race and ethnicity indicated that Blacks and African Americans had lower mean values as compared to the other races and ethnicities. The analyses of levels of education clearly showed that the knowledge of FHH completeness factor means were higher among study participants who had between 1 to 3 years of college. As the level of education augmented, the means increased with participants who had graduate degrees having the highest knowledge of FHH means.

The frequencies for the perception of disease risk were generated to determine which diseases were considered low risk versus high risk for participants. The information is presented in Table 8. Between 8.2% to 15% of people indicated a high risk for stroke, breast cancer, ovarian/cervical cancer, prostate cancer, and colon cancer. By comparison, 30% of participants indicated high risk for heart disease and 31% for diabetes, which is indicative of greater awareness of disease risk factors, knowledge of disease among family members, and or of history of disease among family member.

Table 8

Perception of Risk by Disease (Percent Frequency)

Disease condition	Low risk	High risk
Heart disease	70.0	30.0
Stroke	85.0	15.0
Breast cancer	88.2	11.8
Ovarian/cervical cancer	89.3	10.7
Prostate cancer	90.5	9.5
Colon cancer	90.8	8.2
Diabetes	68.9	31.1

Chi-square test of association was performed between gender and perception of disease risk for heart disease, stroke, colon cancer, and diabetes. All expected cell frequencies were greater than five. There was no statistically significant association between gender and perception of disease risk for heart disease ($X^2(1) = .022$, $p = .882$), stroke ($X^2(1) = 1.350$, $p = .245$), colon cancer ($X^2(1) = .561$, $p = .454$), and diabetes ($X^2(1) = 1.579$, $p = .209$). However, the chi-square test of association between gender and the importance of knowing about diseases in family was statistically significant ($X^2(1) = 4.595$, $p = .032$), but there was no statistical significance for the FHH indicative of increased risk for disease ($X^2(1) = 0.12$, $p = .914$).

The association between place of recruitment and perception of disease risk was also analyzed using chi-square test. The cross-tabulation indicated that approximately the same number of people from the health care facilities and the general population perceived high risk for heart disease (42 versus 40), stroke (18 versus 23), breast cancer (8 versus 13), prostate cancer (5 versus 4), and diabetes (38 versus 47). However, there

was a lower perception of disease risk among individuals from the health care facilities versus the general population for ovarian/cervical cancer (4 versus 15) and for colon cancer (6 versus 19). Cumulatively, 40.7% of individuals recruited from the health care facilities indicated a high risk for disease versus 59.3% of individuals from the general population.

Binary logistic regression was performed to investigate the potential effect of age, gender, race, ethnicity, level of education, experience in health care, and place of recruitment on how the knowledge of FHH might influence perception of disease risk. The results of the analyses for the binary logistic regressions for each individual perception of disease condition are presented in Tables 9 through 15.

Table 9

Binary Logistic Regression - Perception of Disease Risk for Heart Disease (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	.689	.764	.815	1	.367	1.992	.446	8.899
Age	.043	.011	14.809	1	.000	1.044	1.021	1.067
Gender	.130	.308	.178	1	.673	1.139	.623	2.082
Race	-.020	.125	.026	1	.872	.980	.767	1.252
Ethnicity	-.026	.056	.222	1	.637	.974	.873	1.086
Grade	-.115	.132	.755	1	.385	.892	.689	1.155
Healthcare experience	.018	.306	.003	1	.954	1.018	.559	1.855
Place of recruitment	.317	.287	1.223	1	.269	1.373	.783	2.407

Note. *B* = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 10

Binary Logistic Regression - Perception of Disease Risk for Stroke (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	-1.607	.910	3.120	1	.077	.201	.034	1.193
Age	.033	.014	5.413	1	.020	1.033	1.005	1.062
Gender	.692	.415	2.780	1	.095	1.998	.886	4.507
Race	-.110	.183	.348	1	.555	.898	.629	1.283
Ethnicity	.021	.071	.084	1	.772	1.021	.888	1.173
Grade	-.065	.162	.161	1	.688	.937	.682	1.288
Healthcare experience	-.052	.390	.018	1	.894	.949	.442	2.038
Place of recruitment	-.080	.367	.047	1	.828	.923	.450	1.896

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 11

Binary Logistic Regression - Perception of Disease Risk for Breast Cancer (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	.232	1.401	.027	1	.869	1.261	.081	19.621
Age	.034	.019	2.976	1	.084	1.034	.995	1.074
Race	-.013	.211	.004	1	.952	.987	.653	1.494
Ethnicity	.098	.101	.945	1	.331	1.103	.905	1.344
Grade	.336	.241	1.940	1	.164	1.399	.872	2.244
Healthcare Experience	-.510	.501	1.037	1	.309	.600	.225	1.603
Place of Recruitment	-.005	.510	.000	1	.992	.995	.366	2.703

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 12

Binary Logistic Regression - Perception of Disease Risk for Cervical/Ovarian Cancer (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	.740	1.460	.257	1	.612	2.096	.120	36.688
Age	-.007	.020	.133	1	.715	.993	.955	1.032
Race	-.744	.649	1.315	1	.252	.475	.133	1.695
Ethnicity	-.051	.131	.154	1	.695	.950	.735	1.228
Grade	.008	.249	.001	1	.974	1.008	.619	1.642
Healthcare Experience	-.397	.519	.586	1	.444	.672	.243	1.858
Place of Recruitment	-.921	.614	2.249	1	.134	.398	.120	1.327

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 13

Binary Logistic Regression - Perception of Disease Risk for Prostate Cancer (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	-.539	1.764	.093	1	.760	.583	.018	18.512
Age	.073	.034	4.593	1	.032	1.075	1.006	1.149
Race	-.558	.788	.501	1	.479	.572	.122	2.683
Ethnicity	-.188	.190	.981	1	.322	.829	.571	1.202
Grade	-.052	.406	.016	1	.899	.950	.429	2.105
Healthcare experience	-.158	1.057	.022	1	.881	.854	.108	6.776
Place of recruitment	-.234	.817	.082	1	.774	.791	.159	3.927

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 14

Binary Logistic Regression - Perception of Disease Risk for Colon Cancer (Dependent Variable) to Knowledge of Health History and Mediating Factors

							95% CI	
Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	*LL*	*UL*
Knowledge FHH	-.035	1.121	.001	1	.975	.966	.107	8.697
Age	.020	.017	1.318	1	.251	1.020	.986	1.055
Gender	.303	.508	.356	1	.551	1.354	.500	3.668
Race	.079	.183	.189	1	.664	1.083	.757	1.548
Ethnicity	.163	.088	3.483	1	.062	1.178	.992	1.398
Grade	-.224	.206	1.178	1	.278	.799	.533	1.198
Healthcare experience	.035	.479	.005	1	.942	1.036	.405	2.647
Place of recruitment	-1.019	.509	4.012	1	.045	.361	.133	.978

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Table 15

Binary Logistic Regression - Perception of Disease Risk for Diabetes (Dependent Variable) to Knowledge of Health History and Mediating Factors

Predictor	*B*	*S.E.*	*Wald*	*df*	*p*	*OR*	95% CI *LL*	95% CI *UL*
Knowledge FHH	1.227	.750	2.677	1	.102	3.410	.785	14.820
Age	.008	.010	.617	1	.432	1.008	.988	1.029
Gender	.327	.300	1.188	1	.276	1.386	.770	2.495
Race	.068	.109	.386	1	.534	1.070	.864	1.325
Ethnicity	-.003	.054	.003	1	.954	.997	.897	1.108
Grade	-.069	.130	.285	1	.594	.933	.724	1.203
Healthcare experience	-.163	.292	.312	1	.576	.849	.479	1.506
Place of recruitment	-.027	.276	.010	1	.922	.973	.567	1.672

Note. B = B coefficients; *S.E.* = standard error; *Wald* = Wald test, *df* = degrees of freedom, *p* = probability value, *OR* = odds ratio, CI = confidence interval for odds ratio, *LL* = lower level, *UL* = upper level

Of the six mediating factors analyzed, age was statistically significant for heart disease ($p < .001$) with an odds ratio of 1.044 (95% CI [1.021, 1.067]), stroke ($p < .020$) with an odds ratio of 1.033 (95% CI [1.005, 1.062]), and prostate cancer ($p < .032$) with an odds ratio of 1.075 (95% CI [1.006, 1.149]; Tables 9, 10, and 13). Increasing age particularly within the age range of 40 to 57 was associated with increasing levels of perception of disease risk for heart disease, stroke, and prostate cancer.

Place of recruitment was statistically significant for perception of colon cancer ($p < .045$) with an odds ratio of .361 (95% CI [.133, .978]; Table 14). Further, three times as many individuals from the general population indicated "Higher Than Average" risk for colon cancer. A greater proportion of individuals recruited from the general population indicated a higher level of perceived risk of disease (59.3%) as compared to individuals recruited from the health care facilities (40.7%).

Knowledge of FHH appeared to be a strong predictor of perception of disease risk for diabetes with an odds ratio of 3.410 (95% CI [.785, 14.820]) and for perception of

disease risk for cervical/ovarian cancer 2.096 (95% CI [.120, 36.688]) again clarify that these results are not significant. The results of the analysis indicate that the participant's demographics do influence the perception of disease risk and, therefore, the alternate hypothesis is accepted and the null hypothesis for RQ2 is rejected.

Summary

The aim of this study was to assess the possible association of completing the third-degree FHH on a person's perception of disease risk and the influence of the FHH and person's demographics on the perception of disease risk, as ascertained through the knowledge of FHH. Binary logistic regression analysis was performed to also assess if the demographic factors of age, gender, race, ethnicity, education, and/or health care experience had any influence on the perception of disease risk.

Analyses of the data collected among 273 survey questionnaires answered the research questions and hypotheses. The FHH completeness score between zero and 1.000 was calculated for each questionnaire. Descriptive statistics were run on the data to generate frequencies and percentage. For RQ1 chi-square test of association was conducted between knowledge of FHH completeness factors and each perception of disease risk variables. The results of the chi-square analysis indicated there was no statistically significant association between completing the third-degree FHH and the participant's perception of disease risk; consequently, the null hypothesis is accepted.

Spearman correlation analyses was also used to assess the measure of the strength and direction of the association between the two variables. The results of the Spearman correlation did not indicate a strong association between the knowledge of FHH

completeness factor and the perception of disease risk. There was a negative, weak correlation between the knowledge of FHH and perception of risk for stroke, $r_s(271) = -.177$, $p<.053$, as well as between the knowledge of FHH and perception of risk for colon cancer, $r_s(271) = -.103$, $p<.089$ (Laerd Statistics, 2013). However, the analyses was indicative of statistically significant results for the association between knowledge of FHH and perceived risk of stroke ($p <.053$) and perceived risk of colon cancer ($p <.089$) based on using a p value of < 0.1 (Stoddard, 2013).

The presence or absence of disease in a participant's FHH was identified, and the new coded variables were analyzed against the corresponding perception of disease risk response using binary logistic regression. The data analysis indicated there was a statistically significant association between the presence of the disease in the family and the perception of risk for the particular disease noted in the FHH.

For RQ2 chi-square test of association was conducted between each demographic characteristic and each perception of disease question. Additionally, the knowledge of FHH completeness factors were assessed relative to the demographics of the study participants to determine if the demographics influenced the knowledge of FHH. The analyses of the influence of demographic characteristics on the knowledge of FHH indicated that women scored higher than men on FHH and that participants in the age range of 18 to 55 scored higher versus participants in the age range of 56 to 85. The analysis of knowledge of FHH factors by race and ethnicity indicated that Blacks and African Americans had lower mean values as compared to the other races and ethnicities

of the study participants. The analysis of levels of education clearly showed that as the level of education augmented, so did the knowledge of FHH completeness factor.

Binary logistic regression was performed to investigate the effects of demographics on how the knowledge of FHH might influence perception of disease risk. Of the six mediating factors analyzed, age was statistically significant for heart disease, stroke, and prostate cancer, and ethnicity was statistically significant for colon cancer Knowledge of FHH appeared to be a strong predictor of perception of disease risk for diabetes and for perception of disease risk for cervical/ovarian cancer. The results of the study are further discussed in Chapter 5, including the study limitations, generalizability of the study results, recommendations for utilize of the third-degree FHH, and further research.

Chapter 5: Discussions, Conclusions, and Recommendations

Introduction and Key Findings of the Study

The purpose of this research study was to contribute to the knowledge base of the FHH by assessing the possible associations between completing the third-degree FHH and the participant's perception of disease risk as well as the demographics of the participants and the perception of disease risk, as ascertained by completing the third-degree FHH. Convenience sampling was employed in recruiting the 273 participants from health care facilities and from the general population, including recruitment through a dedicated study Facebook page. Information was provided to the participants to voluntarily access an anonymous survey online, and participants recruited at the health care facilities had the option to complete the exact same survey using a paper copy of the survey instrument.

The survey was comprised of three sections, including a section for demographics, the third-degree FHH, and the perception of disease risk questionnaire presented in a 5-point Likert-type scale. The third-degree FHH portion of the questionnaire was scored based on whether the participant knew and documented the health history for each relative indicated (Truell et al., 2002). However, each study participant had a different number of relatives and a different number of possible "Do Not Know About Diseases" selections requiring each third-degree FHH be reviewed individually (Truell et al, 2002). A questionnaire was considered complete if the study participant was able to fill in information on all first, second, and third-degree relatives listed on the questionnaire by the patient.

The knowledge of FHH completeness score was calculated individually for each survey based on the number of relatives indicated by the participant. If the study participant listed a relative and selected the "Do Not Know About Diseases" check box, this was considered an indication of lack of knowledge of the presence or absence of the specific disease conditions listed in the survey. The completeness starting score of 100% or 1.000 was reduced by a proportional amount based on the "Do Not Know About Diseases" responses.

A total of 33 participants or 12.1% had completion factors of .500 or lower. A total of 240 participants or 87.9% had completion factors greater than .500 to 1.000. Only 62 participants or 22.7% had fully completed FHH, as ascertained by the information submitted, thus achieving a 1.000 completion score. These descriptive statistics are indicative that the vast majority of participants had knowledge of the FHH of at least half of their relatives and nearly a quarter of participants (22.7%) had knowledge of the FHH of all of their relatives.

The analyses revealed indicative statistically significant results for the association between knowledge of FHH and perceived risk of stroke ($p < .053$) and perceived risk of colon cancer ($p < .089$) based on using a p value of < 0.1 (Stoddard, 2013). Additionally, binary logistic regression was performed in order to assess if participants who had documented in the FHH specific diseases among family members did perceive a risk for the disease or diseases indicated. The results of these binary regressions indicated there was a significant association between the presence of heart disease ($p < .003$), stroke ($p < .001$), breast cancer ($p < .001$), ovarian/cervical cancer ($p < .027$), prostate cancer

($p < .001$), colon cancer ($p < .001$), and diabetes ($p < .001$) and the perception of risk for the particular disease as noted in the FHH. A history of stroke in the family appeared to be the strongest predictor of perception of disease risk with an odds ratio of 5.84 (95% CI [2.89, 11.78]) followed by heart disease with an odds ratio of 2.38 (95% CI [1.343, 4.215]).

The KNWLGFHH variable (completion factor) was assessed relative to the demographics of the study participants to determine if the demographics influenced the knowledge of FHH. The analyses indicated that women scored higher than men did on FHH, which is in alignment with published data. Analyses of age demonstrated that participants in the age range of 18 to 55 scored higher overall than participants in the age range of 56 to 85. Specifically, participants in the age range of 36 to 55 had the highest mean scores. Noteworthy is that younger participants scored higher versus older participants. The analyses of knowledge of FHH factors by race and ethnicity indicated that Blacks and African Americans had lower mean values as compared to the other races and ethnicities of the study participants. The analyses of levels of education clearly showed that the knowledge of FHH completeness factor means were higher among study participants who had between 1 to 3 years of college. As the level of education augmented, the means increased with participants who had graduate degrees having the highest knowledge of FHH means.

The frequencies for the perception of disease risk indicated that between 8.2% to 15% of people perceived a high risk for stroke, breast cancer, ovarian/cervical cancer, prostate cancer, and colon cancer. By comparison, 30% of participants indicated high risk

for heart disease and 31% for diabetes, which is indicative of greater awareness of disease risk factors, of knowledge of disease among family members, and/or of history of disease among family member.

Additionally, the chi-square test of association between gender and the importance of knowing about diseases in family was statistically significant ($X^2(1) = 4.595$, $p = .032$), but there was no statistical significance between gender and the FHH being indicative of increased risk for disease ($X^2(1) = 0.12$, $p = .914$). Further, binary logistic regression was performed to investigate the potential effect of age, gender, race, ethnicity, level of education, experience in healthcare, and place of recruitment on how the knowledge of FHH might influence perception of disease risk. Of the six mediating factors analyzed, age was statistically significant for heart disease ($p < .001$) with an odds ratio of 1.044 (95% CI [1.021, 1.067]), stroke ($p < 020$) with an odds ratio of 1.033 (95% CI [1.005, 1.062]), and prostate cancer ($p < 032$) with an odds ratio of 1.075 (95% CI [1.006, 1.149]; Tables 9, 10, and 13). Increasing age particularly within the age range of 40 to 57 was associated with increasing levels of perception of disease risk for heart disease, stroke, and prostate cancer.

Place of recruitment was statistically significant for perception of colon cancer ($p < 045$) with an odds ratio of .361 (95% CI [.133, .978]; Table 14). Three times as many individuals from the general population indicated higher than average risk for colon cancer. The increased awareness of colon cancer among the general population due to media awareness may be contributing factor, and this is supported by Steckelberg, Hülfenhaus, Haastert, and Mühlhauser (2011) who noted that availability of information

led to increased awareness of disease risk, although not necessarily an increase in call to actions such as screening.

A comparison of overall perception of disease risk between individuals recruited from the health care facilities and individuals recruited from the general population was indicative of a greater perception of disease risk among the general population (59.3%) as compared to the individuals recruited from the health care facilities (40.7%). Kaufman, Bollinger, Dvoskin, and Scott (2012) pointed to the increased availability of information on the Internet and increased ownership for personal health care with less reliance on health care providers as a reason why individuals are more likely to have a desire for information about their health status. This could explain why the individuals from the health care facilities who are seeking information through the traditional route of health care providers might be less likely to have pursued seeking information on their own to assess their risk of disease.

Interpretation of the Findings

The knowledge of FHH completeness score frequencies indicated that 12.1% fell between .500 to .200 and 87.9% between 1.000 to .500, of which 22.7% had fully completed FHH. These frequencies were indicative that the majority of the participants had knowledge of the FHH of their closest family members with knowledge decreasing relative to aunts, uncles, and cousins. This is in alignment with a number of studies that have shown that information on the FHH tends to become less accurate for second-degree relatives and more so for third-degree relatives (Doerr & Teng, 2012; Facio et al., 2010; Langlands et al., 2010; Wideroff et al., 2010; Ziogas & Anton-Culverl, 2003). For

example, the study conducted by Ziogas and Anton-Culverl (2003) showed that among patients with first-degree relatives who had cancer, the reliability of FHH was 75% to 90%. However, the reliability declined to 50% to 80% for second degree relatives and dropped even further for third-degree relatives. Similar results were obtained by Wideroff et al. (2010) and Yoon et al. (2009).

The amount of knowledge an individual has of FHH was not associated with a greater perception of disease risk based on the lack of statistically significant association between any of the perception of disease risk questions and knowledge of FHH completeness scores, as noted by the results of the chi-square test of association. This is supported by Jorgenson's (2012) conclusion that even after completing an FHH and personalized messaging for disease prevention, people still tended to underestimate their disease risk. Also noteworthy is that 87.9% of the participants rated their health as *excellent*, *very good*, or *good*, while 12.1% rated their health as *fair* or *poor*. Consequently, it is possible that the health status of the study participants may have influenced their perception of future disease risk as was noted by Acheson et al. (2010).

However, the indicative statistically significant results of the Spearman *rho* correlation for stroke and colon cancer revealed that participants who have family members with risk for these specific diseases may perceive a greater risk as compared to other diseases. This was confirmed by the binary logistic regressions that indicated there was a statistically significant association between the presence of the chronic diseases heart disease, stroke, breast cancer, ovarian/cervical cancer, prostate cancer, colon cancer, and diabetes in the family and the perception of risk for the disease. DiLorenzo et al.

(2006) demonstrated in their study that family history of a specific disease was a predictor of perceived risk for that disease. Similarly, Mellon et al. (2008) concluded that the female relatives of women who had breast cancer perceived higher levels of risk for developing the disease. These findings are also supported by the studies conducted by Acheson et al. (2010), O'Neil et al. (2009), Wang et al. (2009, 2012), who independently demonstrated that family history of chronic disease appeared to be associated with risk perception.

From the frequencies for the perception of disease risk, it was noted that between 8.2% to 15% of people perceived a high risk for stroke, breast cancer, ovarian/cervical cancer, prostate cancer, and colon cancer. By comparison, 30% of participants indicated high risk for heart disease and 31% for diabetes, which is indicative of greater awareness of disease risk factors, of knowledge of disease among family members, and/or of history of heart disease and diabetes among family member as similarly noted by O'Neil et al (2009).

According to the results of the various analyses performed, the participant's demographics do influence the perception of disease risk. The frequencies of knowledge of FHH completion factors relative to demographics of the study participants indicated that women scored higher than men on FHH. These results are in alignment with published data that point to women having more extensive knowledge of family health history due to their role as caregivers (Evans et al., 2011; Mahalik et al., 2007). Moore (2010) pointed to women as more cognoscente of health issues and matters of illness and

more willing to adopt healthy lifestyles. Mai et al. (2011) also noted that women were more likely to be the source of and disseminator of health information for their families.

Relative to age, younger participants had higher knowledge of FHH completion factors versus older participants, which is contrary to the results noted by Acheson et al. (2010) and O'Neill et al. (2009) in which older patients appeared to have the greater degree of FHH knowledge. Wang et al. (2009, 2012) noted that younger individuals were more likely to perceive greater baseline risk, which could also lead to increased levels of action on the part of the individual and subsequent increased knowledge of FHH. However, this did not mean that the younger individuals would continue to have increased perception of disease risk as they aged (Wang et al., 2009, 2012).

The analysis of knowledge of FHH factors by race and ethnicity indicated that Blacks and African Americans had lower mean values as compared to the other races and ethnicities. Kupfer et al. (2006) and Wideroff et al. (2010) attributed the decreased levels of knowledge to cultural practices limiting information sharing among family members and lack of knowledge of paternal family history. Ashida, Goodman, Stafford, Lachance, and Kaphingst (2012) recognized in their study that Blacks and African Americans were less likely to recognize the importance of the FHH. Additionally, Bowen, Hickman, and Powers (1997) noted a prevalence of distrust by African Americans towards their physicians that contributed to decreased knowledge of medical care, illness, and levels of knowledge of FHH.

The analysis of levels of education clearly showed that the knowledge of FHH completeness factor means were higher among study participants who had between 1 to 3

years of college; furthermore, as the level of education augmented towards a graduate degree, so did the knowledge of FHH means. Ashida et al. (2012) also noted that higher educational levels were associated with greater knowledge of FHH and awareness of risk. Greater levels of education, therefore, may provide the opportunity for accessing and understanding the importance of the FHH and its relationship to disease risk.

According to the bivariate analyses, age was statistically significant for heart disease, stroke, and prostate cancer with the perception of disease risk increasing as age increased, particularly among individuals between the ages of 40 to 57. O'Neil et al. (2009) also noted that individuals ≥50 years had higher perceived risk as compared to younger individuals. Place of recruitment (health care facility versus general community) was statistically significant for perception of colon cancer with individuals from the general population indicating higher levels of perception of disease risk. This could be attributed to the particular study sample from the general population having a higher level of perceived disease risk for colon cancer due to presence of disease within their family or increased awareness due to media and health care campaigns promoting the benefits of colon cancer screening. However, an opposing perspective was provided by Mai et al. (2011) noting that colon cancer might be a less-discussed type of cancer among family members, thus leading to overall decreased awareness and perceived risk.

Limitations of the Study

A major limitation to the study was the recruitment of participants from the health care facilities within a defined geographical area of Delaware due to the logistical management of the study. Consequently, this portion of the study population was limited

to the individuals who volunteer for the study only from these health care facilities. This may have led to selection bias and limited generalizability of the findings from the study. However, this limitation was partly addressed by the use of the appropriate statistical analysis, such as multivariable analysis. The study participants may have also been a source of recall bias since the data were self-reported.

While measures were taken to ensure that recruitment took place at health care facilities that were known to serve a widely diverse population, the study participants were comprised of almost twice as many women (65.2%) as compared to men (34.8%). Additionally, several ethnic groups were either not represented or lacked adequate representation. A high percentage of participants were also noted to have at least a college degree and many had graduate degrees. Thus, it can be assumed these individuals were above average in education and awareness of FHH as compared to the general population. Another limitation was the exclusion of three individuals who indicated they were adopted. It was assumed that individuals who were adopted would not know the health history of their biological family and could not provide an accurate FHH.

The online survey format had its own limitations. These include short cuts or inaccuracies emanating from the participants when completing the FHH due to time restrictions, technological challenges, lack of computer access, and concerns around privacy (Shannon et al., 2002). Additionally, the electronic survey format may have led to misinterpretation and mistakes by the survey participant when reporting their FHH (Shannon et al., 2002). Since the study did not provide a process for validating the FHH

information entered by study participants, any mistakes or misinformation could not be verified. Furthermore, true lack of knowledge of FHH could not be proven.

Perceived risk of disease was assessed solely from the questions presented and did not take into consideration that aside from the FHH documented, the participant may have had specific risk factors for disease. Additionally, among individuals who had a large percentage of "Do Not Know About Diseases" checked, the perception of disease risk could have been limited by virtue of not knowing whether family members had specific diseases or not.

The use of a cross-sectional design also had limitations such as the study design only being able to infer correlations and not causal relationships and the requirement of a larger sample size to attain a significant power (Creswell, 2009). The cross-sectional study design may have also been subject to selection bias, information bias, and potential for confounding due to factors such as educational level and health care experience or training (Cooper, 2000; Delgado-Rodríguez & Llorca, 2004; LaMonte, 2013).

Recommendations for Future Research and Practice

The results of this study may be of contribution to the body of knowledge on FHH by providing information on the use of the third-degree FHH and the participant's knowledge of FHH in assessing perceived risk of disease. The basic FHH has been considered a core tool for assessment in health care, although its use had declined as a tool for evaluate risk of disease (Orlando et al., 2011). However, the emergence of population management as a way of mitigating health care cost, improving population health, and engaging patients in their health care has led to renewed advocacy for

utilizing a comprehensive FHH (Berg et al., 2009). Nevertheless, barriers for implementation and widespread use exist. Further studies to understand adoption of a third-degree FHH in routine use would provide knowledge on how to overcome perceived barriers.

The perception of disease risk questionnaire was answered by participants after filling in their third-degree FHH. A recommendation for follow up would be to administer the perception of disease risk questionnaire prior to completing the third-degree FHH and then post the third-degree FHH in order to be able to assess change in perception. This methodology was utilized by Acheson et al. (2010) when evaluating the Family Healthware™ questionnaire, which included first and second degree relatives only. Additional studies to consider could explore possible applications of the knowledge of FHH completion factor as it relates to perception of disease risk. For example, it might be valuable to explore whether individuals with high knowledge of FHH completion factors perceived the same level of risk before and after completing the FHH as compared to individuals with lower knowledge of FHH completion factors.

The implications of ethnic and cultural practices, communication, and perception of disease should be considered in subsequent research of the third-degree FHH. As noted in several studies, cultural and ethnic practices may be barriers to communication of disease conditions among family members, which subsequently lead to lack of knowledge of FHH and a lowered sense of health risk (Courtenay, 2000; Evans et al., 2011; Mai et al., 2011; Wideroff et al., 2010).

Applications for the third-degree FHH and perception of disease risk questionnaire should be considered within the scope of health promotions and educational initiatives focused on effectively conveying the need for awareness of personal disease risk. This type of campaign should promote the use of the third-degree FHH beyond genetic screening and consider the comprehensive questionnaire as a first level tool for disease risk assessment (Yoon et al., 2003).

Implications

The findings of this research may be useful in understanding the third-degree FHH, knowledge of FHH as influenced by demographics, and the perception of disease risk as ascertained from completing the third-degree FHH. Despite the recommendations from AAFP, AMA, CDC, HHS, and NIH, the third-degree FHH is not used routinely in medical practice (Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013). Stated barriers for routine use of the third-degree FHH include the availability of time during a medical consultation, training for health care employees collecting the FHH, and patient's knowledge for their family's health history (Annis et al., 2005; Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Cegala, 2011; Claassen et al., 2010; Flynn et al., 2010; Janssens et al., 2012; O'Neill et al., 2009; Parmar, 2003; Powell et al., 2013; Qureshi et al., 2011; Rich et al., 2004; Ruffin et al., 2011; Valdez et al., 2010; Wattendorf & Hadley, 2005; Wilson et al., 2009; Yoon et al., 2003; Yoon et al., 2009).

Several studies point to the association between the extent of knowledge of FHH and gender and age, with women and older patients having greater degree of knowledge

versus men and younger patients (Archer et al., 2011; Beier & Ackerman, 2003; Cegala, 2011; Janssens et al., 2012; O'Neill et al., 2009; Qureshi et al., 2011; Rich et al., 2004). However, a major finding of this study was that younger patients appeared to be more knowledgeable of their FHH than older patients, which may stem from greater levels of perceived baseline risk followed by greater willingness to pursue a call to action to reduce the risk (Wang et al., 2009, 2012). This in turn could result in increased knowledge of FHH, but not necessarily a continued level of perceived risk as the individual ages.

Lower knowledge of FHH completeness scores were evident among Blacks and African Americans, thus further substantiating the need for studies to investigate the association between ethnicity and a patient's knowledge of FHH.

The information obtained through this study may be used in the development of a comprehensive, third-degree FHH that is aligned with AAFP, CDC and NIH recommendations and useful for routine use in assessing chronic disease risk (AAFP, 2012; Berg et al., 2009; CDC, 2013b; O'Neill et al., 2009; Powell et al., 2013). Additionally, the information may be used in the development of health promotions and education initiatives that effectively convey a sense of personal disease risk.

An accurate and complete FHH increases its usefulness as a primary tool for chronic disease risk assessment at a time when chronic diseases use the bulk of health care resources, and the applications for genetic testing based on risk assessment are significantly expanding (Khoury, Feero, & Valdez, 2010; Powell et al., 2013; Rich et al., 2004; Valdez et al., 2010). Herein lay the opportunities for social change that may result

from the study: widespread implementation of a familial health history questionnaire that leads to an impactful, higher degree of disease risk awareness, prompting preventive action on the part of the individual, and leading to improved individual and population health.

Conclusion

In 2007 chronic diseases in the United States accounted for an estimated 107 million cases of illness and greater than 1.7 million deaths annually (CDC, 2012; HealthyPeople.gov, 2011). It is anticipated that the number will increase to 230 million by 2023, with $4.2 trillion in treatment costs and lost economic output (Chatterjee, Kubendran, King, & DeVol, 2010). Risk assessment of chronic disease includes a patient completing a comprehensive FHH in order to understand their risk level for disease due to hereditary predisposition (Acheson et al., 2010; Scheuner et al., 2006; Yoon et al., 2010; Walter et al., 2013). The utilities of using the third-degree FHH in health care practice include providing the physician with an understanding of the patient's current condition and assisting in the development of an intervention or preventive care protocol (Bickley & Szilagyi, 2012; Mai et al., 2011). The third-degree FHH may also be useful to aid patients in appraising and recognizing their individual level of risk for developing a given chronic disease, as well as motivating patients to implement behavioral changes to delay disease onset or improve disease outcomes (Cegala, 2011; Claassen et al., 2010; Ko, Turner, Jones, & Hill, 2010; Valdez et al., 2010). However, demographical characteristics may influence the knowledge that individuals have of their FHH, which may impede fully recognizing the true level of risk for disease.

The purpose of this study was to assess the possible association of completing the third-degree FHH on the participant's perception of disease risk and the influence of the FHH and demographics on the perception of disease risk, as ascertained through knowledge of FHH. Participants were required to complete a three-part survey questionnaire including a comprehensive third-degree FHH. The knowledge of FHH completeness factor was calculated for each survey with only 22.7% of the 273 participants having full knowledge of disease conditions among all listed relatives.

There was no statistically significant association between any of the perception of disease risk questions and knowledge of FHH completeness scores, as noted by the results of the chi-square test of association. However, the results of the Spearman *rho* correlation was indicative of statistically significant results for the association between knowledge of FHH and perceived risk of stroke ($p<.053$) and perceived risk of colon cancer ($p<.089$) based on using a p value of < 0.1 (Stoddard, 2013). Binary logistic regression revealed a statistically significant association between the presence of the disease in the family and the perception of risk for the particular disease noted in the FHH.

Chi-square test of association between each demographic characteristic and each perception of disease question indicated that women scored higher than men on FHH and that participants in the age range of 18 to 55 scored higher versus participants in the age range of 56 to 85. The analysis of knowledge of FHH factors by race and ethnicity indicated that Blacks and African Americans had lower mean values as compared to the other races and ethnicities of the study participants. The analysis of levels of education

clearly showed that as the level of education augmented, so did the knowledge of FHH completeness factor. Binary logistic regression was also performed to investigate the effects of demographics on how the knowledge of FHH might influence perception of disease risk. Of the six mediating factors analyzed, age was statistically significant for heart disease, stroke, and prostate cancer, and ethnicity was statistically significant for colon cancer. Knowledge of FHH appeared to be a strong predictor of perception of disease risk for diabetes and for perception of disease risk for cervical/ovarian cancer.

The information obtained through this study may aid in the development of a comprehensive, third-degree FHH useful for routine use in assessing chronic disease risk, and also aid in the development of health promotions and education initiatives that effectively convey a sense of personal disease risk. An accurate and complete FHH increases its usefulness as a primary tool for chronic disease risk assessment at a time when chronic diseases use the bulk of health care resources, and the applications for genetic testing based on risk assessment are significantly expanding (Khoury, Feero, & Valdez, 2010; Powell et al., 2013; Rich et al., 2004; Valdez et al., 2010). Herein lay the opportunities for social change that may result from the study: widespread implementation of a familial health history questionnaire that leads to an impactful, higher degree of disease risk awareness, prompting preventive action on the part of the individual, and leading to improved individual and population health.

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Appendix A: Example Information Flyer General Population and Healthcare Facility

Volunteers Needed for Research Study

Volunteers are needed to help investigate how much we know about our family's health history of specific chronic diseases and our possible risk for developing these diseases.

Who is Eligible?

- You must be at least 18 years of age
- You must be able to read and understand English

What will you be asked to do?

- Complete an anonymous survey about your family's health history and possible risk for certain chronic diseases.
- Access "Your Third Degree Family Health History" survey online at www.yourfhh.com

If you have any questions about the survey, please contact investigator Liana Romero at

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Who is Eligible?

- You must be at least 18 years of age
- You must be able to read and understand English

What will you be asked to do?

- Complete an anonymous survey about your family's health history and possible risk for certain chronic diseases.
- Access "Your Third Degree Family Health History" survey online at www.yourfhh.com OR complete the paper copy of the questionnaire available at Bijin Inc.

If you have any questions about the survey, please contact investigator Liana Romero at.

Appendix B: Consent Form

Greetings!

You are invited to take part in a research study by completing a survey questionnaire to assess your family health history. The survey will consist of questions about chronic diseases (heart disease, stroke, diabetes, and certain cancers) among all your relatives. The survey will also gather information about you, including your age, gender, race, ethnicity, education, and whether you have experience in health care as a professional.

The researcher is inviting participants that are 18 years of age or older, of any race or ethnicity, and able to read and understand English to participate in the study. The study would require you to complete the anonymous survey questionnaire. This is also part of the "informed consent" process, which allows you the opportunity to understand the scope of the study before deciding whether or not to take part.

This study is being conducted by a research named Liana Romero, wo is a doctoral student at Walden University. The survey questionnaire and consent form are available both in a paper copy version or in an online version available via http://www.yourfhh.com. This consent form is specific for the paper version of the survey questionnaire.

Background Information:

This study aims to investigate and analyze the knowledge that people have of the health history of their family members, specifically about heart disease, stroke, diabetes, and various forms of cancer. This includes the first-degree relatives (parents, siblings, and children), second-degree relatives (maternal/paternal grandparents, aunts/uncles, nieces/nephews, and half-siblings), and third-degree relatives (first cousins).

Procedures:

If you agree to be part of this study, you will be asked to:
Provide information about yourself such as age, gender, race, ethnicity, educational level, and any professional experience in the field of healthcare.
List all the family members, both alive and deceased, their approximate age, and indicate which chronic diseases they may have, or had, whether they have or had no disease, or whether you do not know if they have or had disease.
Respond to questions about how the family health history may affect your own health.

The survey will take approximately 10 minutes to complete

Voluntary Nature of the Study:

This study is completely voluntary. If you decide to join the study now, you can still change your mind later.

Risks and Benefits of Participating in the Study:

Participation in this study will not pose risk to your safety or wellbeing. By completing the paper copy of the survey forms, you may experience some eyestrain, hand strain, and minor fatigue. You may also experience some level of stress in completing the survey. You are free to stop filling in the survey at any time.

The potential benefit of this study is to provide the public with a tool to gather a comprehensive family health history, which can also be used to assess possible disease risks based on the history of disease among family members.

If you would like to obtain information about chronic diseases or other health issues, it is recommended that you contact your primary care physician or other health care resource.

Payment:

There will be no payment incentive to complete the survey.

Privacy:

Any information you provide will be kept anonymous. No names or identifying information will be collected other than age, gender, ethnicity, race, education, and experience in the health care field. The researcher will not use your personal information for any purposes outside of this research project. In addition, the researcher is not requesting your name or any other information that could identify you in the study reports. Data will be kept secure by keeping all results on a computer that is password protected, and the paper copies of the survey will be kept securely looked by the researcher. All data and paper copies of the survey will be kept for a period of at least 5 years, as required by Walden University.

Contacts and Questions:

If you have questions, you may contact the researcher, Liana Romero, via email at

If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is.

Statement of Consent:

I have read the above information, and I feel I understand the study well enough to make a decisions about my involvement. By completing and submitting this survey questionnaire, I understand that I'm agreeing to the terms described above.

You may keep this consent form for your future reference.

Appendix C: Third-Degree FHH

Your Third-Degree Family Health History

Demographics

The following group of questions gathers information about you. Please fill in the answer or check the box that best represents you.
Please answer all questions and mark only one box per item.

1. What is your age in year? _____

2. What is your gender?
   - ▢ Male
   - ▢ Female

3. Which one of the following would you say is your race?
   - ▢ White
   - ▢ Black
   - ▢ Asian
   - ▢ Native Hawaiian or other Pacific Islander
   - ▢ American Indian or Alaska Native
   - ▢ Multiple races

4. Which of the following best describes your ethnicity?
   - ▢ African
   - ▢ African American
   - ▢ Afro-Caribbean
   - ▢ Canadian
   - ▢ East Asian (China, Korea, Mongolia, Tibet)
   - ▢ European
   - ▢ Hispanic /Latino
   - ▢ Japanese
   - ▢ Middle Eastern or Arab
   - ▢ South Asian (Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, Sri Lanka)
   - ▢ Other

5. Are you adopted?
   - ▢ Yes
   - ▢ No
   - ▢ Do not know/Not sure

6. What is the highest grade or year of school you completed?
   - ▢ Never attended school or only Kindergarten
   - ▢ Grades 1 through 8
   - ▢ Grades 9 through 11 (some high school)
   - ▢ Grade 12 or GED (High School Graduate)
   - ▢ College 1 year to 3 years (some college or technical school)
   - ▢ College 4 years or more (college graduate)
   - ▢ Graduate school or advanced degree

7. Do you have experience or training in the field of health care?
   - ▢ Yes
   - ▢ No

8. In general, how would you rate the status of your health?
   - ▢ Excellent
   - ▢ Very Good
   - ▢ Good
   - ▢ Fair
   - ▢ Poor
   - ▢ Don’t know/Not sure

9. Where did you obtain the information to participate in this study?
   - ▢ Physician or medical office; health care or health care-related facility
   - ▢ Nonmedical location (Public location, such as College or University campus, place of employment, shopping location, etc.)

Family Health History:

10. Please complete the following information on YOUR RELATIVES.

- Indicate the age of each living relative or age when deceased.
- Place an "X" in the box indicating "No Disease(s)" if a relative does not or did not have any of the diseases listed.
- Place an "X" in the "Do Not Know" box if you have or had a relative but do not know whether the relative had any of the diseases listed.
- If you have or had a relative who had any of the diseases listed, place an "X" for each disease for that relative.
- If you have more relatives than spaces indicated, use the lined sheet of paper to add the relatives indicating the relationship to you.
- If you do not have relatives for a specific category (for example, you have no siblings), do not check or enter any information in that section.

				Select All That Apply						
Relationship	Age	No Disease	Do Not Know About Diseases	Heart Disease	Stroke	Breast Cancer	Ovarian/ Cervical Cancer	Colon Cancer	Prostate Cancer	Diabetes
Your Children:	Please include all of your children if applicable									
Child #1										
Child #2										
Child #3										
Child #4										
Child #5										
Child #6										
Child #7										
Your Siblings:	Please include all of your brothers and sisters if applicable									
Sibling #1										
Sibling #2										
Sibling #3										
Sibling #4										
Sibling #5										
Sibling #6										
Sibling #7										
Your Nieces/Nephews	Please include all your nieces and nephews if applicable									
Niece/nephew #1										
Niece/nephew #2										
Niece/nephew #3										
Niece/nephew #4										
Niece/nephew #5										
Niece/nephew #6										
Niece/nephew #7										
				Select All That Apply						

Relationship	**Age**	**No Disease**	**Do Not Know About Diseases**	**Heart Disease**	**Stroke**	**Breast Cancer**	**Ovarian/ Cervical Cancer**	**Colon Cancer**	**Prostate Cancer**	**Diabetes**
Your Mother										
Your Father										
	Your maternal grandmother									
Your Mother's Mother										
	Your maternal grandfather									
Your Mother's Father										
Your Mother's Siblings:	Your aunts and uncles on your mother's side									
Sibling #1										
Sibling #2										
Sibling #3										
Sibling #4										
Sibling #5										
Sibling #6										
Sibling #7										
Your Mother's Nieces and Nephews:	Your first cousins on your mother's side									
Niece/nephew #1										
Niece/nephew #2										
Niece/nephew #3										
Niece/nephew #4										
Niece/nephew #5										
Niece/nephew #6										
Niece/nephew #7										
	Your paternal grandmother									
Your Father's Mother										
	Your paternal grandfather									
Your Father's Father										

				Select All That Apply						
Relationship	**Age**	**No Disease**	**Do Not Know About Diseases**	**Heart Disease**	**Stroke**	**Breast Cancer**	**Ovarian/ Cervical Cancer**	**Colon Cancer**	**Prostate Cancer**	**Diabetes**
	Your paternal grandfather									
Your Father's Parents										
Your Father's Siblings:	Your aunts and uncles on your father's side									
Sibling #1										
Sibling #2										
Sibling #3										
Sibling #4										
Sibling #5										
Sibling #6										
Sibling #7										
Your Father's Nieces and Nephews:	Your first cousins on your father's side									
Niece/nephew #1										
Niece/nephew #2										
Niece/nephew #3										
Niece/nephew #4										
Niece/nephew #5										
Niece/nephew #6										
Niece/nephew #7										

Appendix D: Perception of Disease Risk Survey

Disease Risk:

The following group of questions is about your perception of disease risk.
Please check the box that best represents how you feel.
Please answer all questions and mark only one box per item.

11. It is important for my own health to know if diseases like cancer, diabetes, stroke or heart disease run in my family.

    - ▢ Strongly Agree
    - ▢ Agree
    - ▢ Neither Disagree or Agree
    - ▢ Disagree
    - ▢ Strongly Disagree

12. A person's family health history can make him/her more likely to get diseases like cancer, diabetes, stroke or heart disease.

    - ▢ Strongly Agree
    - ▢ Agree
    - ▢ Neither Disagree or Agree
    - ▢ Disagree
    - ▢ Strongly Disagree

13. Compared to most people of your age and sex, what would you say your chances are for developing coronary heart disease, or having a heart attack?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

14. Compared to most people of your age and sex, what would you say your chances are for having a stroke?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average

- ▢ Lower Than Average
- ▢ Much Lower Than Average

(For Females Only)

15. Compared to most women of your age, what would you say your chances are for developing breast cancer?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

(For Females Only)

16. Compared to most women of your age, what would you say your chances are for developing ovarian or cervical cancer?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

(For Males Only)

17. Compared to most men of your age, what would you say your chances are for developing Prostate cancer?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

18. Compared to most people of your age and sex, what would you say your chances are for developing colon cancer?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

19. Compared to most people of your age and sex, what would you say your chances are for developing diabetes?

    - ▢ Much Higher Than Average
    - ▢ Higher Than Average
    - ▢ About the Same as Average
    - ▢ Lower Than Average
    - ▢ Much Lower Than Average

20. Have you ever actively collected health information from your relatives for purposes of recording a family health history?

    - ▢ Yes
    - ▢ No
    - ▢ Do Not Know

You are finished with the Survey!
Thank you very much for your time and assistance.

Appendix E: Permission to Use the Risk Perception Questionnaire

Subject: Re: Permission for Pre / Post Risk Perception Questionnaire

Date : Mon, Mar 10, 2014 09:09 PM CDT
To : Liana Romero
From : Louise Acheson
Dear Ms. Romero,

I've heard back from the other PIs, who approve of sharing the questionnaires with other researchers upon request. Please acknowledge the source in any publications. I will attach copies. The questionnaire had a branching structure, administered online. The questionnaire for men omitted the sections on breast and ovarian cancer, but was otherwise the same as for women.

Comments from the team include that the instrument was not validated in its entirety (other than being used for FHITr study), though components of it were items validated by others. Also that this questionnaire itself, we observed, may have prompted participants to take preventive actions, even without exposure to the family history tool. Mack Ruffin, IV, Professor at University of Michigan, made the following suggestion about family history tools:

> I would encourage her to check out Family Health Heritage. It covers far more diseases and has been developed to interface with electronic health records. It was started at UVa and has migrated to Chicago. I can put her in contact with the lead investigators.
>
> http://www.northshore.org/genetics/patient-services/health-heritage/
>
> Mack T. Ruffin IV, MD, MPH
>
> Professor
> Associate Chair for Research Programs
> Dr. Max and Buena Lichter Research Professor
> Department of Family Medicine
> University of Michigan Health System

Best regards to you.
Louise Acheson

S, & Green, S, & Salkind, N (2004). , N (2004). Using SPSS for Windows and Macintosh: Analyzing Using SPSS for Windows and Macintosh: Analyzing and Understanding and Understanding Data.New York: Prentice Hall. York: Prentice Hall.