

ASSESSING THE EFFECTIVENESS OF FAMILY HEALTH HISTORY
(FHH) INTERVENTIONS AND EXAMINING FACTORS AFFECTING
COLLEGE STUDENTS' INTEREST AND USES OF FHH

A Dissertation

by

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ABSTRACT

An individual's family health history (FHH) plays a significant role in early disease detection and prevention. It is important for college students to know their FHH and establish a life-long healthy lifestyle. Obtaining accurate and comprehensive FHH information from family members is the first step to apply FHH in health promotion. The purpose of this dissertation is to assess college students' behavior of FHH collection and associated psychological factors, as well as examine college students' FHH educational needs. Beginning with a systematic literature review, the first manuscript summarized and evaluated existing FHH interventions for the general public. The second manuscript is a needs assessment that investigated college students' interests, preferred information, and desired delivery methods for FHH education. The third manuscript presents a survey study examining college students' behavior of FHH collection from family members and associated factors using an integrated theoretical framework.

There were several key findings in this dissertation. First, the systematic literature review identified 35 articles evaluating 28 different FHH interventions. These studies included diverse settings, a wide range of chronic diseases, and different ethnic groups. Although articles in this review assessed various behaviors and/or health-related cognitive outcomes associated with FHH interventions, significant positive changes were only reported in certain aspects. Future research should address more complicated health behaviors, especially communication with healthcare providers, in their FHH

interventions. This review also highlighted the need to improve the methodological quality of this body of literature. Second, more than half of college students were not interested in FHH education mainly because of low prioritization. The most desired topics regarding FHH education included interpretation of FHH information, FHH applications in disease prevention, and FHH collection methods. Computer-based learning was the most preferred education method among college students. Third, over half of the college students had never or seldom obtained their own FHH from family members. Participants' FHH collection behavior was associated with various psychological and demographic factors in the proposed theoretical framework.

This dissertation contributes to the current literature by critically evaluating existing FHH interventions, assessing college students' behavior in FHH collection, and providing future directions for FHH interventions for college students.

DEDICATION

To my parents and husband.

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Contributors

This work was supervised by a dissertation committee consisting of Drs. Lei-Shih Chen [chair], Patricia Goodson and Adam Barry of the Department of Health and Kinesiology, and Dr. Wen Luo of the Department of Educational Psychology.

All other work conducted for the dissertation was completed by the student, under the advisement of Dr. Lei-Shih Chen of the Department of Health and Kinesiology. This dissertation presents the results of preliminary data analysis, which may be different from future publications.

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CHAPTER I

INTRODUCTION

Family health history (FHH) is a widely accepted and easy-to-use genomic tool used to predictively assess an individual's risks for common chronic diseases (e.g., certain types of cancers, type 2 diabetes, and cardiovascular diseases).¹ FHH serves as a resource not only for risk information regarding genetic susceptibility to a particular disease, but it also captures the interactions between shared environmental and behavioral factors within the family.² The value of FHH collection across three generations and its comprehensive interpretation has long been recognized in both clinical genetic settings and primary care (e.g., early disease diagnosis, decisions on genetic testing, and reproductive choices).³ Moreover, FHH plays an important role in disease prevention and health promotion by increasing risk awareness for many diseases as well as motivating people to engage in risk-reducing behaviors.³ Based on FHH, personalized medical recommendations and tailored health messages can be provided to patients. FHH has been considered as an essential entry point for precision medicine,⁴ which is defined as “an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.”⁵ Thus, in the area of precision medicine, it is important for everyone to collect/update their FHH, communicate their FHH with health care providers, and use FHH information to promote a healthier lifestyle.

A national survey conducted in 2004 revealed that few Americans actively collected their FHH.⁶ Similarly, recent research studies reported that most of the general public, especially racial and ethnic minorities, has limited awareness of FHH and failed to collect their FHH.⁷⁻¹⁰ To increase people's use of FHH, leading health agencies and authorities have diligently promoted FHH initiatives and campaigns. For example, the U.S. Surgeon General and the Department of Health and Human Services launched a national public health campaign, "My Family Health Portrait," in 2004 to encourage all families to learn more about their FHH. The campaign included launching "My Family Health Portrait," a web-based and free of charge tool to help the public collect and document FHH.¹¹ State-level agencies, such as the Connecticut Department of Public Health's Genomics office¹² and Illinois Department of Public Health¹³, have demonstrated persistent efforts in the promotion and dissemination of FHH to use in regards to disease prevention.

In line with the national public health initiatives, researchers have implemented FHH educational programs in various settings for diverse populations. For instance, Kaphingst and colleagues⁹ conducted a FHH intervention among underserved Latino communities using lay health advisors. After the intervention, participants' intentions and self-efficacy to discuss FHH with family members and doctors increased. Murthy and colleagues¹⁴ conducted a FHH intervention to improve cancer risk perceptions in an African Americans community. Following their FHH intervention, more participants demonstrated accurate risk perceptions for breast, colon, and prostate cancers. Li and colleagues¹⁵ reported that Chinese American participants' attitudes, self-efficacy, and

intention regarding FHH communication with family members and health care providers increased after attending a FHH-based colorectal cancer prevention program.

All of these efforts have shed light on the use of FHH. Yet, there are limitations in the current literature. First, to the best of our knowledge, no literature evaluates the features, characteristics, and effectiveness of participants' health outcomes from these FHH interventions. Additionally, there are limited FHH interventions for college students. College students should not be excluded from FHH interventions. They need to understand their family health risks and be able to develop healthy habits based on information found in their FHH. Previous research has shown that college students perceived barriers to collect FHH. Many college students did not know how to obtain their FHH or what questions should be asked in regards to FHH.¹⁶ Lack of knowledge, time, and family support to obtain FHH, as well as geographical separation from family members, cultural stigma, incorrect perceptions of a healthy family, privacy issues, and concerns about resulting negative emotions from FHH were also identified by college students as obstacles to collect FHH.¹⁶⁻¹⁸

To address these limitations, the purpose of this dissertation is to (1) evaluate existing FHH interventions programs, (2) assess college students' educational needs for FHH, and (3) examine college students' behavior of FHH collection and associated factors using an integrated theoretical framework. The advantages and lessons learned from this systematic review will contribute to the development and implementation of FHH interventions. Meanwhile, understanding young adults' behavior of FHH collection

and their educational needs for FHH are essential for delivering, in the future, a successful FHH educational program for this particular group.

This dissertation consists of five chapters using the journal article format. Chapter II, III, and IV are independent manuscripts to be submitted for publication in peer-reviewed journals. Specifically, Chapter I is an overview of the dissertation project. Chapter II (manuscript #1) is a systematic literature review to evaluate the characteristics and effectiveness of existing FHH intervention programs for the lay public. Chapter III (manuscript #2) is a survey study to examine college students' educational needs for FHH. Chapter IV (manuscript #3) consists of a quantitative study to assess the factors that influence college students' behavior of FHH collection using an integrated theoretical framework. Chapter V is a conclusion of the overall dissertation findings. Implications for health education, recommendations for future research and practice, as well as limitations of this dissertation are discussed in this chapter. Additionally, four appendices are attached at the end of this dissertation, including Appendix A (characteristics and main outcomes of FHH interventions in the reviewed articles), Appendix B (formal test information sheet), Appendix C (formal test survey instrument), and Appendix D (formal test invitation email).

CHAPTER II
EFFECTS OF FAMILY HEALTH HISTORY INTERVENTIONS: A SYSTEMATIC
LITERATURE REVIEW

Introduction

Family health history (FHH) is a traditional medical screening tool.¹⁹ The discoveries from the Human Genome Project and relevant efforts in genomics have given FHH new meaning and greater powers.^{1,20} With more than 2,000 types of genetic tests available, FHH can be used to help determine the needs and appropriate genetic tests for patients.^{19,21} The combination of FHH information and genotypic data is also the most effective method to guide personalized care.⁴ Moreover, FHH is an essential basis for precision medicine, which contributes to a more precise diagnosis, accurate treatment, and effective disease prevention strategy.⁴ In the public health field, FHH is an easy-to-use and important public health genomics tool which represents the interactions among genes, behavior, and the environment.^{1,2,19} In other words, FHH – an increasingly invaluable tool that bridges genetics/genomics and disease prevention – can be used to assess disease risks, promote early disease detection, and motivate individuals to adopt healthier lifestyles.^{3,19}

In light of the importance of FHH in the medical and public health fields, lay individuals should be aware of and collect FHH and act based on their FHH. To promote such actions, leading health authorities, such as the National Institutes of Health (NIH),²² the Centers for Disease Control and Prevention (CDC),²³ the United States (U.S.) Office

of Surgeon General,²⁴ and state level health agencies, such as the Connecticut Department of Public Health's Genomics Office,¹² have promoted the implementation of a variety of FHH initiatives and campaigns. For example, the Department of Health and Human Services launched a national public health campaign– the U.S. Surgeon General's Family History Initiative. Based on the initiative, "My Family Health Portrait," an easier-to-use Web-based FHH collection tool, was developed to promote the use of FHH by the public.¹¹ Meanwhile, various health agencies, such as the NIH²⁵ and the Genetic Alliance,²⁶ have provided funding to support FHH-based interventions and education among diverse populations and settings.

Nevertheless, the number of FHH-based interventions targeting the public is unknown. In addition, there is a lack of literature that summarizes the effectiveness of those FHH-based interventions on health outcomes. To fill this gap, to the best our knowledge, this first-of-its-kind systematic literature study aims to examine the characteristics and effectiveness of existing FHH-based interventions. We seek to answer the following three questions: (1) What are the study features and characteristics of existing FHH-based interventions? (2) What are the health outcomes for those interventions? (3) What are the methodological qualities of these FHH-based interventions?

Methods

Literature Search Strategy

This review followed the Preferred Reporting Items for Systematic Review and Meta-analysis guidelines.²⁷ An initial search on three databases, including Medline

(Ebsco), Embase (Ovid), and CINAHL (Ebsco), was conducted to identify abstracts focusing on FHH-based interventions for the general public. We chose these databases because they indexed the literature from the fields of medicine, healthcare, nursing, allied health, public health, and social and behavioral science. The search terms, including “family health history,” “family history,” “genetic,” “genetic risk,” “familial risk,” “genetic predisposition to disease,” “intervention,” “education,” “health promotion,” “program,” “project,” and “tool”, were used to retrieve articles regarding FHH-based interventions. The time frame for the search was from January 1, 2003, to April 26, 2019. The year of 2003 was chosen because it was the year that the Human Genome Project was completed. The identified abstracts and titles from the literature search were then exported to Rayyan QCRI²⁸ (a free web tool for article screening in systematic literature reviews) for screening articles and elimination of duplicates. To ensure the reliability of the article selection process, two authors (ML and CY) independently reviewed and screened the title and abstract of each potential article. When the title and abstract of an article were insufficient in determining a study’s eligibility, these two authors independently reviewed full-text articles. Disagreements were discussed between the two authors (ML and CY), as well as the corresponding author (LSC), to reach a final agreement.

Inclusion and Exclusion Criteria

The inclusion criteria of the studies in this systematic literature review included: (1) participants were lay people; (2) studies focused on FHH-based interventions, programs, or education; (3) studies reported health outcomes due to FHH-based

interventions, programs, or education; and (4) articles were published in peer-reviewed journals and written in English. Studies were excluded based on our exclusion criteria: (1) protocol or pilot studies without evaluation data; (2) participants who were either health professionals, patients of certain health conditions (e.g., cancer patients), or patients' relatives; (3) interventions where FHH was not the main focus; (4) studies that aimed to evaluate FHH tools without health outcome data from participants; (5) studies that were conducted in a genetic counseling/prenatal setting or as a part of genetic services (because these settings were specific to genetic evaluation and testing, which were beyond our topic); (6) conference abstracts or non-peer reviewed journal articles; and (7) non-English publications.

Data Extraction and Methodological Quality Assessment

The characteristics, methods, and evaluation outcomes of the articles in this review were coded in a matrix presented in Appendix A. To evaluate the methodological quality of reviewed studies, a methodological quality score (MQS) consisting of nine items with a possible theoretical score ranging from 3 to 20, was developed based on previous literature.²⁹⁻³² Table 1 presents the MQS criteria and summarized findings from the included studies.

Table 1 Frequency distributions of methodological criteria among 35 reviewed articles.

Methodological criterion	Description	Points	Frequency distribution	
			N	%
Sample size	Not reported	0	0	0.0
	Small sample size (<100)	1	10	28.6
	Medium sample size (≥ 100 and <300)	2	9	25.7
	Large sample size (≥ 300)	3	16	45.7
Age	Not reported	0	5	14.3
	Reported	1	30	85.7
Gender	Not reported	0	3	8.6
	Reported	1	32	91.4
Ethnicity	Not reported	0	5	14.3
	Reported	1	30	85.7
Theoretical basis of the intervention	Not reported	0	18	51.4
	Reported	1	17	48.6
FHH intervention content (Basic information of FHH, the importance of FHH to health, FHH communication, and the applications of FHH)	Only one	1	16	45.7
	Two	2	9	25.7
	Three	3	8	22.9
	Four	4	2	5.7
Study design	Cross-section /qualitative design	1	11	31.4
	Pre/post design	2	17	48.6
	Quasi-experimental	3	1	2.9
	Experimental (randomized controlled trial)	4	6	17.1
Data	Self-reported	0	35	100.0
	Objective data	1	0	0.0
Follow-up data	Not reported/not applicable	0	28	80.0
	Reported	1	7	20.0

Table 1 Continued

Methodological criterion	Description	Points	Frequency distribution	
			N	%
Data analysis	Descriptive statistics/qualitative	1	5	14.3
	Inferential statistics without controlling for covariates (ANOVA, chi-square)	2	13	37.1
	Inferential statistics controlling for covariates (linear regression, ANCOVA)	3	17	48.6

Note: FHH, family health history; ANOVA, analysis of variance; ANCOVA, analysis of covariance

Results

Figure 1 shows the procedure of article search and selection. A total of 13,619 articles were initially reviewed. Based on the screening of abstracts and titles, full texts (n=82) were obtained and further screened. Among these articles, 30 articles met our inclusion criteria. We next reviewed the reference lists of these 30 articles for any additional studies that could be included in this systemic literature review. The first and corresponding authors of the included 30 articles were also searched via Google Scholar for more potential studies. Through these steps, five additional articles were found. Accordingly, 35 articles with 28 FHH-based interventions formed the final sample of this review.^{9,10,14,15,33-63} Appendix A presented the main characteristics and findings of the 35 included articles.

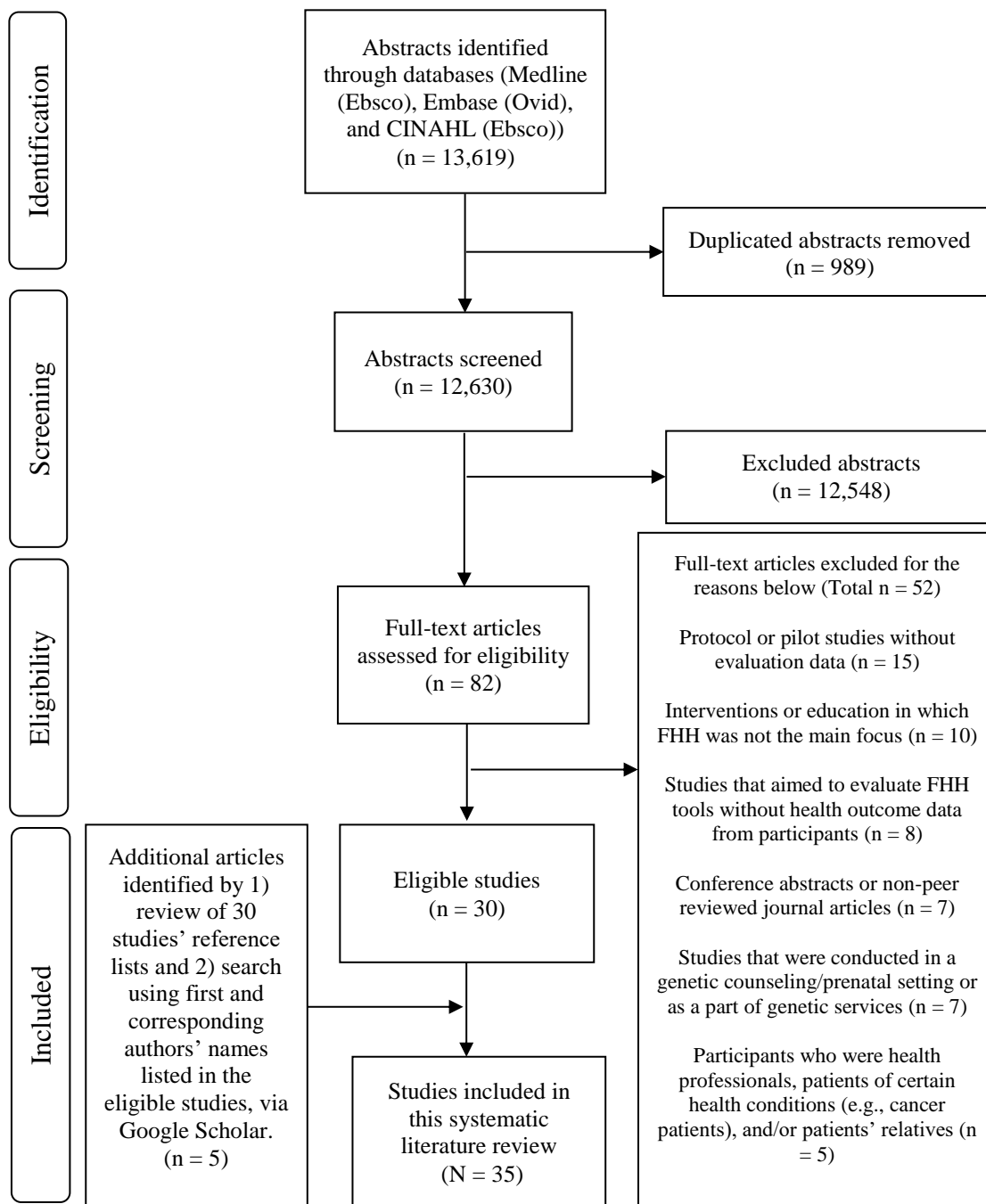


Figure 1 Article search and selection procedure

Study Features

Study sites, years, and participants. Among the 35 reviewed articles, the majority were conducted in the U.S. (n=30; 85.7%) while the remaining studies were carried out in Australia (n=3; 8.6%) and the Netherlands (n=2; 5.7%). The years of publication ranged from 2005 to 2019, with a growing trend in the number of publications: 2003-2007 (n=1; 2.9%), 2008-2012 (n=16; 45.7%), 2013-2017 (n=16; 45.7%), and 2018-April 2019 (n=2; 5.7%). Participants were mainly recruited from communities (n=24; 68.6%); other participant recruitment sites included primary care (n=5; 14.2%), college (n=5; 14.2%), and a mixed setting of high-school and community (n=1; 2.9%). The number of participants of these interventions varied, ranging from 15 to 3,786, with the exception of one large FHH campaign in Utah⁴² that had served 151,188 participants from the general public over more than ten years. Over half of the studies (n=21; 60.0%) had more than 70% of female participants in their samples (five studies recruited women only). The ages of the participants were between 17.0 to 94.0 years. Of 35 studies, ten (28.6%) were specifically tailored to racial/ethnic minority groups, including Latinos (n=5), Blacks (n=3), mixed with Latinos and Blacks (n=1), and Asians (n=1).

Study design. Interventions were evaluated using randomized controlled trials (RCT) (n=6; 17.1%), quasi-experimental design (n=1; 2.9%), pre/post design (n=17; 48.6%), and cross-sectional /qualitative design (n=11; 31.4%). Seven studies (20.0%) also adopted a community-based participatory research approach. Moreover, five

(14.3%) studies reported follow-up data. The follow-up durations varied from 1-week to 14-months.

Statistics. Evaluation data of FHH-based programs were obtained via surveys, focus groups, qualitative interviews, questionnaires, and pedigrees. For the statistical analysis employed in the reviewed articles, nearly half of the articles (n=17; 47.2%) utilized inferential statistics with controlling for covariates, such as linear regression and mixed model analysis of variance. Thirteen studies (36.1%) used inferential statistics without controlling for covariates, including paired *t* test, chi-square, and Wilcoxon signed-rank test. The remaining articles used descriptive statistics (n=4; 11.1%) or a qualitative method (n=1; 2.9%).

Intervention Characteristics

Theory. Less than half of the articles (n=17, 48.6%) we reviewed reported that their interventions were based on health behavior theories. Among those articles, six studies specifically used the Health Belief Model,^{14,37,40,46,57} one study employed the Social Cognitive Theory,³³ one study adopted the Stages of Change Model,⁴⁸ one study utilized the Communal Coping Model,³⁸ and one study adopted the Protect Motivation Theory.⁴¹ The remaining seven articles^{9,15,36,44,49,58,61,62} developed their own conceptual models or utilized integrated theoretical frameworks based on health behavior theories such as the Health Belief Model, Social Cognitive Theory, Theory of Planned Behavior, or Social Marketing Principles.

Delivery. The characteristics of FHH-based interventions varied. Intervention delivery methods included: distributing printed education materials (n=2; 34.3%), such

as booklets, posters, brochures, or worksheets; offering face-to-face education and/or consultation (n=9; 25.7%); and utilizing web/computer-based interventions (n=6; 17.1%). Additionally, seven studies (20%) adopted more than one method to deliver interventions (e.g., a face-to-face workshop with an individual phone call consultation and face-to-face education with printed brochure reading). One article reported various FHH-based interventions across Connecticut using different intervention approaches (i.e., radio with handouts, educational materials, and health consultations) based on the needs of each community.

Content. The contents of interventions included basic information of FHH (n=10; 27.8%), the important of FHH to health (n=16; 44.4%), FHH communication with family members and health care providers (n=16; 44.4%), and the applications of FHH in health promotion and disease prevention (n=26; 72.2%). More than half of the studies (n=19; 54.3%) contained more than one of the above topics. Also, the majority of programs (n=29; 80.6%) integrated FHH education with a certain disease(s), including asthma, cancer, cardiovascular diseases, diabetes, thrombophilia, and sickle cell anemia. Furthermore, over half of the interventions (n=20, 55.6%) contained FHH collection and risk assessment tools. The most frequently used tools were the CDC's Family Healthware (n=9, 25.0%) and the U.S. Surgeon General's My Family Health History Portrait (n=5, 13.9%).

FHH Intervention Outcomes

FHH interventions in this systemic review measured various health outcomes. The main outcomes were categorized as health behavioral constructs that are listed by

the order of frequencies. Detailed findings were presented in Appendix A and outcomes with statistically significant findings were discussed below.

Health Behavior (n=23; 65.7%). Over half of the reviewed articles^{10,35-40,42,44-48,50-56,58,62,63} assessed participants' behavioral modifications in various aspects (i.e., FHH collection or communication with family members,^{10,36,37,39,40,44,46-48,50,53,55,62} FHH communication with healthcare providers,^{39,45,51,53,54,62} healthy diets adoption,^{40,48,50,52,56,58,63} physical activity level,^{38,40,48,50,52,56,58,63} and uptake of medical screenings and genetic tests^{42,50,58}, and engagement in healthcare matters, such as doctoral visits and communication with healthcare providers⁵⁰). Statistically significant results were presented as follows:

FHH collection or communication with family members (n=13; 37.1%). Among the thirteen articles, the outcome was measured by participants' self-reported behavior of either FHH discussion with family members (n=9)^{37,39,44,46,48,50,53,55,62} or FHH collection (n=4)^{10,36,40,47}. Five^{10,36,37,54,62} of the 13 studies indicated statistically significant findings (two were RCT studies). For example, in a RCT study aiming to promote family communication about cancer history, Bodurtha et al.³⁷ found that participants in the intervention group who received a 20-minute individual FHH education session demonstrated significant increase behaviors in cancer FHH communication with family members comparing with the control group that only received a general handout about cancer prevention.

Physical activity (n=8; 22.9%). Four studies^{38,52,56,58} (two were RCT) suggested significant increases in physical activity level after FHH-based interventions. Mudd-

Martin et al.⁵², for instance, revealed that participants exercised more after receiving 8 weekly, 2-hour sessions of a FHH-based healthy lifestyle intervention.

Healthy diets (n=7; 19.4%). Among seven papers^{40,48,50,52,56,58,63} assessing healthy diets as the intervention outcome, only two^{56,58} noticed a significant improvement of participant diets after FHH-based interventions, and these two studies adopted a RCT approach. For example, a RCT study carried out by Pijl and colleagues⁵⁶ demonstrated that their FHH-based diabetes risk assessment intervention significantly promoted healthier eating habits among individuals with a FHH of diabetes.

Medical screening (n=2; 5.6%). Only one article reported a significant change in participants' behavior of medical screening, but the direction was different from the proposed hypothesis. Specifically, at the 6-month follow-up of a RCT, a smaller percentage of participants in the intervention group which completed Family HealthwareTM and received personalized risk-tailored messages based on FHH underwent cholesterol screening than the control group which received an age- and gender-specific health message.⁵⁸

Intention (n=17; 48.6%). Nearly half of the articles in this systematic literature review examined participants' changes of intention in various domains. Those domains included FHH communication with family members,^{9,15,33,44,48,49,53,55,57,59,60} FHH communication with healthcare providers,^{9,15,33,35,43,45,49,53,55,59,60} healthy diets,^{33,34,41,46,48,55-57,60} physical activity,^{34,41,46,48,55-57,60} alcohol consumption,⁵⁷ tobacco use,⁶⁰ as well as medical tests⁵⁶ and physical checkups.⁶⁰ Statistically significant differences were indicated below:

Intention of FHH communication with family members (n=11; 31.4%). Only two^{44,57} of eleven^{9,15,33,44,48,49,53,55,57,59,60} studies evaluating FHH communication with family members showed statistically significant findings. For example, in a quasi-experimental study performed by Prichard and colleagues,⁵⁷ young adults receiving a FHH assessment with an “average risk” classification were more likely to communicate their risk of getting chronic diseases with family members, comparing with the control group participants who did not received FHH assessment intervention.

Intention of adopting healthy diets (n=9; 25.7%). Merely one of nine articles^{33,34,41,46,48,55-57,60} examining intentions of adopting healthy diets as outcomes reported a significant intervention effect. Particularly, after using a FHH educational workbook, Koehly et al.⁴⁶ found a significant increase in the likelihood of mothers with young children’s to eat more fruits, vegetables, and fibers.

Intention of reducing alcohol consumption (n=1; 2.9%). Only one study measured participants’ intention of alcohol intake and found that the FHH assessment significantly reduced young adults’ drinking behavior.⁵⁷

FHH Knowledge (n=9; 25.7%). Nine articles^{9,33,44,48,51,52,54,55,59} evaluated the changes of participants’ FHH knowledge due to FHH-based interventions and five found significant improvements. A national community-centered FHH project, for instance, found that significantly more participants reported knowing of FHH after using the “Does It Run In the Family?” toolkit, a set of two customizable booklets on health, genetics, as well as FHH collection and communication.⁵⁴

Perceived Susceptibility (n=9; 25.7%). Over one-fourth of reviewed articles examined participants' perceived risk of chronic diseases (e.g., cancer, diabetes, and cardiovascular disease). Nine research groups^{14,15,41,43,44,56,57,61,63} examined participants' perceived susceptibility of getting various chronic diseases, and four concluded that there were significant increases due to FHH interventions. For example, in the paper of Li and colleagues,¹⁵ Chinese Americans' perceptions of susceptibility in acquiring colorectal cancer were significantly increased after attending a culturally and linguistically appropriated FHH-based colorectal cancer prevention workshop.

Attitudes toward FHH (n=9; 25.7%). Nine reviewed studies^{9,15,44,49-51,53,54,59} examined the changes in participants' attitudes toward FHH, but only two showed that FHH interventions significantly lead to favorable attitudes among participants toward FHH. For example, in a FHH intervention implemented by Kelly et al.⁴⁴, after receiving a 20-minute face-to-face FHH pedigree education, undergraduate students exhibited more positive attitudes toward FHH collection.

Self-efficacy (n=8; 22.9%). One-fifth of reviewed papers measured participants' changes of self-efficacy in FHH communication with family members,^{9,15,51} FHH communication with healthcare providers,^{9,15,60} controlling over disease risks,^{33,56} healthy eating behaviors,⁴⁶ physical activity,⁴⁶ and medical screenings.¹⁵ Significant outcomes were only found in the following two aspects:

Self-efficacy in controlling over disease risks (n=2; 5.6%). Two articles^{33,56} acknowledged that their FHH-based interventions significantly enhanced participants' confidence in controlling over disease risks. For instance, a RCT paper with a sample of

individuals with FHH of diabetes suggested that the intervention group who received a FHH-based diabetes intervention perceived significantly more control over diabetes prevention than the control group with no intervention.⁵⁶

Self-efficacy in healthy diet (n=1; 2.8%). One study showed that mothers of young children were significantly more confident in eating healthy after reading the FHH educational workbook.⁴⁶

Disease Risk Worries (n=5; 14.3%). Five articles^{33,44,50,56,63} in this systematic review assessed participants' worries about developing diseases. Two studies reported statistically significant changes; yet, the findings were inconsistent. Particularly, in a RCT diabetes prevention study performed by Wijdenes et al.,⁶³ researchers found that individuals receiving familial risk information had less worry about getting diabetes than those receiving general diabetes prevention information. By contrast, Arar et al.³³ reported that participants' worries about developing complications related to FHH conditions and diseases statistically increased after attending FHH learning sessions.

MQS

The average MQS of the reviewed studies was 11.8 ± 2.4 , ranging from 7 to 17. As shown in Table 1, about half of the included articles (n=16; 45.7%) have a large sample size (≥ 300). The majority reported participants' age (85.7%), gender (91.4%), and ethnicity (85.7%). Slightly above half (n=18, 51.4%) of the interventions in the reviewed articles were not based on theory. Regarding the context, 45.7% (n=16) of the interventions included only one aspect (i.e., basic information of FHH, the importance of FHH to health, FHH communication, or the applications of FHH). Approximately half of

the studies (48.6%) adopted a pre/post design to evaluate the effectiveness of their FHH interventions and used inferential statistics controlling for covariates (e.g., linear regression and mixed linear analysis) (48.6%) for data analysis. Health outcome data associated with FHH interventions were self-reported in all (100.0%) studies. Moreover, the majority (85.7%) did not report post-intervention follow-up data.

Discussion

To the best of our knowledge, this study is the first to systematically review existing literature of FHH interventions for lay people. After a thorough and careful search, a total of 35 articles met our inclusion criteria in this systematic review. We found that there was an increase in the number of publications regarding FHH interventions over the past years. These studies also included diverse settings, a wide range of chronic diseases, and different ethnicity, age, and gender groups. It appears that researchers are more aware of the importance of FHH in the fields of public health and preventive medicine.

The mean MQS score for all included articles in this systematic review was 11.8, which was slightly above the theoretical mean MQS score (11.5). This finding suggested that the methodology of this body of literature is generally needed to be improved. For example, a RCT is more rigorous research method, but only six studies adopted a RCT design to examine the outcomes of FHH-based interventions. Adopting a RCT approach may enhance the quality of the reviewed studies. Furthermore, developing FHH interventions based on theory, including more FHH context in interventions, gathering

post-intervention follow-up data, and using inferential statistics controlling for covariates may address the limitations of this body of the literature.

Moreover, based on the MQS findings, it is worthy to notice that all studies we reviewed merely collected participants' self-reported data to evaluate the behavior outcomes associated with FHH-based interventions. Although self-reported data are common for social and behavioral research, and it is challenging to acquire objective data, future researchers may consider incorporating objective measurements in their evaluation plans. For example, with participants' permission, researchers may obtain medical charts/records to examine participants' behavior of medical screening uptake and FHH communication with healthcare providers. Collecting blood testing results, such as from lipid panel and diabetes blood tests, along with measuring blood pressure, body weight, and body mass index, and using physical activity trackers to monitor exercise levels may also enhance the validity of data and expand the health outcomes related to FHH-based interventions.

Our systematic review indicated that the majority of the included articles (n=23; 65.7%) assessed behavior outcomes associated with FHH-based interventions. Yet, FHH-based interventions only led to significantly positive behavioral changes in physical activity and healthy diets engagement as well as FHH collection and communication with family members. No statistically significant findings were found in other behavioral outcomes related to healthcare, including doctoral visits and FHH communication with healthcare providers. Moreover, there was an inconsistent finding in medical screening behavior. These findings might be due to the limited number of

articles assessing certain behavior outcomes. For example, participants' medical screening behavior was reported by only two articles in this review. Furthermore, compared with FHH communication with family members, communication with healthcare providers was a more complex behavior, which required participants to have a high level of trust with their provider and to know how to communicate effectively with physicians.^{33,54,62} Thus, along with behavior construct, intention and self-efficacy in FHH communication with healthcare providers in the reviewed studies were not significant, either. Future FHH interventions may need to address the healthcare provider trust issue and teach the strategies of effective communication with healthcare providers.

Of note, the majority of 35 articles (n=30) in the present review were conducted in the U.S. Among those articles, 9 papers targeted on Latinos (n=5), African Americans (n=3), and a mixed sample of Latinos and African Americans (n=1). Only one study exclusively served Chinese Americans. For the five papers carried out outside the U.S., three were from Australia,^{39,49,57} and two were from the Netherlands.^{56,63} These results suggested the paucity of research in the Asian populations. According to data from the United Nations, about 60% of the global population lives in Asian countries.⁶⁴ In the U.S., Asian is the fastest growing racial/ethnic minority.⁶⁵ Previous research also showed that Asians lacked FHH collection and perceived unique cultural barriers in the use of FHH.^{7,66} As such, more FHH-based interventions tailored for Asian populations are needed in the future.

Interestingly, 60% of the studies (n=21) we reviewed had more than 70% of female participants in their samples. Among those 21 papers, five intended to recruit

women exclusively because females were more likely to lead FHH communication with family members.^{46,67-69} The majority of other studies acknowledged predominantly female participants as their study limitation. Because men tend to be less aware of their own FHH and to be the blocker of FHH communication within a family,⁶⁷ it is important to recruit more male participants and focus on men's roles in FHH communication for future FHH-based interventions. Including a sufficient number of men in FHH interventions may not only lead participants to gather accurate and complete FHH but also promote men's awareness of FHH and use of FHH to adopt a better lifestyle.

There are three major limitations related to this systematic literature review. First, we tried our best to search for articles in multiple databases and adopt several search strategies. Yet, relevant articles that were not indexed in these databases might not be included in this review. Second, we only included articles written in English. Those papers written in languages other than English were excluded in this systematic review. Finally, because the study designs of the reviewed articles varied, we had to adopt evaluation criteria from past systematic literature literature²⁹⁻³² to develop our own MQS to be tailored to this body of the literature.

To the best of our knowledge, this is the first systematic review which identified and evaluated peer-reviewed articles regarding FHH-based interventions. The findings of this review address the advocacy of FHH from leading health agencies and add to this body of the literature by presenting a comprehensive picture of existing FHH-based interventions. We identified 35 articles in this review and merely six studies were RCT. While the majority of the included articles assessed various health outcomes,

significantly positive changes were only found in certain health behaviors, such as FHH communication with family members and engagements in physical activity and healthy diets. Furthermore, the MQS suggested that the methodological quality of this body of literature has space for improvement. Lastly, future FHH-based interventions may need to reach, recruit, and include more diverse samples, such as males, Asians, and the population outside the U.S.

CHAPTER III
ARE COLLEGE STUDENTS INTERESTED IN FAMILY HEALTH HISTORY
INTERVENTION? A NEEDS ASSESSMENT

Introduction

In the era of precision medicine, family health history (FHH) is the most cost-effective and powerful genomic tool¹⁹ and an essential foundation for personalized disease prevention.⁴ Specifically, reflecting the interactions of genes, behaviors, and environment, FHH is an important risk factor for many diseases.^{1,19} Individuals should first collect their FHH from three degree of relatives. Based on their FHH, healthcare providers and public health professionals can provide personalized medical and lifestyle recommendation to prevent diseases. A number of studies also suggested that FHH can motivate individuals to adopt healthy behavior, such as exercise, eating healthy, and undergoing medical screening.^{40,42,48,50,52,56,58}

As the incidence and prevalence of early-onset chronic diseases (e.g., cancer, diabetes, and obesity) are increasing among college students, it is important to educate college students to gather and learn about their FHH as well as modify lifestyles based on their FHH for three main reasons. First, many chronic conditions are preventive by adopting and maintaining healthy behavior. Yet, college students usually perceive they are healthy, ignore their potential health risks, and face barriers in the use of FHH.¹⁶ Second, approximately half of the college students in the United States fail to meet the Physical Activity Guidelines for Americans recommended levels of physical activity (at

least 150 minutes moderate-intensity or 75 minutes vigorous-intensity aerobic physical activity per week) and do not achieve the recommendation guidelines for dietary from the Dietary Guidelines for Americans.⁷⁰⁻⁷² Third, as most college students live away from home for the first time, they begin to have autonomy and responsibility for dietary choice, weight management, as well as physical activity engagements.^{70,73} It is critical to educate those young adults to learn their FHH and establish a healthy habit that can continue later in life.^{73,74}

To effectively educate this particular group, information should be first collected to understand college students' interests in receiving FHH education, and their preferred topics and desired learning methods. This is because that today's college students face many competing time demands, such as entertainments, academic and social activities, and multiple commitments.⁷⁵ Such needs assessment data are particular important because there are limited FHH interventions for college students.^{40,41,44,50,57} The purpose of this first study, to the best of our knowledge, seeks to answer the following questions: (1) Are college students' interested in receiving FHH education? (2) What kind of FHH topics would college students like to know? (3) What are their desired learning strategies for FHH education?

Methods

Survey instrument

This study is a part of a research project to assess college students' behavior of FHH collection and educational needs. A web-based survey was developed based on past literature.^{9,11,16,76-83} The draft of the survey was reviewed by a panel of experts to

ensure content validity. This panel included experts from statistics, health education, health behavior, health communication, and college health. The revised survey was tested through cognitive interviews with 9 college students and retrospective interviews with 8 additional college students. The survey was then pilot tested with 63 college students recruited from two undergraduate health courses. The survey was modified according to students' feedback, such as revising some questions for clarification and removing confusing items.

Data collection

The survey data were collected through Qualtrics, a web-based survey platform (<http://www.qualtrics.com>). Responses were anonymous and participation was voluntary. The eligibility participation criteria were undergraduate and graduate students (1) who were young adults with the ages of 18 and 35 years-old and (2) who were registered on two campuses of Texas A&M University – a large public research intensive university in the south of the U.S. Via the university bulk email service, 55,346 students received an initial recruitment email and three reminder emails with the survey link. At the end of the survey, all participants were linked to a separate survey which could not be traced back to the initial survey to enter their names and emails for incentives. The incentives were a drawing for \$50 electronic gift cards (40 winners). The first 100 participants who completed the survey each also received a \$5 electronic gift card. A total of 2,809 students filled out the survey with a response rate of 5.08%. Participants who missed the section of needs assessment and/or whose age were below 18 or over 35 years were excluded. Thus, the final sample consisted of 2,276 college

students. The study protocol was approved by Texas A&M University's Institutional Review Board.

Measures

Interest in FHH education. Adopted from a past study,⁸⁰ educational interest in FHH education was assessed by asking “how interested would you be in participating in an educational program for FHH in the future, which will assist you in collecting you FHH, understanding your risk level, and obtaining personalized disease prevention recommendations based on this risk?” [1= “not at all interested”; 5= “extremely interested”]. Only the participants who reported “interested,” “very interested,” or “extremely interested” were navigated to the questions regarding the desired topics and preferred educational strategies.

Desired topics in FHH education. Participants' desired contexts in FHH education were measured by asking them to choose five themes which were adopted from the past literature.⁸² We also provided an open-ended “other” option for participants to fill out their preferred topics. Participants could choose more than one theme as they wanted.

Preferred educational strategies. We asked participants to choose their preferred educational strategies from a list of eight teaching strategies (i.e., traditional lectures, discussions, simulated games, computer technologies, written materials, audiovisual sources, demonstration, role playing, and others). These strategies were based on a systematic review of effective teaching strategies and methods of delivery for health education.⁸⁴ Participants could choose more than one option.

FHH of major diseases. Participants were asked to report their FHH of 15 major diseases (e.g., cancer, dementia/Alzheimer, diabetes, and heart diseases) listed by the U.S. Surgeon General’s “My Family Health Portrait.”¹¹ If participants had any first degree of relatives with any of the above 15 major diseases, they were coded as having a FHH of major diseases.

Lifestyle. The survey included questions regarding fruits consumption (0 cup, 0.5 cup or less, 0.5 to 1 cup, 1 to 1.5 cups, 1.5 to 2 cups, 2 to 2.5 cups, 3 or more cups each day), vegetables consumption (0 cups, 0.5 cup or less, 0.5 to 1 cup, 1 to 1.5 cups, 1.5 to 2 cups, 2 to 2.5 cups, 3 or more cups each day), red meat intake per week (from 0 to 20 ounces), weekly processed meat intake (from 0 to 20 ounces), alcohol consumption (no or yes), current smoking status (no, yes, or smoked before but have now quit), physical activity (frequency of exercise per week multiply the average duration for each time).⁸⁵

Genetic/genetic-related course(s) at college. We asked participants if they had taken a course in genetics or genomics (no or yes) and had ever enrolled in a course containing genetics/genomics-related information in college (no or yes).⁸⁶

Sociodemographic characteristics. The survey measured participants’ age, gender, birthplace, race/ethnicity, religion, marital status.

Statistical analysis

Descriptive statistics were conducted to measure the frequencies of participant responses to each survey item. Data missingness analysis was conducted to assess the potential difference between participants who merely provided their demographic information and those who filled out the rest of the survey.⁸⁷ Non-significant differences

were found between these two groups of respondents. The bivariate correlations were conducted to examine the relationships between FHH education interest and continuous variables (i.e., age, fruits and vegetable consumption, intake of red and processed meat, as well as physical activity level) and binary variables (i.e., gender, birthplace, race/ethnicity, marital status, alcohol consumption, current smoking status, and whether or not having taken genetic/genetic-related courses in the college). Analysis of variance was conducted to test the relationship between FHH education interest and the categorical variable (i.e., religion). Only the statistically significant variables (i.e., age, gender, birthplace, race/ethnicity, marital status, fruit consumption, red meat intake, FHH of major diseases, and whether or not having taken a genetic-related course in the college) were then included in the multiple linear regression analysis. All statistical programming was completed with STATA Version 15.0 with $p < 0.05$ as a thread hold.

Results

Sample characteristics

Table 2 summarized the sociodemographic characteristics of the sample. Respondents were predominantly female (66.0%), Christians (64.3%), being born in the United States (78.9%), and had a mean age of 21.0 years ($SD = 3.4$, range: 18-35). Nearly half of the participants were self-identified as non-Hispanic White (45.5%). Less than one-fifth of the college students in our sample (15.6%) reported that they had taken any genetics or genomics course in college, while more participants (33.7%) had taken a course containing information on genetics or genomics.

Table 2 Demographic characteristics of college students (N = 2276)

Characteristics	(%)
Age	21.0 (3.4)
Mean (SD)	
Gender	
Male	34.0
Female	66.0
Birthplace	
Born outside of the U.S.	21.1
Born in the U.S.	78.9
Race and ethnicity	
Non-Hispanic White	45.5
Other	54.5
Marital status	
Married/living as married	6.1
Others	93.9
Religion	
Christian (including Catholic, Protestant and all other Christian denominations)	64.3
Unaffiliated/none	23.2
Other	12.5
Took a course in genetics or genomics in college	
No	84.4
Yes	15.6
Took a course containing genetics/genomics-related information in college	
No	66.3
Yes	33.7

Note: SD, standard deviation

Interest in receiving FHH education

We asked participating college students if they would be interested in receiving FHH education. Less than half of the participants (46.13%) expressed that they were “interested” (25.26%), “very interested” (13.44%), or “extremely interested” (7.43%). As shown in Table 3, the multiple regression revealed that older and female students as well as those with FHH of major diseases were more interested in receiving FHH

education ($\beta = 0.021, p < 0.01, \beta = 0.206, p < 0.001, \beta = 0.185, p < 0.05$, respectively).

Students who self-identified as racial/ethnic minorities also had more interests in FHH

education than non-Hispanic White students ($\beta = 0.105, p < 0.05$).

Table 3 Multiple linear regression analysis for college students' interest in receiving FHH education

Variable	β	SE	t	Sig.(p)
(Constant)		0.269	6.83	0.000
Age (in years)**	0.021	0.008	2.61	0.009
Gender (male/female)***	0.206	0.508	4.05	0.000
Birthplace (born outside of the U.S./born in the U.S.)	-0.114	0.065	-1.76	0.078
Race/ethnicity (non-Hispanic White/others)*	0.105	0.049	2.13	0.033
Marital status (married or living as married/others)	-0.059	0.109	-0.54	0.587
Took a course in genetics or genomics in college (no/yes)	0.030	0.078	0.39	0.697
Took a course containing genetics/genomics-related information in college (no/yes)	0.114	0.059	1.94	0.052
Fruit consumption	0.030	0.015	1.94	0.053
Red meat consumption	-0.003	0.004	-0.87	0.382
FHH of FDR (no or not sure/yes)*	0.185	0.062	3.00	0.003

Note: FHH, family health history

*** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$

For those students who were not interested in FHH education (53.87%) were asked to provide reasons. As shown in Figure 2, these reasons, listed by the frequency included: (1) FHH is not a priority (63.10%); (2) lack of interest (13.20%); (3) already know FHH (2.30%); (4) no access to FHH information from family members (1.00%); (5) privacy concerns (0.70%); (6) emotional consequences of knowing FHH (0.50%); (7)

perception that the family was healthy (0.40%); and (8) having already participated in something similar (0.09%).

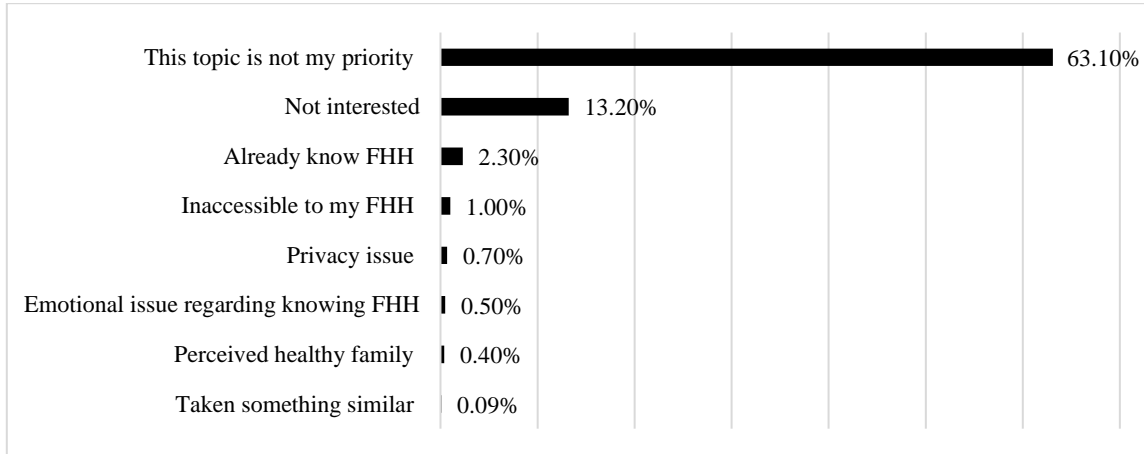


Figure 2 The reasons for not interesting in FHH education program

Desired topics regarding FHH education

For those participants who expressed interests in receiving FHH education, we asked their desired topics. According to Figure 3, the 5 most frequently mentioned themes were: (1) How can I interpret my FHH results (76.1%)? (2) How can I use my FHH to improve my health (72.0%)? (3) How can I collect my FHH (63.6%)? (4) Why is FHH important for my health (37.4%)? (5) What is FHH (30.5%)? Other topics mentioned by participants included: the costs of collecting FHH (0.29%), how to use FHH in family planning (0.19%), how to obtain hereditary information (0.09%), and how to handle the emotions associated with knowing FHH (0.09%).

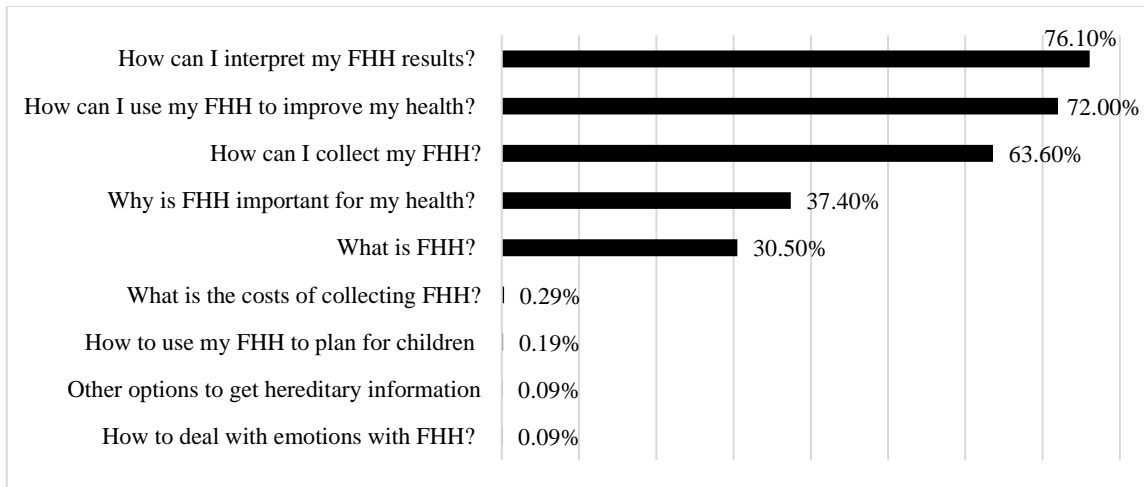


Figure 3 Preferred topics regarding FHH education

Preferred educational strategies

As presented in Figure 4, computer technology (e.g., computer-based education or computer-assisted learning) was reported as the most preferred strategy (51.1%) among participants who were interested in attending FHH education. Others desired educational method were demonstration (44.2%), traditional lectures (43.3%), discussions (42.3%), written materials (41.5%), simulated games (36.8%), audiovisual sources (36.1%), and role playing (14.8%).

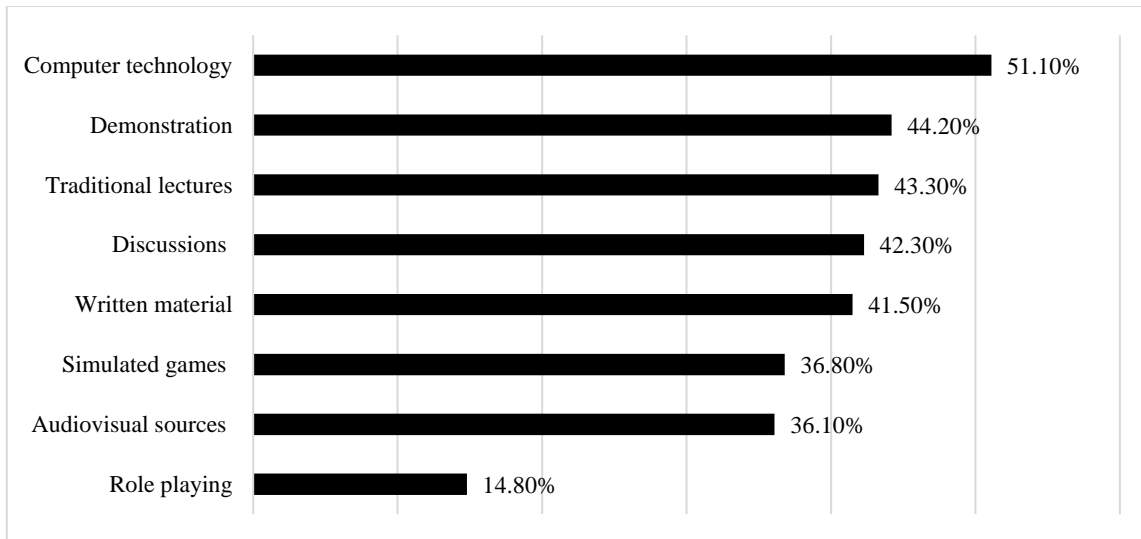


Figure 4 Preferred FHH educational strategies

Discussion

Results from the current study contribute to literature and practice by documenting young adults' educational needs toward FHH. To practice precision medicine, it is important to educate young adults about FHH. About half of participants in our study were interested in receiving information about FHH. The main reason mentioned by those who were not interested in FHH education was that learning FHH was not a priority for them. A previous study showed that college students, as a young and relatively healthy population, tend to be unrealistically optimistic about their health risks. As a consequence, this optimism bias undermined their self-protection motivation or interest in adopting precautions to reduce the risks.⁸⁸ Future health education in college settings should help these young adults to understand their actual health risks based on FHH.

Our findings showed that female, older, and racial/ethnic participants tended to be interested in FHH education. Previous literature reported that females and older people usually play active roles in collecting and communicating FHH with family members.^{16,67,89} Therefore, they are probably more motivated about receiving education about FHH. Past literature indicated the racial/ethnic minorities were less likely to collect their FHH.^{6,90} This may be because of limited knowledge of FHH and low self-efficacy in FHH collection and communication. Our findings suggested racial/ethnic minority participants were eager to learn more about FHH. However, among the limited number of FHH interventions in college settings, only a few were tailored for racial/ethnic minorities. To meet their needs and reduce racial/ethnic disparities in FHH, more FHH education for these group of students should be offered.⁹⁰

It is also worthwhile to note that college students who reported FHH in the FDR were more likely to be interested in FHH education. This finding is consistent with previous results from a community-based survey collected from adult participants, which found a significant association between FHH and engagement with general health education; this association was mediated by perceived threat.⁹¹ Knowing FHH information, especially the FHH of close family relations, increases the motivation to engage in health education activities. To increase the engagement and effectiveness of health education on campus, our findings support the need to incorporate FHH into future health education programs.

This study results also highlighted the preferred topics of FHH education among college students. Notably, how to interpret FHH results and how to use FHH to improve

health were the most desired topics among the participants in our sample. This findings indicated that comparing with basic knowledge of FHH, our participants were eager to learn more about the application and use of FHH in health promotion and disease prevention. In addition, they wanted to learn FHH collection methods. Future FHH education for college students should therefore emphasize the use of FHH and improve young adults' self-efficacy in FHH collection.

In addition to preferred topics, this study provides insights into college students' desired educational strategies for FHH intervention. Our results showed that most participants preferred computer-based technology as learning method. Such a finding is not a surprise. Comparing to other population, college students are very familiar with using computers. They may feel comfortable with an eHealth intervention. Meanwhile, previous literature has indicated the effectiveness of computer-based health education programs among college students.^{92,93} However, to the best of our knowledge, among the limited number of FHH intervention/education in college settings, none of them adopted computer-based technology. We suggested that future FHH education in college settings use computer-based technology to increase participant engagement.

Several limitations in this study should be noted. First, since this was a voluntary survey, it is possible that the study sample has a selection bias. The college students who completed the survey might be more aware of their FHH and be more interested in the topic of FHH. Second, this study only assessed FHH educational needs in the two campuses of a large university in the U.S. The results of this study may therefore not generalize to other college students. However, our study did included participants who

were diverse in age, race and ethnicity. We hope that we have captured a broad scope of perspectives, which would make the findings more applicable to a large population.

Third, we didn't ask participants' majors in the survey. Given that majors may also be a potential factors that influences college students' interest in FHH education, future study may need to include the major as a modifying factor. However, we asked the students if they have taken genetic/genomics or related courses before, which were not significant in the linear regression model.

Despite these limitations, to the best of our knowledge, this is the first needs assessment study to assess college students' interests along with their preferred topics and educational strategies. Our results showed that about half of college students were interested in FHH education. The application of FHH in health promotion and FHH collection methods are the most desired topics. Moreover, computer-based education was the most preferred educational strategy. The remaining students did not see FHH education as their current priority. This study serves as an initial window to assess college students' educational needs in FHH and contributes to the development and implementation of future's FHH education in college settings.

CHAPTER IV
FACTORS INFLUENCING FAMILY HEALTH HISTORY COLLECTION AMONG
COLLEGE STUDENTS: A STRUCTURAL EQUATION MODELING

Introduction

Capturing genetic, behavior and environmental factors of diseases which run in one's family, family health history (FHH) is a significant risk factor for many common and multifactorial health conditions.^{1,19} College is a critical time for young adults with age from 18 to 35 to seek their FHH information from family members for a number of reasons. First, the incidences of many chronic diseases are increasing. Some of the chronic diseases also have a trend of earlier onset (e.g., obesity, cancers, and type 2 diabetes).⁹⁴⁻⁹⁶ Given that chronic diseases are often related to FHH,⁹⁷ college students who are unaware of their FHH may not recognize health threats and take preventive actions. Second, college is a critical time for young adults to establish a lifestyle pattern in the future.⁷⁰ Knowing FHH may help college students to build-up healthy behaviors. Third, past literature shows that FHH can motivate individuals' to adopt healthy behavior. Thus, FHH information may encourage college students to exercise, eating healthy, and maintain appropriate weight.³ Fourth, college students are usually fast learners and early adopters of new knowledge.⁹⁸ In addition, college students ,as a young generation, are more likely to be openness in FHH communication.⁹⁹ Their FHH information seeking behavior may influence and engage other family members to discuss and collect FHH.⁹⁹ Lastly, with the increased genetic tests application in

precision medicine to help with disease prevention, diagnosis, and treatment¹⁰⁰, FHH information can help physicians to determine the needs of genetic tests for young adults.

Although it is important for college students to gather their FHH, only limited studies have assessed this behavior.^{16,76,77} In a quantitative study, Smith and colleagues reported that although female college students were more likely to seek FHH information and share it with family members, both genders perceived barriers in FHH collection.¹⁶ Another two studies investigated FHH information seeking intention among college students/young adults using the Theory of Motivated Information Management (TMIM). Both of these two studies supported the TMIM by demonstrating the role of uncertainty discrepancy of FHH and associated emotional factors in intention to seek FHH information from relatives.^{76,77} These findings demonstrated that FHH collection was a complex behavior which associated with multiple sociodemographic and psychological factors.

In the light of previous research, current study aims to map the college students' behavior of FHH collection by developing and examining an integrated theoretical framework. Thus, the purpose of this study is twofold. First, we seek to assess college students' behavior in FHH collection from family members. Second, we attempt to examine the psychological and sociodemographic factors influencing such behavior using an integrated theoretical framework.

Methods

Previous research findings have demonstrated that obtaining one's FHH was a complex behavior which associated with multiple sociodemographic and psychological

factors. It may be not enough to use unifying health behavior theory to predict this complex behavior. Thus, It is necessary to develop an integrated theoretical framework from multiple levels (e.g., interpersonal and intrapersonal; health behaviors and health communication). An integrated theoretical framework may offer a better and comprehensive understanding of the relationships among relevant variables and explain more of the variance in the behavior of FHH collection.¹⁰¹ Variables in the framework were adopted from the key health behavior and communication theories used in previous studies (i.e., the Health Belief Model, the Theory of Planned Behavior, and the TMIM).^{16,76,77,102} Sociodemographic characteristics, FHH conceptual knowledge, FHH issue importance, and whether taking a course in genetics in college were added in to the framework as moderator variables because those factors may also influence FHH collection behavior.^{16,67,86}

Participants and procedures

This study was approved by the Institutional Review Board at Texas A&M University. We used Qualtrics (<http://www.qualtrics.com>) to collect data. The eligibility participation criteria were: 1) undergraduate and graduate students registered on two campuses of a public research intensive university; and 2) between the ages of 18-35 years. Responses were anonymous and participation was voluntary. The first 100 participants who completed the survey each also received a \$5 electronic gift card. Additionally, all participants who completed the survey entered a drawing for \$50 electronic gift cards (40 winners). To protect participants' privacy, participants were linked to a separate survey which could not be traced back to the initial survey to enter

their names and emails for incentives. We utilized university bulk email service to send the initial recruitment email and three reminder emails with the survey link. A total of 2,809 students filled out the survey (response rate: 5.08%). The participants who completed only the sociodemographic information were excluded from the data analysis.

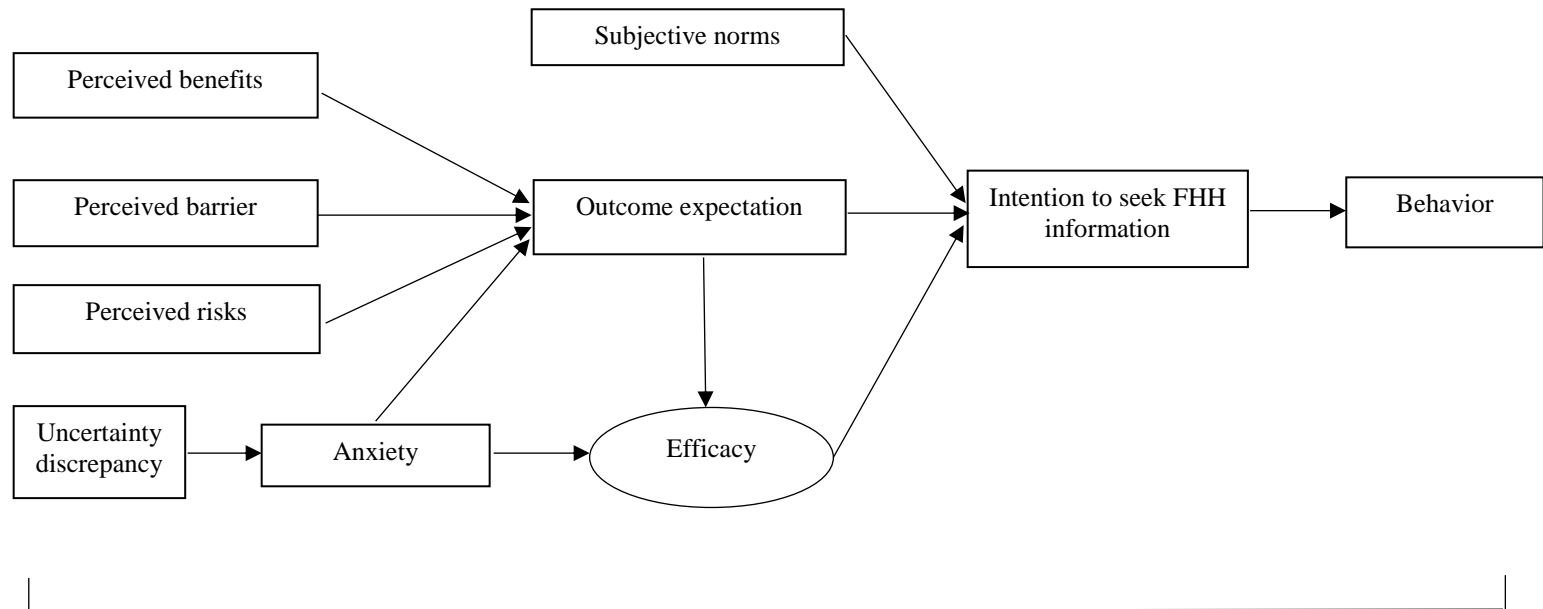
Instruments development

We developed a 15-minute anonymous web-based survey based on the aforementioned theoretical framework and previous literature.^{9,11,16,76-83} To ensure content validity, experts from multiple related fields, including statistics, health education, health communication, and college health reviewed the survey. Subsequently, cognitive interviews with 9 college students and retrospective interviews with additional 8 college students were conducted. The survey was then pilot tested with 63 college students recruited from two health courses via Qualtrics. Survey questions were revised based on feedback from experts, participants, and pilot test findings. The final version of the survey included 16 sections with 95 items and covered the following domains: (1) demographic information, (2) issue importance, (3) outcome expectancy, (4) efficacy, (5) knowledge, (6) FHH information seeking intention, (7) FHH information seeking behavior, (8) uncertainty discrepancy, (9) anxiety, (10) risk perception, (11) perceived benefits in FHH collection, (12) perceived barriers in FHH collection, and (13) subjective norms.

Variables and measures

As presented in Figure 5, conceptually, efficacy, outcome expectation, and subjective norms for FHH collection from family members were correlated with FHH

information seeking intention, which was directly associated with FHH collection behavior. Outcome expectation regarding FHH collection was associated with risk perception of developing diseases that run in one's family, perceived benefits of FHH collection, and perceived barriers of FHH collection. Moreover, efficacy was associated with outcome expectation and anxiety toward the unknowing of FHH, which was linked with uncertainty discrepancy toward FHH information. The definition, detailed measures, and corresponding psychometric testing results of reliability and validity of each psychological construct are described in Table 4. In addition, sociodemographic characteristics (e.g., age, gender, birthplace, race/ethnicity, religion, and marital status), FHH knowledge, FHH issue importance, as well as having taken genetic/genetic-related course(s) in college were measured in the survey and added in SEM model as moderator variables.



Covariates: Sociodemographic characteristics (i.e., age, gender, race, religion, birthplace, parents' household income, marital status, and taken a genetic course or not) and FHH knowledge

Figure 5 Proposed theoretical model of FHH information seeking behavior among college students

Table 4 Description, reliability, and validity of the main psychological constructs measured in the survey

Constructs	Definition	# of Items	Example Question	Mean	SD	Theoretical Range for Mean Score	Survey Data Mean Score Range	Cronbach's alpha	Validity	Interpretation
Perceived benefits	Perceptions of the health advantage of FHH collection	4	Knowing my FHH will help me prevent disease/health conditions that run in my family. <i>[1= Strongly agree; 7= Strongly disagree]</i>	5.500	1.077	1-7	1-7	0.730	$\chi^2 = 14.539$, $df = 1$, $p < 0.001$, RMSEA = 0.076, CFI = 0.994, SRMR = 0.016	Higher score = Perceived more benefits of FHH collection
Perceived barriers	Beliefs concerning the actual and imagined costs of FHH collection from family members	13	I don't know what questions to ask to obtain my FHH. <i>[1 = Strongly disagree; 7 = Strongly agree]</i>	2.718	1.118	1-7	1-7	0.869	$\chi^2 = 847.632$, $df = 55$, $p < 0.001$, RMSEA = 0.079, CFI = 0.935, SRMR = 0.056	Higher score = Perceived more barriers in FHH collection
Perceived risks of developing diseases that run on one's family	Beliefs about a likelihood and seriousness of developing a disease that runs in family	3	How likely is it that you will get diseases that run in your family? <i>[1 = I definitely will not develop the diseases; 7 = I definitely will develop the diseases]</i>	4.304	1.155	1-7	1-7	0.753	CFA result showed a saturated model due to the three items for this construct, and all three items were significantly related to the construct ($p < 0.001$)	Higher score = Perceived high risks of developing disease that run in one's family

Table 4 Continued

Constructs	Definition	# of Items	Example Question	Mean	SD	Theoretical Range for Mean Score	Survey Data Mean Score Range	Cronbach's alpha	Validity	Interpretation
Outcome expectation	The belief places on outcomes of FHH collection from family members	3	Asking my family members about my FHH would produce _____. [1 = A lot more negatives than positives; 7 = A lot more positives than negatives]	5.304	1.306	1-7	1-7	0.928	CFA result showed a saturated model due to the three items for this construct, and all three items were significantly related to the construct (p<0.001)	Higher score = Perceived more value on the outcomes of FHH collection
Uncertainty discrepancy	Awareness of a discrepancy between the amount of uncertainty desire about FHH information and the amount of uncertainty they currently have about FHH information	6	I know less than I would like to about my FHH [1 = Strongly disagree; 7 = Strongly agree]	4.204	1.300	-2.5-6.5 ^a	-2-6.5	0.778	$\chi^2 = 16.182$, $df = 1$, $p < 0.001$, $RMSEA = 0.080$, $CFI = 0.995$, $SRMR = 0.011$	Higher score = Perceived more discrepancy between current knowledge and desired knowledge of FHH
Anxiety	The level of anxiety associated with uncertainty discrepancy of FHH information	3	Not having as much information about my FHH as I would like makes me worried. [1 = Strongly disagree; 7 = Strongly agree]	3.493	1.635	1-7	1-7	0.934	CFA result showed a saturated model due to the three items for this construct, and all three items were significantly related to the construct (p<0.001)	Higher score = Perceived high level of anxiety associated with uncertainty discrepancy of FHH information

Table 4 Continued

Constructs	Definition	# of Items	Example Question	Mean	SD	Theoretical Range for Mean Score	Survey Data Mean Score Range	Cronbach's alpha	Validity	Interpretation
Target efficacy	Perceptions of the information target's (i.e., family members) ability to provide complete and accurate FHH information	4	My family members would tell me everything they know about our FHH. [1 = <i>Strongly disagree</i> ; 7 = <i>Strongly agree</i>]	5.245	1.240	1-7	1-7	0.836	$\chi^2 = 31.058$, $df = 1$, $p < 0.001$, RMSEA = 0.109, CFI = 0.993, SRMR = 0.012, and all four items were significantly related to the construct ($p < 0.001$)	Higher score = More confidence in information target's (i.e., family members) ability to provide complete and accurate FHH information
Coping efficacy	Ability to handle discovering that one's family members have certain health conditions	4	Imagine that some family members became upset with you for asking them about your FHH and called you 'nosy'. How well would you cope with this sort of reaction? [1 = <i>Could not cope</i> ; 7 = <i>Could cope perfectly well</i>]	4.506	1.199	1-7	1-7	0.771	$\chi^2 = 32.838$, $df = 2$, $p < 0.001$, RMSEA = 0.079, CFI = 0.988, SRMR = 0.020	Higher score = More confidence in handling issues during FHH collection
Subjective norms	Perception of what other people think about FHH collection	4	My family expects me to seek information about my FHH. [1 = <i>Strongly disagree</i> ; 7 = <i>Strongly agree</i>]	3.555	1.542	1-7	1-7	0.904	$\chi^2 = 3.832$, $df = 1$, $p = 0.050$, RMSEA = 0.035, CFI = 1.000, SRMR = 0.004	Higher score = Perceived more social pressure from other important people regarding FHH collection
Intention	Likelihood of collecting FHH from family members	6	I would directly approach my family to talk about it. [1 = <i>Strongly disagree</i> ; 7 = <i>Strongly agree</i>]	4.838	1.093	1-7	1-7	0.802	$\chi^2 = 3.207$, $df = 2$, $p = 0.201$, RMSEA = 0.016, CFI = 1.000, SRMR = 0.006	Higher score = higher likelihood of seeking FHH information from family members

Table 4 Continued

Constructs	Definition	# of Items	Example Question	Mean	SD	Theoretical Range for Mean Score	Survey Data Mean Score Range	Cronbach's alpha	Validity	Interpretation
Behavior	Frequency of FHH communication with family members in the past half-year	4	During the past half-year, I sought information directly about my FHH from my family members. [1 = <i>Never</i> ; 7 = <i>Always</i>]	2.962	1.676	1-7	1-7	0.873	$\chi^2 = 0.26$, $df = 1$, $p = 0.611$, $RMSEA = 0.000$, $CFI = 1.000$, $SRMR = 0.001$	Higher score = higher frequent action of FHH collection from member members in the past half-year

Note: The internal consistency and construct validity for each construct were examined using Cronbach's alpha and confirmatory factor analysis, respectively. Cronbach's alpha values larger than 0.70 indicated a good reliability for each construct. For construct validity, a root mean square error of approximation (RMSEA) less than 0.08; comparative fit index (CFI) larger than 0.95; and standardized Root Mean Residual (SRMR) less than 0.08 indicated a good model fit for each construct.

Data analysis strategies

Data cleaning, missingness⁸⁷, descriptive statistics, and psychometric testing of the survey instrument were conducted by STATA 15.¹⁰³ Data missingness analysis was conducted to examine any difference between respondents who only provided their demographic information and those who filled in the rest of the survey.⁸⁷ The bivariate correlations were then conducted to examine the relationships between main dependent variables of the psychological constructs (i.e., anxiety, outcome expectancy, efficacy, intention, and behavior) and covariates (i.e., social-demographic characteristics, issue importance, FHH knowledge, and having taken genetics/genomics related courses in college). Those with non-significant bivariate associations with the psychological constructs were excluded from the final SEM model.¹⁰² Mplus 8.0 was used to analyze the relationships among the constructs in the proposed theoretical framework.¹⁰⁴ As the Chi-square is sensitive to large sample size,¹⁰⁵ model fit was assessed based on three fit indices: the root mean square error of approximation (RMSEA), comparative fit index (CFI), and standardized root mean residual (SRMR). In this study, a RMSEA < 0.08, a CFI > 0.90, and a SRMR < 0.06, was adopted as the cut-point for an adequate model fit.¹⁰⁶

Results

Demographic characteristics

The final sample consisted of 2,670 college students. None significant differences were found between respondents who only filled out the demographic information and respondents who started the rest of the survey. A majority of the

participants were female (66.3%), with some religion beliefs (76.8%) and born in the United States (78.4%), with an average age of 21.0 years ($SD = 3.4$, range: 18-35). Approximately half of the participants self-identified as non-Hispanic White (44.9%). Nearly two thirds of the participants (64.3%) practicing Christian (including Catholic, Protestant, and all other Christian denominations). About one fourth (23.2%) were nonbelievers, and the remaining 12.5% practiced other religions, such as Hindu, Muslim, Buddhism, and Judaism. Only a small percentage of participants (15.0%) reported that they had taken a course in genetics or genomics in college, while a few more participants (32.7%) stated that they were enrolled in a course containing genetics or genomics-related information in college. The average score for the FHH knowledge scale was 3.5 ($SD = 1.3$, range: 0-6). Table 5 presents the percentage of correct answers for each FHH knowledge item. The high scale mean of 5.2 ($SD = 1.3$) for the construct of issue importance indicated that participants believed seeking FHH information from their family members were important.

Table 5 Conceptual knowledge of FHH among college students

Conceptual knowledge items	Correct (%)	Incorrect/don't know (%)
FHH tells you which diseases you will certainly develop. (False)	70.6%	29.4%
If you have a FHH of a disease, you are more likely to get the disease yourself. (True)	84.6%	15.4%
It is important to know how old your relatives were when they were diagnosed with cancer. (True)	77.2%	22.8%
You can only inherit breast cancer from your mother's side of the family. (False)	66.9%	33.1%
People are genetically more similar to their parents than to their brothers or sisters. (False)	25.9%	74.1%
In terms of FHH, my biological brothers and sisters are considered my second-degree relatives. (False)	21.8%	78.2%

Note: FHH, family health history

FHH collection behaviors

As summarized in Table 6, the majority of the participants had never or seldom collected FHH information from their family members. Specifically, during the past half-year, over half of the participants had never, rarely, or occasionally sought FHH information from family members (50.4%). Moreover, 50.8% of the participants had never, rarely, or occasionally sought FHH information from their first-degree relatives; a majority of the participants had never, rarely, or occasionally sought FHH information from their second-degree, or third-degree relatives (70.5% and 79.7%, respectively).

Table 6 FHH information seeking behavior among college students

<i>During the past half-year,</i>	Never			Sometimes			Always
	1	2	3	4	5	6	7
I sought information directly about my FHH from my family members	26.2%	12.5%	11.7%	10.6%	15.7%	11.8%	11.7%
I sought information directly about my FHH from my first degree relatives ^a	28.3%	11.8%	10.7%	10.9%	13.4%	12.3%	12.6%
I sought information directly about my FHH from my second-degree relatives ^b	46.0%	13.9%	10.6%	11.9%	7.0%	5.8%	4.9%
I sought information directly about my FHH from my third-degree relatives ^c	58.3%	14.1%	7.3%	8.0%	5.3%	3.7%	3.3%

Note: FHH, family health history

^a*First-degree relatives include: father, mother, sister(s), brother(s), and child(ren).*

^b*Second-degree relatives include: half-sibling(s), aunt(s), grandparents, niece(s), nephew(s), and grandchild(ren).*

^c*Third-degree relatives include: cousin(s), great-grandparent(s), and half-sibling's child(ren).*

SEM findings

As shown in Figure 6, the SEM model fit the survey data adequately based on the model fit indices (i.e., RMSEA = 0.072; CFI = 0.905; SRMR = 0.046). The overall model Chi-square was significant (χ^2 [df = 48] = 633.451, $p < 0.001$). Perceived barriers of FHH collection, uncertainty discrepancy, perceived risks of getting disease that run in one's family, and subjective norms were significantly and positively associated with anxiety ($\beta = 0.312$, $p < 0.001$; $\beta = 0.246$, $p < 0.001$; $\beta = 0.118$, $p < 0.001$; and $\beta = 0.115$, $p < 0.001$, respectively). Perceived benefits of FHH collection and subjective norms were significantly and positively associated with outcome expectation toward FHH collection ($\beta = 0.147$, $p < 0.001$ and $\beta = 0.018$, $p < 0.05$, respectively). However, perceived barriers and perceived risks were negatively associated with outcome expectation ($\beta = -0.244$, $p < 0.001$ and $\beta = -0.051$, $p < 0.005$, respectively). Outcome expectation and subjective norms were positively correlated with efficacy toward FHH collection ($\beta = 0.351$, $p < 0.001$ and $\beta = 0.210$, $p < 0.001$, respectively), while perceived barrier was negative associated with efficacy ($\beta = -0.387$, $p < 0.001$). Efficacy, anxiety, subjective norms, and outcome expectation were significantly and positively associated with the intention to collect FHH information ($\beta = 0.471$, $p < 0.001$; $\beta = 0.147$, $p < 0.001$; $\beta = 0.132$, $p < 0.001$; and $\beta = 0.074$, $p < 0.001$, respectively). Stronger intention and high level of subjective norms were correlated with participants' behavior of FHH collection ($\beta = 0.320$, $p < 0.001$ and $\beta = 0.272$, $p < 0.001$, respectively).

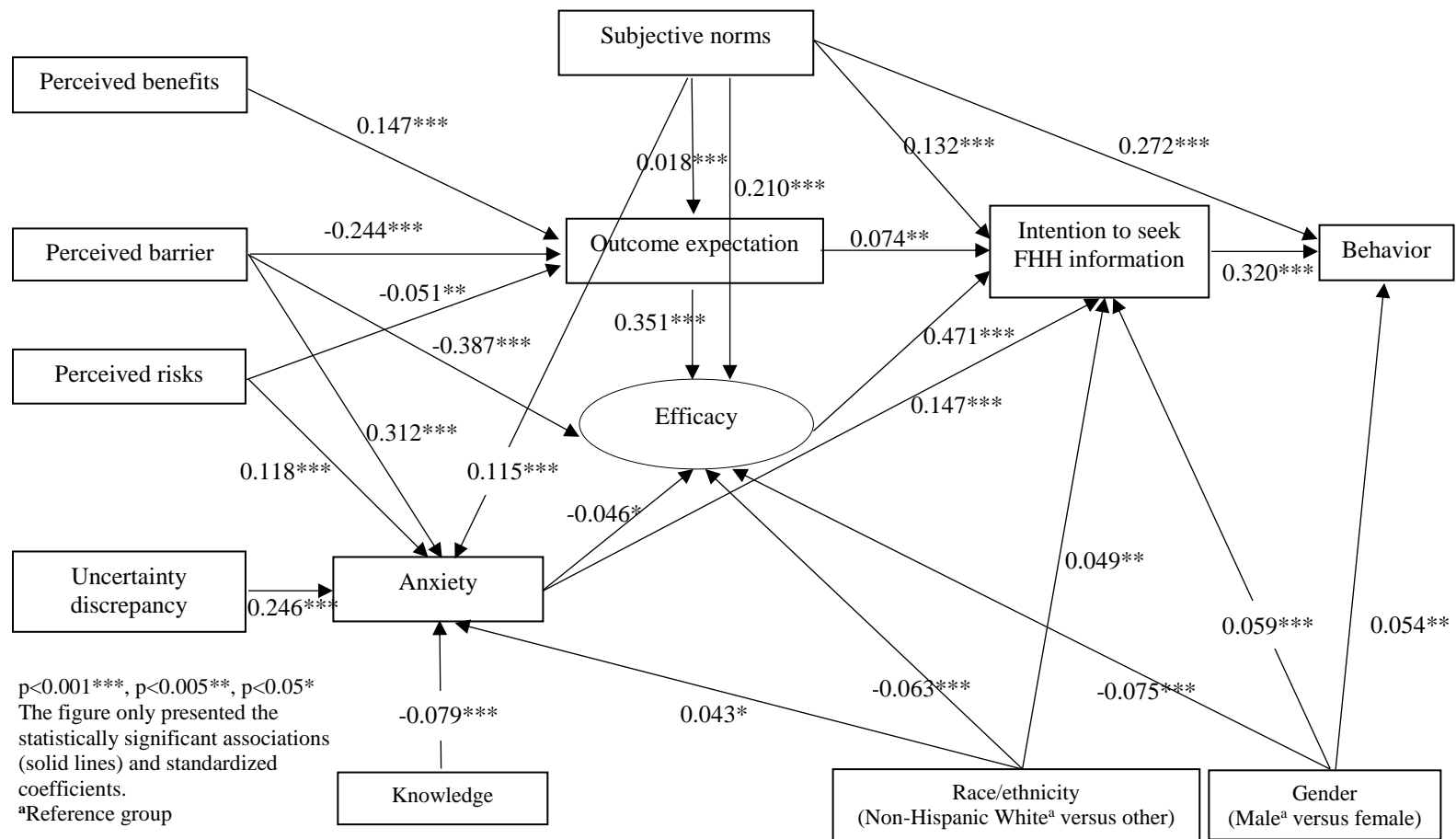


Figure 6 SEM model for FHH information seeking behavior among college students

In terms of the covariates, female participants were more likely to have collected their FHH from family members compared to male during the past half-year ($\beta = 0.054$, $p < 0.005$). Female and racial/ethnic minority college students reported stronger intention in FHH collection in the future ($\beta = 0.059$, $p < 0.005$ and $\beta = 0.049$, $p < 0.005$, respectively). Meanwhile, female and non-Hispanic White college students reported more confidence in FHH communication with family members ($\beta = -0.075$, $p < 0.001$ and $\beta = -0.063$, $p < 0.001$, respectively). In addition, racial/ethnic minority participants appeared to have higher level of anxiety associated with lacking FHH collection compared to their non-Hispanic White counterparts ($\beta = 0.043$, $p < 0.05$), while college students with better conceptual knowledge of FHH reported fewer forms of such anxiety ($\beta = -0.079$, $p < 0.001$).

Discussion

Our finding indicates that college students lacked of FHH collection from family members. Consistent with national survey data,⁶ majority of the college students in our study considered collecting FHH was important. However, fewer participants reported actively seeking FHH information from their family members. Specifically, near one third college students (28.3%) had never seek FHH information from their first-degree relatives. Moreover, a greater percentage of respondents reported that they had never seek FHH information from their second- (46.0%) or third-degree relatives (58.3%). In addition, our finding suggested that college students had a deficient knowledge of FHH. Only 21.8% of the respondents provided the correct answer for a knowledge item regarding FHH pedigree.

Our SEM findings suggested a good model fit between the proposed theoretical model and survey data. The constructs in the model explained 32.7% of the variance in our participants' behavior of FHH collection and 48.0% of the variance in their likelihood of seeking FHH information from family members in the future. College students behavior of FHH information collection was directly associated with their intention to seek FHH information and social pressures from people around them (i.e. subjective norms). Their intention was directly related to the efficacy in FHH communication with family members, outcome expectancy toward FHH collection, as well as subjective norms.

Our study findings suggested that a few covariates were indirectly associated with college students' behavior in FHH collection. Similar to past studies,^{9,16,67} female participants were more likely to gather FHH information and have higher level of efficacy in FHH communication with family members. Furthermore, racial/ethnic minority college students had higher level of anxiety and higher intention to obtain their FHH in the future. However, they had perceived lower confidence in FHH collection compared with non-Hispanic White counterparts. These findings indicated that more FHH education programs tailored for race/ethnicity minority aiming to improve FHH collection were needed in college setting.

It is worthy to note that the psychological construct of anxiety associated with uncertainty discrepancy of FHH information was not statistically significant with outcome expectancy. This could be that outcome expectancy were associated with other stronger variables (i.e., perceived benefits, perceived barrier, perceived risks and

subjective norms). Subsequently, the effect of anxiety toward uncertainty discrepancy on outcome expectancy was weakened. The SEM findings also suggested that intention of FHH collection was significantly and positively associated with anxiety. This findings suggested that a certain degree of anxiety may motivate college students to seek FHH information. However, anxiety was negatively related to efficacy and FHH conceptual knowledge. Therefore, future FHH education for college students should improve students' FHH conceptual knowledge to reduce anxiety associated with uncertainty discrepancy.

This study has limitations. First of all, as the nature of cross-section survey, we were unable to ascertain the causal relationships among each constructs. Second, the findings may have a limited generalizability because the participants were recruited from two campuses of a single university. Future efforts may aim to assess behavior of FHH collection among college students from a diverse sample. Third, we may have sample selection bias. The respondents of this survey may have more awareness and knowledge toward FHH than those who had not participated. Fourth, although we employed multiple strategies to increase response rate (e.g., providing post-incentives and sending three follow-up reminder emails),¹⁰⁷ the response rate of for this web-based survey was low (5.08%). The possible reasons for this low rate may be due to students not checking their university email account or ignoring messages sending from the university bulk email system.¹⁰⁸ However, it was not unexpected because the response rates for email or web-based survey are generally low in college settings, with a range from 2.07% to 31.54%.^{108,109}

Despite these limitations, this study contribute to develop and test an integrated theoretical framework to predict college students' behavior in FHH collection. The findings from our study indicated that college students lacked of FHH collection and had a deficient conceptual knowledge in FHH. The SEM findings supported our proposed theoretical framework overall. Psychological factors, such as intention, efficacy, outcome expectancy, subjective norms, anxiety, perceived benefits, perceived barriers, perceived risks, uncertainty discrepancy, knowledge of FHH, as well as demographics variables, were related to behavior of FHH collection among college students. More FHH intervention for college students are needed. The SEM findings can be utilized for the development of FHH education for college students in the future.

CHAPTER V

CONCLUSION

The overall purpose of this dissertation was to examine college students' behaviors regarding FHH collection and associated factors as well as to provide recommendations for future FHH education. Specifically, this dissertation has three purposes: (1) to identify, summarize, and evaluate existing FHH intervention for the general public; (2) to examine the behavior of FHH collection and associated factors using an integrated theoretical framework; and (3) to assess educational needs, preferred topics, and desired educational methods for FHH education among college students.

Chapter II (manuscript #1) presents the findings from peer-reviewed literature regarding FHH interventions for the lay public. A total of 35 articles were identified and evaluated. These interventions included diverse populations and settings. However, there is a need to improve the methodological quality of this body of literature. Developing FHH interventions based on theory, including more FHH context in interventions, adopting experimental study design, gathering post-intervention follow-up data, using inferential statistics controlling for covariates, acquiring objective data to evaluate the behavior outcomes may enhance the quality of reviewed studies. Although the majority of the included articles assessed various behavioral outcomes associated with FHH interventions, significant positive changes were only reported in certain domains. Future FHH interventions may need to address the healthcare provider trust issue and teach the strategies of effective communication FHH with healthcare providers.

The needs assessment study presented in Chapter III (manuscript #2) examined college students' interests, preferred topics, and desired delivery methods regarding FHH education. The findings of this need assessment study revealed that more than half of the sample was not interested in FHH education mainly due to low prioritization on learning more about FHH. Females, older students, and racial/ethnic participants with a FHH in major diseases showed greater interest in FHH education. The most desired topics mentioned by participants included the ability to interpret FHH information, the use of FHH applications in disease prevention, and FHH collection methods. Computer-based learning was the most preferred educational method. Strategies to promote college students' use of FHH are needed. Computer-based FHH intervention programs focusing on preferred topics identified in this study should be developed and implemented for college students.

The quantitative study presented in Chapter IV (manuscript #3) assessed college students' behavior in FHH collection. An integrated theoretical framework was developed to examine the factors influencing college students' collection of FHH from family members. A total of 2,670 college students completed a web-based survey. The findings from this study revealed that college students overall lacked FHH collection from their family members. The SEM findings suggested a good model fit between survey data and the proposed theoretical framework. Specifically, psychological factors (i.e., intention, efficacy, outcome expectation, subjective norms, anxiety, perceived benefits, perceived barriers, perceived risks, uncertainty discrepancy, and conceptual

knowledge of FHH) and certain demographic variables (i.e., gender and race/ethnicity) were related to the behavior of FHH collection among college students.

Several limitations of this dissertation should be noted. First, in the systematic literature review (Chapter II), even though multiple databases were searched, it is possible that some articles in other language and unpublished FHH interventions were overlooked. Second, regarding the survey study (Chapters III and IV), the findings may have a limited generalizability because the participants were recruited from a single university. Future efforts may aim to assess the behavior of FHH collection among college students from a diverse sample. Third, given this was a voluntary survey, it is possible that the study sample has a selection bias. The respondents of this survey may have more interests and knowledge skewed toward FHH than students who did not participate. Fourth, the response rate of this anonymous online survey was low.

However, it was not surprising because the response rates for email or web-based survey are generally low in college settings, with a range from 2.07% to 31.54%.¹⁰⁸⁻¹¹² This may be due to students not checking their university email account or ignoring messages sending from the university bulk email system.¹⁰⁸

Despite the stated limitations, the findings of this dissertation contribute to the current literature by evaluating FHH interventions and offer insights for future programs. The findings of this dissertation showed that college students generally lacked FHH collection. As such, more FHH interventions are needed for college students because they typically undergo a critical developmental period in which they should understand their potential health risks based on FHH. The SEM results showed that the integrated

theoretical framework was supported by the data obtained from 2,670 college students. Based on the framework, young adult behavior for FHH collection were influenced by multiple psychological constructs as well as sociodemographic factors. This framework, as well as the findings from the educational needs assessment study, will contribute to the development and implementation of FHH education programs for college students.

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APPENDIX A

CHARACTERISTICS AND MAIN OUTCOMES OF FHH INTERVENTIONS IN THE REVIEWED ARTICLES (N=35)

Authors (Location)	Sample characteristic	Targeted diseases	Study design	Theoretical basis	Delivery and content	FHH collection tool	Data analysis	Main evaluation findings (+*/+/-/-)
Arar et al. ³³ , 2013 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=75 • Age: Mean=48.1 (SD=13.3) • Gender: 79% female • Race/ethnicity: 55% non-Hispanic White 	<ul style="list-style-type: none"> • Chronic common diseases 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Social Learning Theory 	<ul style="list-style-type: none"> • Delivery: Face-to-face learning session (30mins) delivered by a trained certified health educator + online educational video + online FHH tool + printed brochure • Content: <ol style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication d. The applications of FHH into disease prevention and health promotion. 	<ul style="list-style-type: none"> • My Family Health Portrait 	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> +* Knowledge of FHH = Worries about developing chronic disease due to FHH +* Worries about developing chronic disease complications +* Self-efficacy in controlling over disease risks = Intention to FHH communication with family members = Intention to FHH communication with healthcare providers = Intention to have a healthy diet
Ashida et al. ³⁴ , 2012 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=475 from 161 families • Age: Mean=41.0 (SD=15.0) • Gender: 44.4% male • Race/ethnicity: 100% Mexican origin 	<ul style="list-style-type: none"> • Cancer • Diabetes • Heart disease 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	<ul style="list-style-type: none"> Not reported 	<ul style="list-style-type: none"> • Delivery: Mail participants printed materials • Content: <ol style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion. 	<ul style="list-style-type: none"> • Family Healthware 	Inferential statistics <i>with</i> controlling for covariates	<ul style="list-style-type: none"> + Intention to have a healthy diet + Intention to increase physical activity
Au et al. ³⁵ , 2010 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=88 • Age: Not reported • Gender: 100% female 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Diabetes • Heart disease 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	<ul style="list-style-type: none"> • CBPR approach 	<ul style="list-style-type: none"> • Delivery: Face-to-face education sessions delivered by Family History Working Group members • Content: 	<ul style="list-style-type: none"> • My Family Health Portrait 	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> + Intention to FHH communication with healthcare providers + Behavior of FHH communication with healthcare providers

	<ul style="list-style-type: none"> • Race/ethnicity: 84% white, 14% black 	<ul style="list-style-type: none"> • Ovarian cancer • Stroke 			<ul style="list-style-type: none"> a. The basic information of FHH b. FHH communicate c. The applications of FHH into disease prevention and health promotion 			
Beadles et al. ³⁶ , 2014 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=100 • Age: Mean=58.1 (SD =11.4) • Gender: 50% male • Race/ethnicity: 88% white, 9% black, 2% other 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Hereditary cancer syndromes • Ovarian cancer • Thrombophilia 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Genomic Medicine Model (Health Belief Model and Adult Learning Theory) 	<ul style="list-style-type: none"> • Delivery: Educational materials (a brochure + a booklet + a worksheet) • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication d. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> • MeTree 	Inferential statistics <i>without</i> controlling for covariates	+* Behavior of FHH collection
Bodurtha et al. ³⁷ , 2014 (United States)	<ul style="list-style-type: none"> • Clinical-based sample • N=490 • Age: Mean=33.4 (SD=11.9) • Gender: 100% female • Race/ethnicity: 59% Black, 33% White, 2% Other 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer 	<ul style="list-style-type: none"> • RCT • Follow-up data: Baseline, 1, 6, and 14 months follow-up assessment 	<ul style="list-style-type: none"> • Health Belief Model 	<ul style="list-style-type: none"> • Delivery: <ul style="list-style-type: none"> Intervention group: Individual 20-minute KinFact intervention delivered by study recruiters + booklet Control group: a handout promoting ways to lower breast and colon cancer risks, screening recommendations, and services contact information. • Content: <ul style="list-style-type: none"> a. FHH communication b. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> • CAGene v.5.1 	Inferential statistics <i>with</i> controlling for covariates	+* Behavior of FHH communication with family members
de Heer et al. ³⁸ , 2017 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=320 (parents) 	<ul style="list-style-type: none"> • Diabetes disease • Heart disease 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Communal Coping Model 	<ul style="list-style-type: none"> • Delivery: Mail participants printed materials 	<ul style="list-style-type: none"> • Family Healthware 	Inferential statistics <i>with</i> controlling for covariates	+* Behaviors of increasing encouragement and co-engagement in physical

	<ul style="list-style-type: none"> • Age: Mean=49.1 (SD=9.9) • Gender: 55% female and 45% male • Race/ethnicity: Mexican Americans 				<ul style="list-style-type: none"> • Content: a. The applications of FHH into disease prevention and health promotion 			activity among parents and children
Dunlop et al. ³⁹ , 2010 (Australia)	<ul style="list-style-type: none"> • Community-based sample • N=400 (pre-poll survey); 403 (post-poll survey) • Age: 59% >40 years (pre-poll survey); 58% >40 years (post-poll survey) • Gender: 51% female (pre-poll survey); 51% female (post-poll survey) • Race/ethnicity: Not reported 	Not reported	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Posters, websites promotion, a small pocket chart • Content: a. The importance of FHH b. FHH communication 	Not reported	Univariate statistics	+ Behavior of FHH communication with family members + Behavior of FHH communication with healthcare provider
Goergen et al. ¹⁰ , 2016 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=444 • Age: Mean=41 (SD=15) • Gender: 44.1% male • Race/ethnicity: 100% Mexican origin 	<ul style="list-style-type: none"> • Diabetes • Heart disease 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Mail participants printed materials • Content: a. The applications of FHH into disease prevention and health promotion 	• Family Healthware	Inferential statistics <i>with</i> controlling for covariates	+* Behavior of FHH collection
Holland et al. ⁴⁰ , 2014 (United States)	<ul style="list-style-type: none"> • College-based sample • N=20 • Age: 80% 18-19 years; 20% 20-24 years • Gender: 70% female • Race/ethnicity: 100% African Americans 	<ul style="list-style-type: none"> • Cardiovascular disease 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	• Health Belief Model	<ul style="list-style-type: none"> • Delivery: A curriculum consisted of six weekly 2-hour sessions delivered by researchers • Content: a. The applications of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>without</i> controlling for covariates	+ Behavior of FHH collection + Behavior of healthy diet + Behavior of increasing physical activity

Imes et al. ⁴¹ , 2016 ^b (United States)	<ul style="list-style-type: none"> • College-based sample • N=15 • Age: Mean=20.8 (SD=2.2) • Gender: 86.7% female • Race/ethnicity: 66.7% white 	• Cardiovascular disease	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	• Protect Motivation Theory	<ul style="list-style-type: none"> • Delivery: Two intervention sessions • Content: <ul style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion 	• Progeny Clinical	Inferential statistics <i>without</i> controlling for covariates	+* Perceived susceptibility + Intention in increasing physical activity + Intention in healthy diet
Johnson et al. ⁴² , 2005 (United States)	<ul style="list-style-type: none"> • High school and community mixed sample • N=151,188 families • Average age: Not reported • Gender: Not reported • Race/ethnicity: Not reported 	• Common chronic diseases	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Education were delivered by high school teacher. • Content: <ul style="list-style-type: none"> a. The importance of FHH b. The applications of FHH into disease prevention and health promotion 	• Health Family Tree Questionnaire	Univariate statistics	+ Behavior in healthy lifestyle behaviors (such as yearly medical exams and blood pressure checks)
Kaphingst et al. ⁹ , 2011 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=474 • Age: 29% 18-30 years; 51% 31-50 years; 17% >70 years • Gender: 66% female • Race/ethnicity: 97% Hispanic/Latino 	Not reported	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	• HINT conceptual framework	<ul style="list-style-type: none"> • Delivery: Intervention group: Educational session (1-hour) delivered by lay health advisors (LHA) Control group: A session wherein the lay health advisor read aloud a Spanish language brochure developed by the U.S. Surgeon Generals family history initiative entitled “Family History is Important for Your Health” • Content: <ul style="list-style-type: none"> a. The importance of FHH b. FHH communication 	• My Family Health Portrait	Inferential statistics <i>with</i> controlling for covariates	+ Self-efficacy in FHH communication with family members + Self-efficacy in FHH communication with healthcare providers + Intention to FHH communication with family members + Intention to FHH communication with healthcare providers Intervention group versus comparison group: +* Knowledge of FHH +* Attitude toward FHH +* Self-efficacy in FHH communication with family members +* Self-efficacy in FHH communication with healthcare providers

								+* Intention to FHH communication with family members = Intention to FHH communication with healthcare providers
Kelly et al. ⁴³ , 2008 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=166 • Age: Mean=44.6 (SD=13.9) • Gender: 75.3% female • Race/ethnicity: 71.2% white, non-Hispanic 	<ul style="list-style-type: none"> • Cancer 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Complete the CD-ROM version of the Jameslink and receive a print-out of risk assessment and recommendations about general diet and screening, and those at elevated risk received recommendations to seek genetic counseling. • Content: <ul style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> • CD-ROM version of the Jameslink 	Inferential statistics <i>with</i> controlling for covariates	+ Perceived susceptibility + Intention to FHH communication with healthcare provider
Kelly et al. ⁴⁴ , 2015 (United States)	<ul style="list-style-type: none"> • College-based sample • N=200 • Age: Mean=21.2 (SD=4.4) • Gender: 73.0% female • Race/ethnicity: 73.0% white, 12.8% Asian, 10.7% African American, 2.0% Native American 	<ul style="list-style-type: none"> • Cancer 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Dynamic Communication Model (Self-Regulation Model and McGuire's Input-output Model) 	<ul style="list-style-type: none"> • Delivery: Group educational sessions (1-1.5hr) delivered by researchers • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The applications of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>with</i> controlling for covariates	+* Knowledge of FHH = Disease worry = Perceived susceptibility +* Attitude toward FHH collection +* Intention to FHH communication with family members + Behavior of FHH communication with family members
Koehly et al. ⁴⁵ , 2011 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=475 • Age: Mean=41.0 (SD=15.0) • Gender: 44.4% male 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Diabetes • Heart disease 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Mail participants printed materials • Content: 	<ul style="list-style-type: none"> • Family Healthware 	Inferential statistics <i>with</i> controlling for covariates	+ Intention to FHH communication with healthcare providers + Behavior of FHH communication with healthcare providers

	<ul style="list-style-type: none"> • Race/ethnicity: 100% Mexican origin 				a. The applications of FHH into disease prevention and health promotion			
Koehly et al. ⁴⁶ , 2015 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=35 (phase 1); N=36 (phase 2) • Age: Mean=39.3 (phase 1); Mean=37.3 (phase 2) • Gender: 100% female • Race/ethnicity: 77.1% White (phase 1); 61.1% White (phase 2) 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Heart disease • Type 2 diabetes 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Health Belief Model 	<ul style="list-style-type: none"> • Delivery: Mailed Families SHARE workbook to participants • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. FHH communication c. The applications of FHH into disease prevention and health promotion 	Not reported	<ul style="list-style-type: none"> Inferential statistics <i>without</i> controlling for covariates 	<ul style="list-style-type: none"> + Behavior of FHH communication with family members + Assessed personal and family risks based on FHH +* Self-efficacy in increasing fruit, vegetable, and fiber consumptions +* Intention increasing fruit, vegetable, and fiber consumptions = Self-efficacy in increasing physical activity = Intention in increasing physical activity
Li et al. ¹⁵ , 2019 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=11 • Age: Mean=63.7 (range: 56.0 -75.0 years) • Gender: 60% female • Race/ethnicity: 100% Chinese Americans 	<ul style="list-style-type: none"> • Colorectal cancer 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	<ul style="list-style-type: none"> • An integrated theoretical framework (Health Belief Model, Social Cognitive Theory, and the Theory of Planned Behavior) • CBPR approach 	<ul style="list-style-type: none"> • Delivery: Face-to-face educational workshops (1 hour) delivered by researchers + personalized CRC prevention phone call consultation 2 months after the workshop • Content: <ul style="list-style-type: none"> a. The importance of FHH b. FHH communication c. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> • Colorectal Cancer Family Health History Questionnaire 	<ul style="list-style-type: none"> Inferential statistics <i>without</i> controlling for covariates 	<ul style="list-style-type: none"> +*Perceived susceptibility of getting CRC = Attitudes toward FHH communication with family members and physicians = Self-efficacy toward FHH communication with family members = Self-efficacy toward FHH communication with physicians = Intention regarding FHH communication with family members. = Intention regarding FHH communication with healthcare providers. = Self-efficacy in undergoing FOBT

								= Perceived barriers in FHH collection and communication, undergoing FOBT, and physician visits
Lin et al. ⁴⁷ , 2018 (United States)	<ul style="list-style-type: none"> Community-based sample N=353 (comprising 222 parents and 131 adult children) from 125 families Age: Mean=48.3 for parents; 22.3 for children Gender: 55% female for parents; 63% female for children Race/ethnicity: 100% Latinos 	<ul style="list-style-type: none"> Diabetes Heart disease 	<ul style="list-style-type: none"> Pre/post Follow-up data: Baseline, 3, and 10 months post-intervention assessment 	Not reported	<ul style="list-style-type: none"> Delivery: Mail participants printed materials Content: a. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> Family Healthware 	Inferential statistics <i>with</i> controlling for covariates	+Behavior in FHH agreement (Providing risk assessment without behavioral recommendations to the parent, but not the adult child, shifts the dyads toward agreement.)
Manswell et al. ⁴⁸ , 2012 (United States)	<ul style="list-style-type: none"> Community-based sample N=183 Age: 60% were 65 years and older Gender: 84% female Race/ethnicity: 97% African American 	Not reported	<ul style="list-style-type: none"> Pre/post Follow-up data: Baseline, immediately post-intervention assessment, 2 month follow-up assessment 	<ul style="list-style-type: none"> Stage of Change Model CBPR approach 	<ul style="list-style-type: none"> Delivery: Community-based workshop (45 min) delivered by facilitators + 1 minute FHH video + FHH booklet Content: a. The importance of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>without</i> controlling for covariates	+ Knowledge of FHH + Intention to FHH communication with family members + Intention to have healthy diet + Intention to increase physical activity. + Behavior of FHH collection from family members + Behavior of healthy diet + Behavior of increasing physical activity
Molster et al. ⁴⁹ , 2011 (Australia)	<ul style="list-style-type: none"> Community-based sample N=606 Age: 85% under 65 years 	Chronic diseases	<ul style="list-style-type: none"> Post only Follow-up data: Not reported 	<ul style="list-style-type: none"> Health Belief Model Behavioral Intentions Theory 	<ul style="list-style-type: none"> Delivery: Distribute a color print brochure with photos to illustrate key messages and a pedigree chart to record the FHH. 	Not reported	Inferential statistics <i>with</i> controlling for covariates	+ Attitude toward FHH + Intention to FHH communication with family members + Intention to FHH communication with healthcare providers

	<ul style="list-style-type: none"> • Gender: 100% female • Race: Not reported 			<ul style="list-style-type: none"> • Social Marketing Principles • Precede-proceed Model 	<ul style="list-style-type: none"> • Content: <ul style="list-style-type: none"> a. The importance of FHH b. The applications of FHH into disease prevention and health promotion 			
Moore et al. ⁵⁰ , 2012 (United States)	<ul style="list-style-type: none"> • College-based sample • N=29 students and 66 family members • Age: Not reported • Gender: 82.8% female • Race/ethnicity: Not reported 	Not reported	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Distribute a booklets “Does it run in the family booklets” • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication 	Not reported	Qualitative	<ul style="list-style-type: none"> + Behavior of FHH communication with family members + Behavior changes in diet + Behavior changes in physical activity + Behavior changes in doctor visits + Behavior in inquiring genetic testing + Self-efficacy in FHH communication with healthcare providers + Attitude of FHH - A sense of relief
Moore et al. ⁵¹ , 2015 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=30 • Age: Range: 55-94 years • Gender: Not reported • Race/ethnicity: 47% Caucasian, 43% Black, 3% Latino 	Not reported	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Distribute a booklets “Does It Run in the Family?” • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication 	Not reported	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> = Knowledge of FHH = Attitude toward FHH = Self-efficacy in FHH communication with family members + Behavior of FHH communication with healthcare providers
Mudd-Martin et al. ⁵² , 2013 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=22 • Age: Mean=44.5 years • Gender: 73% female • Race/ethnicity: 100% Latinos 	<ul style="list-style-type: none"> • Cardiovascular disease • Type 2 diabetes 	<ul style="list-style-type: none"> • Pre/post • Follow-up data: Not reported 	• CBPR approach	<ul style="list-style-type: none"> • Delivery: Face-to-face 8 weekly 2-hour learning sessions • Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication 	Not reported	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> +* Knowledge of FHH +* Behavior of increasing physical activity = Behavior of improving healthy diet = Spiritual growth +* Health responsibility +* Interpersonal relations +* Stress management + Weight control + Awareness of unhealthy eating habits

Murthy et al. ¹⁴ , 2011 (United States)	<ul style="list-style-type: none"> Community-based sample N=665 Age: 57.6% >50 years Gender: 84.4% female Race/ethnicity: 100% African American 	<ul style="list-style-type: none"> Breast cancer Colorectal cancer Prostate cancer 	<ul style="list-style-type: none"> Pre/post Follow-up data: Not reported 	Health Belief Model	<ul style="list-style-type: none"> Delivery: An interview session (30 min) delivered by genetic counseling students. Content: <ul style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>with</i> controlling for covariates	+ Perceived susceptibility
Newcomb et al. ⁵³ , 2014 (United States)	<ul style="list-style-type: none"> Community-based sample N=33 Age: 55% age between 40-60 years Gender: 76% female Race/ethnicity: 97% Caucasian 	Not reported	<ul style="list-style-type: none"> Post only Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> Delivery: <ul style="list-style-type: none"> Intervention group: Education training sessions delivered by faith community nurses + a fact sheet of My Family Health Portrait Control group: informational sheet regarding the My Family Health Portrait tool Content: <ul style="list-style-type: none"> a. The importance of FHH b. FHH communication c. The applications of FHH into disease prevention and health promotion 	My Family Health Portrait	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> Attitudes of FHH Behavior of FHH discussion with family members Behavior of FHH communication with healthcare providers Intention of FHH discussion with family members Intention of FHH communication with healthcare providers
O'Leary et al. ⁵⁴ , 2011 (United States)	<ul style="list-style-type: none"> Community-based sample N=304 Age: Not reported Gender: 75% female Race/ethnicity: Not reported 	Not reported	<ul style="list-style-type: none"> Pre/post Follow-up data: Not reported 	CBPR approach	<ul style="list-style-type: none"> Delivery: A set of two customized booklets "Does It Run in the Family?" Content: <ul style="list-style-type: none"> a. The basic information of FHH b. The importance of FHH c. FHH communication 	Not reported	Inferential statistics <i>without</i> controlling for covariates	<ul style="list-style-type: none"> +* Knowledge of FHH +* Attitude of FHH +* Behavior of FHH collection from family members = Behavior of FHH communication with healthcare provider

Petruccio et al. ⁵⁵ , 2008 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=76 African Americans and 40 Latinos • Age: 67.1% <50 years old (African Americans); 72.5% <50 years old (Latinos) • Gender: 71% female (African Americans) and 87.5% female (Latinos) 	<ul style="list-style-type: none"> • Asthma • Cancer • Diabetes • Heart disease • Sickle cell anemia 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	• CBPR approach	<ul style="list-style-type: none"> • Delivery: Distributed 16-page booklet, entitled “Understanding genetics and disease” • Content: <ul style="list-style-type: none"> a. The importance of FHH b. FHH communication 	Not reported	Univariate statistics	<ul style="list-style-type: none"> + Knowledge of FHH + Intention of FHH communication with family members + Intention of FHH communication with healthcare providers + Intention of having healthy diet + Intention of increasing physical activity + Behavior of FHH communication with family members
Pijl et al. ⁵⁶ , 2009 (Netherlands)	<ul style="list-style-type: none"> • Clinical-based sample • N=118 • Age: Mean=67.1 (SD=5.3) • Gender: 43% were men • Race/ethnicity: 100% Dutch Caucasian 	• Diabetes	<ul style="list-style-type: none"> • RCT • Follow-up data: Baseline, 1 week, 3 month follow-up assessment 	Not reported	<ul style="list-style-type: none"> • Delivery: Intervention group: A personal consultation with a researcher Control group: General risk factors of diabetes alone. • Content <ul style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>with</i> controlling for covariates	<ul style="list-style-type: none"> -* Perceived severity = Perceived susceptibility = Diabetes risk worry +* Self-efficacy in personal control over preventing disease risks = Intention to have healthy diet = Intention to increase physical activity = Intention to have medical tests +* Behavior of healthy diet +* Behavior of increasing physical activity
Prichard, et al. ⁵⁷ , 2015 (Australia)	<ul style="list-style-type: none"> • College-based sample • N=116 • Age: Mean=20.0 (SD=2.9) • Gender: Not reported • Race/ethnicity: Primarily Caucasian 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Cardiovascular disease • Diabetes 	<ul style="list-style-type: none"> • Quasi-experimental design • Follow-up data: Not reported 	• Health Belief Model	<ul style="list-style-type: none"> • Delivery: Intervention group: Complete an FHH assessment Control group: did not complete a FHH assessment • Content: 	Not reported	Inferential statistics <i>with</i> controlling for covariates	<ul style="list-style-type: none"> +* Perceived susceptibility +* Intention to FHH communication with family members = Intention to have healthy diet = Intention to increase physical activity

					a. The applications of FHH into disease prevention and health promotion			+* Intention to decrease alcohol consumption
Ruffin et al. ⁵⁸ , 2011 (United States)	<ul style="list-style-type: none"> • Clinical-based sample • N=3,344 • Age: Mean=50.6 (range: 35 – 65 years) • Gender: 70% female • Race/ethnicity: 91% White 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Coronary heart disease • Diabetes • Ovarian cancer • Stroke 	<ul style="list-style-type: none"> • RCT • Follow-up data: Not reported 	• Own conceptual model	<ul style="list-style-type: none"> • Delivery: Intervention group: Completed a web-based tool to assess familial risk for the diseases and received personalized risk-tailored messages. Control group: group received an age- and sex-specific health message related to lifestyle and screening. • Content: a. The applications of FHH into disease prevention and health promotion 	• Family Healthware	Inferential statistics <i>with</i> controlling for covariates	+* Behavior of healthy diet +* Behavior of increasing physical activity -* Behavior of receiving medical screening
Senier et al. ⁵⁹ , 2015 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=160 • Age: 18 or under: 11.6%; 19-49: 68.1%; 50+: 20.3% • Gender: 71% female • Ethnicity/race: Latino/Hispanic: 29.0%; Asian 40.6%; White: 19.5%; Black or African American 10.1% 	• Chronic diseases	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	Not reported	<ul style="list-style-type: none"> • Delivery: Community group #1: radio with handouts Community group #2: educational materials Community group #3: health consultations Community group #4: health consultations • Content: a. The importance of FHH b. FHH communication 	Not reported	Univariate statistics	+ Attitude toward FHH + Knowledge of FHH + Intention of FHH communication with family members + Intention of FHH communication with healthcare providers
Wallace et al. ⁶⁰ , 2009 (United States)	<ul style="list-style-type: none"> • Community-based sample • N=100 • Age: Not reported • Gender: 100% female 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Diabetes, stroke 	<ul style="list-style-type: none"> • Post only • Follow-up data: Not reported 	• CBPR approach	<ul style="list-style-type: none"> • Delivery: Two education learning sessions delivered by Family History Working Group members + a handout about how to 	• My Family Health Portrait	Inferential statistics <i>without</i> controlling for covariates	+ Self-efficacy in FHH communication with healthcare providers + Intention to FHH communication with family members

	<ul style="list-style-type: none"> • Race/ethnicity: 79% White 	<ul style="list-style-type: none"> • Heart disease • Ovarian cancer 			<p>speak with a healthcare provider about FHH</p> <ul style="list-style-type: none"> • Content: <ul style="list-style-type: none"> a. The importance of FHH b. FHH communication 			<ul style="list-style-type: none"> + Intention to FHH communication with healthcare provider + Intention to have healthy diet + Intention to increase physical activity + Intention to have a physical checkup + Intention to stop smoking
Wang et al. ⁶¹ , 2012 (United States)	<ul style="list-style-type: none"> • Clinical-based sample • N=3,786 • Age: 50.6 years (range: 35 – 65 years) • Gender: 70% female • Race/ethnicity: 91% White 	<ul style="list-style-type: none"> • Breast cancer • Coronary heart disease • Colorectal cancer • Diabetes • Ovarian cancer • Stroke 	<ul style="list-style-type: none"> • RCT • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Own conceptual model 	<ul style="list-style-type: none"> • Delivery: Intervention group: Completed a web-based tool to assess familial risk for the diseases and received personalized risk-tailored messages. Control group: Group received an age- and sex-specific health message related to lifestyle and screening. • Content: <ul style="list-style-type: none"> a. The applications of FHH into disease prevention and health promotion 	<ul style="list-style-type: none"> • Family Healthware 	<p>Inferential statistics <i>with</i> controlling for covariates</p>	<ul style="list-style-type: none"> +* Perceived susceptibility (Significant increased among those who underestimated risk for heart disease, stroke, diabetes, and colon cancer. But not for breast or ovarian cancer)
Wang et al. ⁶² , 2015 (United States)	<ul style="list-style-type: none"> • Clinical-based sample • N=3,344 • Age: 50.6 years (range: 35 – 65 years) • Gender: 70% female • Race/ethnicity: 91% White 	<ul style="list-style-type: none"> • Breast cancer • Colorectal cancer • Coronary heart disease • Diabetes • Ovarian cancer • Stroke 	<ul style="list-style-type: none"> • RCT • Follow-up data: Not reported 	<ul style="list-style-type: none"> • Own conceptual model 	<ul style="list-style-type: none"> • Delivery: Intervention group: Completed a web-based tool to assess familial risk for the diseases and received personalized risk-tailored messages. Control group: Received an age- and sex-specific health message related to lifestyle and screening. • Contents: 	<ul style="list-style-type: none"> • Family Healthware 	<p>Inferential statistics <i>with</i> controlling for covariates</p>	<ul style="list-style-type: none"> +* Behavior of FHH communication with family members = Behavior of FHH communication with healthcare provider

a. The applications of FHH into disease prevention and health promotion								
Wijdenes et al. ⁵³ , 2013 (Netherlands)	<ul style="list-style-type: none"> Community-based sample N=1,174 Age: <ul style="list-style-type: none"> With FHH Control group: 53.2 years Intervention group: 53.5 years Without FHH Control group: 53.5 years Intervention group: 53.4 years Gender: <ul style="list-style-type: none"> With FHH Control group: 54.2% female Intervention group: 55.2% female Without FHH Control group: 43.9% female Intervention group: 48.9% female Race/ethnicity <ul style="list-style-type: none"> With FHH Control group: 97.2% native Dutch origin Intervention group: 95.8% native Dutch origin Without FHH Control group: 97.8% native Dutch origin Intervention group: 98.5% native Dutch origin 	<ul style="list-style-type: none"> Diabetes 	<ul style="list-style-type: none"> RCT Follow-up data: Baseline, immediately post-intervention assessment, and 3-month follow up assessment 	Not reported	<ul style="list-style-type: none"> Delivery: Completed an evidence-based computer-tailored lifestyle modification tool advising on approaches to reduce saturated fat intake and improve physical activity. Control group: Received general tailored diabetes prevention information Content: a. The applications of FHH into disease prevention and health promotion 	Not reported	Inferential statistics <i>with</i> controlling for covariates	<ul style="list-style-type: none"> = Attitude toward testing for diabetes -* Disease risk worries = Perceived susceptibility = Behavior of increasing physical activity = Behavior of decreasing saturated fat intake

*Note: CBPR, community-based participatory research; FHH, family health history; RCT, randomized controlled trial
Statistically significant effects: +*, positive effect; =, not significant difference; -*, negative effect
Descriptive statistics: +, positive effect.*

^aIn the matrix, our coding of the study design, data analysis, and main evaluation findings may differ from those presented in the articles, as we only presented the results examining the effectiveness of FHH interventions on participants' health outcomes. In addition, we chose to only present the intervention content related to the topic of FHH.

APPENDIX B

FORMAL TEST INFORMATION SHEET

A Survey of Family Health History (FHH) Use Behavior among College Students

You are invited to take part in a research study being conducted by Dr. Lei-Shih Chen, a researcher from Texas A&M University and Ming Li, a Ph.D. candidate at Texas A&M University. The information in this form is provided to help you decide whether or not to take part in this study. If you decide that you do not want to participate, there will be no penalty to you, and you will not lose any benefits you normally would have.

Why am I being asked to take part in this research study?

You are invited to participate in this study because we are trying to learn more about college students' family health history (FHH) information seeking behavior.

You were selected as a possible participant in this study because you are college student registered at Texas A&M University. You must be 18 years of age or older to participate.

Why is this research being done?

The survey is designed to explore the factors that influence college students' family health history (FHH) information seeking behavior.

How long will the research last?

This one-time survey will take about 15 minutes to complete.

What happens if I say “Yes, I want to be in this research”?

If you decide to participate, please click the “Next” button at the bottom of this page, and you will be taken to the survey. Please follow the instructions to complete the survey.

The data collected in this survey includes factors influencing family health history (FHH) seeking behavior and educational needs toward future FHH interventions. Your personal lifestyle and FHH will also be asked. To protect your privacy, please take this survey in a private setting.

What happens if I do not want to be in this research?

Your participation in this study is voluntary. You can decide not to participate in this research, and it will not be held against you. You *can* leave the study at any time.

Is there any risk that could harm me in this study?

There are no sensitive questions in this survey that should cause discomfort. However, you can exit the survey at any point. Breach of confidentiality is a potential risk. As with all research, there is a chance that confidentiality could be compromised; however, we are taking precautions to minimize the risk.

What happens to the information collected for the research?

You may view the survey host's confidentiality policy at:
<https://www.qualtrics.com/terms-of-service/>.

Your email address will be stored separately from your survey data, and is only being collected for payment purposes. All information will be kept on a password protected computer and is only accessible by the research team. The results of the research study may be published but no one will be able to identify you.

What else do I need to know?

If you agree to take part in this research study, once you complete the survey and provide your email address at the end, you will be entered into a drawing for a \$50 gift card to a major retailer (40 participants). The winners will be informed via email. This is optional if you do not want to provide your email address.

Who can I talk to?

Please feel free to ask questions regarding this study. You may contact Ming Li if you have additional questions or concerns at 979-324-1089 or mingli0124@tamu.edu.

You may also contact the Human Research Protection Program at Texas A&M University (which is a group of people who review the research to protect your rights) by phone at 1-979-458-4067, toll free at 1-855-795-8636, or by email at irb@tamu.edu.

If you want a copy of this consent for your records, you can print it from the screen.

If you wish to participate, please click the “Next” button and you will be taken to the survey.

If you do not wish to participate in this study, please close your browser.

APPENDIX C

FORMAL TEST SURVEY INSTRUMENT

Section I Sociodemographic Characteristics

1. What is your age?

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 Years

2. What is your gender?
 Male
 Female
 Other gender identify (*Please specify: _____*)

3. Were you born in the United States?
 No (***CONTINUE TO QUESTION #4***)
 Yes (***GO TO QUESTION #5 BELOW***)

4. In what year did you come to live in the United States?

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 Year

5. Are you of Hispanic or Latino ethnicity?
 No
 Yes

6. Please mark the following box to indicate what you consider your race to be.
What race do you consider yourself?
 African American or Black
 Alaska Native or American Indian
 White or Caucasian
 Asian or Asian American
 Hawaiian or Pacific Islander
 Multiple Races
 Other: (*Please specify: _____*)

7. What is your marital status?
- Married
 - Living as married
 - Divorced
 - Widowed
 - Separated
 - Single, never been married
8. What is your religion?
- Christian (including Catholic, Protestant and all other Christian denominations)
 - Jewish
 - Muslim
 - Hindu
 - Buddhist
 - Unaffiliated/None
 - Other (please specify: _____)
9. Have you taken a course in genetics or genomics in college?
- No
 - Yes
10. Have you ever enrolled in a course containing genetics/genomics-related information in college?
- No
 - Yes

Section II Issue Importance

The following questions ask your opinion about the importance of family health history (FHH) collection. Select one number between 1 and 7.

11. It is important to me that I know my family health history (FHH).
- 1 2 3 4 5 6 7

Strongly disagree Strongly agree

12. It is important to me that I discuss FHH with my family.

1 2 3 4 5 6 7
Strongly disagree Strongly agree

13. The issue of FHH is important to me right now.

1 2 3 4 5 6 7
Strongly disagree Strongly agree

Section III Outcome Expectation

The following questions ask about your outcome expectation of family health history (FHH) collection. Select one number between 1 and 7 for the following questions.

14. Asking my family members about my FHH would produce_____.

1 2 3 4 5 6 7
A lot more negatives than positives A lot more positives than negatives

15. Talking to my family members about my FHH would produce_____.

1 2 3 4 5 6 7
A lot more negatives than positives A lot more positives than negatives

16. Approaching my family members with questions about my FHH would produce_____.

1 2 3 4 5 6 7
A lot more negatives than positives A lot more positives than negatives

Section IV Efficacy

Select one number between 1 and 7 for the following questions.

Communication Efficacy

17. I know what to ask my family members in order to get information about my FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

18. I can talk to my family members about my FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

19. I am confident that I can access all members of my family (including those who do not live near to me) to get information of my FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

Target Efficacy

20. My family would be completely honest about our FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

21. My family can provide me with information about our FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

22. My family members would tell me everything they know about our FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

23. My family has complete information about our FHH.

1	2	3	4	5	6	7
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Strongly
disagree

Strongly
agree

Coping Efficacy

24. Imagine that some family members became upset with you for asking them about your FHH and call you “nosy.” How well would you cope with this sort of reaction?

1	2	3	4	5	6	7
Could not cope						Could cope perfectly well

25. Imagine you discover that information about your FHH had been kept from you. How well would you cope with this information?

1	2	3	4	5	6	7
Could not cope						Could cope perfectly well

26. Imagine you find out you might be more at risk for some diseases than you thought. How well would you cope with this information?

1	2	3	4	5	6	7
Could not cope						Could cope perfectly well

27. Imagine you discover no one in your family really knows anything about your FHH. How well would you cope with this information?

1	2	3	4	5	6	7
Could not cope						Could cope perfectly well

36. I would ask my family directly.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

37. During the next half-year, I will seek information directly about my FHH from my first-degree relatives (i.e., father, mother, sister(s), brother(s) and children(ren)).

1	2	3	4	5	6	7
Never						Always

38. During the next half-year, I will seek information directly about my FHH from my second-degree relatives (i.e., half-sibling(s), aunt(s), grandparents, niece(s), nephew(s), and grandchildren).

1	2	3	4	5	6	7
Never						Always

39. During the next half-year, I will seek information directly about my FHH from my third-degree relatives (i.e., cousin(s), great-grandparent(s), and half-sibling's children).

1	2	3	4	5	6	7
Never						Always

Section VII FHH Seeking Behavior

Please select one number from 1 to 7 for the following questions.

40. During the past half-year, I sought information directly about my FHH from my family members.

1	2	3	4	5	6	7
Never						Always

41. During the past half-year, I sought information directly about my FHH from my first-degree relatives (i.e., father, mother, sister(s), brother(s) and child(ren)).

1	2	3	4	5	6	7
Never						Always

Strongly
disagree

Strongly
agree

49. I want to know more than I currently know about my FHH.

1
Strongly
disagree

2

3

4

5

6

7
Strongly
agree

Section IX Anxiety

Select one number between 1 and 7 for the following questions.

50. It makes me anxious to think about how little I know, compared to what I would like to know, about my FHH.

1
Strongly
disagree

2

3

4

5

6

7
Strongly
agree

51. Not having as much information about my FHH as I would like makes me worried.

1
Strongly
disagree

2

3

4

5

6

7
Strongly
agree

52. The gap between how much I know and how much I would like to know about my FHH makes me nervous.

1
Strongly
disagree

2

3

4

5

6

7
Strongly
agree

Section X Risk Perception

The following questions ask about your risk perception of developing diseases that run in your family. To answer these questions, select one number from 1 to 7.

53. How likely is it that you will develop diseases that run in your family?

1	2	3	4	5	6	7
I definitely will not develop the diseases						I definitely will develop the diseases

54. How vulnerable do you feel about getting the diseases that run in your family at some point in your lifetime?

1	2	3	4	5	6	7
Not at all						Extremely

55. If you were to develop diseases that run in your family, how serious would it be?

1	2	3	4	5	6	7
Not at all serious						Very serious

Part XI Perceived Benefits in FHH Collection

**The following questions ask about your perceived benefits from FHH collection.
Select one number between 1 to 7.**

56. Knowing my FHH will help me prevent diseases/health conditions that run in my family.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

57. Knowing my FHH will help me know my risk for diseases/health conditions that run in my family.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

58. Knowing my FHH is important when deciding to have children.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

59. Knowing my FHH is important if I become ill.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

Part XII Perceived Barriers in FHH Collection

The following questions ask about your obstacles preventing you from collecting FHH from your family members. Select one number between 1 to 7.

60. I don't know what questions to ask to obtain my FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

61. I don't think my family members know my FHH.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

62. I am not in contact with one or both of my biological parents.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

63. I don't live close to my family members with who I need to discuss my FHH with.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

64. Those with information about my FHH are deceased.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

65. The exact cause of death for one or more of my relatives is unknown.

1	2	3	4	5	6	7
Strongly disagree						Strongly agree

66. My biological parents would not be able to tell me about my FHH.

78. We are planning to develop a FHH education program for college students. If this education program is available for you to take, what **kind of information** do you want to learn about FHH? (*Select all that apply*)

- What is FHH?
- Why is FHH important for my health?
- How can I use my FHH to improve my health?
- How can I collect my FHH?
- How can I interpret my FHH results?
- Others (*please specify:* _____)

79. What kind of educational strategies would you prefer to receive? (*Select all that apply*).

- Traditional lectures
- Discussions
- Simulated games
- Computer technology (e.g., computer-based education or computer-assisted learning)
- Written material (e.g., flyer, brochures, or booklets)
- Audiovisual sources
- Demonstration
- Role playing
- Others (*please specify:* _____)

80. The reasons why you are not interested in FHH education program: (*Select all that apply*)

- Lack of time (WGS qualitative interview)
- This topic is not my priority (WGS qualitative interview)
- Not interested (WGS qualitative interview)
- Others (*please specify:* _____)

Section XV Lifestyle

81. How many cups of fruit (including 100% pure fruit juice) do you eat or drink *each day*?

- None
- 0.5 cup or less
- 0.5 cup to 1 cup
- 1 to 1.5 cups
- 1.5 to 2 cups
- 2 to 2.5 cups
- 3 or more cups

1 cup of fruit could be:	
1 small apple	1 large banana
1 large orange	8 large strawberries
1 medium pear	2 large plums
32 seedless grapes	1 cup (8 oz.) fruit juice
0.5 cup dried fruit	1 inch-thick wedge of watermelon

82. About how many cups of vegetables (including 100% pure vegetable juice) do you eat or drink *each day*?

- None
- 0.5 cup or less
- 0.5 cup to 1 cup
- 1 to 1.5 cups
- 1.5 to 2 cups
- 2 to 2.5 cups
- 3 or more cups

1 cup of vegetables could be:	
3 broccoli spears	1 cup cooked leafy greens
2 cups lettuce or raw greens	12 baby carrots
1 medium potato	1 large sweet potato
1 large ear of corn	1 large raw tomato
2 large celery sticks	1 cup of cooked beans

83. Do you smoke?

- No (GO TO QUESTION #85)
- Yes (GO TO QUESTION #84)
- I smoked before but have now quit (GO TO QUESTION #85)

84. How many cigarettes *a day* do you smoke?

85. How many days *per week* (on average) do you perform moderate aerobic exercise (e.g., brisk walking, swimming, cycling, and stair climbing)?

- None (GO TO QUESTION 87)
- 1 day per week
- 2 days per week
- 3 days per week
- 4 days per week

- 5 days per week
- 6 days per week
- 7 days per week

86. The average time for each day of moderate aerobic exercise is:

Minutes

87. In a typical week, outside of your job or work around the house, how many days do you do leisure-time physical activities specifically designed to strengthen your muscles such as lifting weights or circuit training (do not include cardio exercise such as walking, biking, or swimming)?

- None
- 1 day per week
- 2 days per week
- 3 days per week
- 4 days per week
- 5 days per week
- 6 days per week
- 7 days per week

88. What is your average weekly consumption of red meat (e.g. beef, pork, lamb, or mutton)? (Three ounces of meat is approximately the same size as the palm of your hand.)

palm(s) of your hand



89. What is your average weekly consumption of processed meat (e.g. sliced turkey, bologna deli meats, pork balls, fish balls, sausages, hot dogs, ham, bacon, etc.)? (Three ounces of meat is approximately the same size as the palm of your hand.)

palm(s) of your hand



90. In the last 30 days, did you drink alcohol?

- No (GO TO Section XVI)
- Yes (GO TO QUESTION 91)

91. In the last 30 days, how many days did you drink alcohol?

Day(s)

92. How many alcoholic drinks did you have on a typical day when you drank alcohol?

Drink(s)

One drink is half ounce of absolute alcohol, for example:

- 12 oz. can or glass of beer or cooler
- 5 oz. glass of wine
- A drink containing 1 shot of liquor

Section XVI Your FHH

93. Please select if any of your *first-degree relatives* (FDR) has experienced or is experiencing any of the following conditions: (first-degree family members include father, mother, sister(s), brother(s) and child(ren))

	No, my FDR hasn't experienced this condition	Yes, my FDR has experienced or is experiencing this condition	I don't know/Not sure
Cancer (e.g., Breast Cancer, Lung Cancer, and Leukemia)			
Clotting Disorders (e.g., Deep Vein Thrombosis, and Pulmonary Embolism)			
Dementia/Alzheimer			
Diabetes (e.g., Type 1 diabetes, Type 2 diabetes, Insulin Resistance, and Gestational Diabetes)			
Gastrointestinal (GI) Disorders (e.g., Colon Polyp, Crohn's Disease, Familial Adenomatous Polyposis (FAP), Lynch Syndrome/Hereditary Non-polyposis Colorectal Cancer (HNPCC), and Irritable Bowel Syndrome)			
Heart Disease (e.g., Angina, Coronary Artery Disease, and Heart Attack)			
High Cholesterol			
Hypertension/High Blood Pressure			
Kidney Disease (e.g., Cystic Kidney Disease, Diabetic Kidney Disease, and Nephritis)			
Lung Disease (e.g., Asthma, COPD, Chronic Bronchitis, Chronic Lower Respiratory Disease, and Influenza/Pneumonia)			
Osteoporosis/Bone Mineral Loss			
Psychological Disorder (e.g., Anxiety, Attention Deficit Disorder-Hyperactivity, Autism, Bipolar Disorder, Depression, Eating Disorder, Mental Disorder, Schizophrenia, and Post Traumatic Stress Disorder)			
Septicemia/Bloodstream infection			
Stroke/Brain Attack			
Sudden Infant Death Syndrome			

Other disease: (please specify) _____

94. Please select if any of your *second-degree relatives* (SDR) has experienced or is experiencing any of the following conditions: (second-degree family members include half-sibling(s), aunt(s), grandparents, niece(s), nephew(s), and grandchildren)

	No, my SDR hasn't experienced this condition	Yes, my SDR has experienced or is experiencing this condition	I don't know/Not sure
Cancer (e.g., Breast Cancer, Lung Cancer, and Leukemia)			
Clotting Disorders (e.g., Deep Vein Thrombosis, and Pulmonary Embolism)			
Dementia/Alzheimer			
Diabetes (e.g., Type 1 diabetes, Type 2 diabetes, Insulin Resistance, and Gestational Diabetes)			
Gastrointestinal (GI) Disorders (e.g., Colon Polyp, Crohn's Disease, Familial Adenomatous Polyposis (FAP), Lynch Syndrome/Hereditary Non-polyposis Colorectal Cancer (HNPCC), and Irritable Bowel Syndrome)			
Heart Disease (e.g., Angina, Coronary Artery Disease, and Heart Attack)			
High Cholesterol			
Hypertension/High Blood Pressure			
Kidney Disease (e.g., Cystic Kidney Disease, Diabetic Kidney Disease, and Nephritis)			
Lung Disease (e.g., Asthma, COPD, Chronic Bronchitis, Chronic Lower Respiratory Disease, and Influenza/Pneumonia)			
Osteoporosis/Bone Mineral Loss			
Psychological Disorder (e.g., Anxiety, Attention Deficit Disorder-Hyperactivity, Autism, Bipolar Disorder, Depression, Eating Disorder, Mental Disorder, Schizophrenia, and Post Traumatic Stress Disorder)			
Septicemia/Bloodstream Infection			
Stroke/Brain Attack			
Sudden Infant Death Syndrome			

Other disease: (please specify) _____

95. Please select if any of your *third-degree relatives* (TDR) has experienced or is experiencing any of the following conditions: (third-degree family members include cousin(s), great-grandparent(s), and half-sibling's children)

	No, my TDR hasn't experienced this condition	Yes, my TDR has experienced or is experiencing this condition	I don't know/Not sure
Cancer (e.g., Breast Cancer, Lung Cancer, and Leukemia)			
Clotting Disorders (e.g., Deep Vein Thrombosis, and Pulmonary Embolism)			
Dementia/Alzheimer			
Diabetes (e.g., Type 1 diabetes, Type 2 diabetes, Insulin Resistance, and Gestational Diabetes)			
Gastrointestinal (GI) Disorders (e.g., Colon Polyp, Crohn's Disease, Familial Adenomatous Polyposis (FAP), Lynch Syndrome/Hereditary Non-polyposis Colorectal Cancer (HNPCC), and Irritable Bowel Syndrome)			
Heart Disease (e.g., Angina, Coronary Artery Disease, and Heart Attack)			
High Cholesterol			
Hypertension/High Blood Pressure			
Kidney Disease (e.g., Cystic Kidney Disease, Diabetic Kidney Disease, and Nephritis)			
Lung Disease (e.g., Asthma, COPD, Chronic Bronchitis, Chronic Lower Respiratory Disease, and Influenza/Pneumonia)			
Osteoporosis/Bone Mineral Loss			
Psychological Disorder (e.g., Anxiety, Attention Deficit Disorder-Hyperactivity, Autism, Bipolar Disorder, Depression, Eating Disorder, Mental Disorder, Schizophrenia, and Post Traumatic Stress Disorder)			
Septicemia/Bloodstream Infection			
Stroke/Brain Attack			
Sudden Infant Death Syndrome			

Other disease: (please specify) _____

Thank you for filling out the survey!

Thank you so much for participating in this FHH research. Your feedback is important and valuable for this study. In thanks for your participation, we would like to invite you to join a drawing for a chance to win one of 40 Amazon e-gift cards valued at \$50. You will be redirected to a separate web link below where you can fill out your name and preferred e-mail address. As this will be done through a separate web link, there will be no way to trace your responses and your identity. Please note that we will need both your name and email address to process the payment. If you do not want to enter the drawing for \$50 Amazon e-gift card, you can just close the browser.

Please click the **'Next'** button below to enter your name and email address.

Please enter your name and preferred email address for entering the drawing. The winners will be informed via email.

1. Your name:

2. Email address:

Thank you very much for your participation in this important study. For further information regarding FHH and disease prevention, please refer to:

1. Family Health History
(<https://www.cdc.gov/genomics/famhistory/index.htm>)
2. About the Surgeon General's Family Health History Initiative
(<https://www.hhs.gov/programs/prevention-and-wellness/family-health-history/about-family-health-history/index.html>)
3. Why is It Important to Know My Family Medical History
(<https://ghr.nlm.nih.gov/primer/inheritance/familyhistory>)

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APPENDIX D

FORMAL TEST INVITATION EMAIL

Howdy,

I am a doctoral student in the Department of Health & Kinesiology at Texas A&M University. I am conducting my dissertation study to understand college students' views, knowledge, and use of family health history. I need your help! You are invited to participate in this study by filling out an online survey. Your participation is greatly appreciated. The findings of this study will be beneficial to all students of Texas A&M University.

WHO IS ELIGIBLE TO PARTICIPATE?

Undergraduate and graduate student at Texas A&M University, between the ages of 18–35 years.

WHAT TO DO:

Complete a one-time (about 15 minutes) anonymous survey online. The survey will be closed on November 15th, 2018.

INCENTIVES:

First 100 participants who complete the survey will each receive a \$5 Amazon gift card. All participants (including the first 100 participants) will be entered into a drawing for a \$50 Amazon gift card (40 winners).

HOW:

Please follow the link below to access the survey. You may copy the link and paste the link into your browser as well.

SURVEY LINK: https://tamucehd.qualtrics.com/jfe/form/SV_bdjiW17jXAZ8usB

CONTACT: If you have any questions about this study, please contact me by email mingli0124@tamu.edu. You may also contact my dissertation chair Dr. Lei-Shih Chen at [lacechen@tamu.edu](mailto:lancechen@tamu.edu).

IRB Number: IRB2017-0743M

Approval Date: 10/27/2017

Expiration Date: 10/27/2023

Thank you for your time and consideration!