

**HEALTH LOCUS OF CONTROL,
RISK PERCEPTION, AND HEALTH BEHAVIOR
IN
AFRICAN AMERICANS**

by

Vera Cherepakho

B.S. Biological Sciences, California Polytechnic State University

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This thesis was presented

by

Vera Cherepakho

It was defended on

March 31st, 2008

and approved by

Thesis Director: Stephen B. Thomas, PhD, Philip Hallen Professor of Community Health and Social Justice, Behavioral and Community Health Sciences, Graduate School of Public Health, University of Pittsburgh

Angela F. Ford, PhD, Associate Director, Center for Minority Health, Graduate School of Public Health, University of Pittsburgh

Elizabeth A. Gettig, MS, Associate Professor, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

Robin E. Grubs, PhD, CGC, Assistant Professor, Department of Human Genetics, Graduate School of Public Health, University of Pittsburgh

John W. Wilson, PhD, Assistant Professor, Department of Biostatistics, Graduate School of Public Health, University of Pittsburgh

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Vera Cherepakho, M.S.

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PURPOSE: The multidimensional health locus of control (MHLC) measures the degree to which an individual feels they are in control of their own health. In order to better tailor interventions to the psychosocial needs of Healthy Black Family Project (HBFP) participants, we explored relationships between MHLC, risk perception, and participation in health behaviors.

METHODS: Risk perception analysis was assessed in 87 participants using Fisher's exact tests to search for relationships between MHLC scores and risk perception accuracy for diabetes, cardiovascular disease, and cancer (breast, ovarian and colon). Health behavior was assessed in 68 participants. Outcome measures included physical activity level, information seeking behavior and enrollment in the Minority Research Recruitment Database. Change in physical activity was assessed using the Transtheoretical model. Wilson's model was used to assess changes in information seeking behavior. Fisher's exact tests were used to test for relationships among MHLC and the outcome measures.

RESULTS: Individuals at high risk for diabetes were more likely to underestimate their risk if they scored low on powerful others ($p= 0.011$). Individuals at moderate risk for cardiovascular

disease were more likely to overestimate their risk if they scored high on powerful others ($p=0.005$). Women at low risk for ovarian cancer were more likely to overestimate their risk if they were externals ($p= 0.04$). Overall, the majority of individuals maintained or increased their level of physical activity, and information seeking and enrolled in the database regardless of their health locus of control.

CONCLUSIONS: These findings highlight diabetes, cardiovascular disease, and ovarian cancer as areas in which participants would benefit from risk education tailored to their locus of control. Maximizing the role of community members, improving patient doctor communication, and the family health history initiative may be appropriate approaches to improve risk awareness. The pattern of behavior change observed in this study may be preliminary evidence that the HBFP is effective at promoting positive health behavior change in individuals regardless of their health locus of control.

PUBLIC HEALTH SIGNIFICANCE: Community health outreach programs can use MHLC to explore how to better tailor interventions to their target population. The HBFP may serve as a model for future health promotion efforts.

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1.0 INTRODUCTION

This research was conducted through the Center for Minority Health (CMH) at the Graduate School of Public Health at the University of Pittsburgh. The CMH was founded in 1994 and has been under the leadership of Dr. Stephen Thomas since 2000. The CMH is a leader in the national Healthy People 2010 Campaign to eliminate racial and ethnic health disparities by the year 2010. The CMH is focused on seven main areas of health disparities: cancer screening and management, cardiovascular disease, diabetes, HIV and AIDS, infant mortality, immunization, and mental health. The CMH runs the Healthy Black Family Project (HBFP), headquartered in the East Liberty neighborhood of Pittsburgh, Pennsylvania. The HBFP is a community-based outreach intervention project aimed at educating and empowering its members in order to decrease their risk for common diseases such as hypertension, and diabetes. The aim of the HBFP is to empower individuals to be in control of their health by providing them with avenues by which they can lead healthier lives. The HBFP has implemented programs to help individuals to increase their level of physical activity, increase their level of information seeking behavior, improve their nutrition, decrease stress level, decrease exposure to tobacco smoke and increase participation in the medical research.

In order to be most effective, a community based intervention must be tailored to the needs of the targeted community. This study set out to explore the psychosocial needs of HBFP participants, primarily their health locus of control. The Multidimensional Health Locus of Control (MHLC) scale is used to measure the degree to which an individual feels that their own actions determine their health, or conversely, to which degree external factors such as health

professionals, luck, chance and fate are in control of their health. A better understanding of health locus of control of the community population can facilitate the development of better tailored outreach efforts, and in turn maximize the success of the HBFP as an intervention. The following is a literature review to provide a basis for this research and includes information about racial and ethnic health disparities, the importance of accurate risk perception, and background on the multidimensional health locus of control and its applications. In addition, this review outlines the transtheoretical model of behavior change, Wilson's model of information seeking behavior, and how these models can be used as outcome measures to search for relationships between health locus of control and health behavior.

1.1 HEALTH DISPARITIES IN THE US

Recent advances in medical care have allowed for better prevention methods, earlier detection, and reduced morbidity and mortality from common chronic conditions such as hypertension, diabetes, cardiovascular disease (CVD), and cancer. Despite recent medical advances African Americans continue to carry a disproportionate burden of common chronic disease (Center for Disease Control and Prevention (CDC), 2005; Graham et al. 2006).

African Americans constitute 13.4% (40.2 million individuals) of the U.S. population (U.S. Department of Health and Human Services (UDHHS), 2007). In 1999, the average life expectancy for African Americans was 73.1 years, compared to a life expectancy of 77.8 years for Caucasians (CDC, 2003). In 2003, African Americans had the highest age- adjusted death rate for CVD, cancer, and diabetes (CDC, 2003). Obesity is a major risk factor for CVD, stroke, and diabetes. African Americans are more likely to be overweight or obese than Caucasian

individuals. In the US in the year 2000, 22% of African American children compared to 12% of Caucasian children, and 40% of African American adults compared to 29% of Caucasian adults were classified as overweight or obese. African American women are 1.7 times as likely as Caucasian women to be obese (CDC, 2006).

In 2002, African Americans had three times as many years of potential life lost, when compared to Caucasians for both stroke and diabetes (CDC, 2005). Hypertension is a major risk factor for heart disease, stroke, peripheral vascular disease, and end stage renal disease (CDC, 2005). Stroke is third most common leading cause of death for both African Americans and Caucasians. During 1999-2002, African Americans aged 20-74 had higher age adjusted rates of hypertension per 100,000 than Caucasian individuals (36.8 vs. 23.9 for males; 39.4 versus 23.3 for females) (CDC, 2005, Graham et al. 2006). African Americans are 1.5 times as likely to have hypertension as Caucasians (CDC, 2006). It is estimated that 40.5% of African Americans are living with hypertension; however, approximately 25% of African Americans remain undiagnosed (Graham et al. 2006). African Americans are 50% more likely experience a stroke, and African American males are 60% more likely to die from a stroke than their Caucasian counterparts. African American stroke survivors are more likely to become disabled and have lower quality of life (USDHHS, 2007). In 2004, African American males were 30% more likely to die from CVD than Caucasian individuals (CDC, 2006).

Diabetes increases the risk for cardiovascular disease, obesity, hypertension, and dyslipidemia. Individuals with diabetes are at risk for vision loss, kidney damage, and lower limb amputations (Graham et al. 2006). It is estimated that 18 million Americans have diabetes. The prevalence of diabetes in African Americans aged 20 and older is 11.4% (Graham et al 2006). They are 1.8 times as likely to have been diagnosed with diabetes and to have complications

from diabetes as their Caucasian counterparts. In 2002, African American men with diabetes were more than twice as likely to be started on dialysis, 1.8 times as likely to be hospitalized, and 2.2 times as likely to die from complications of diabetes as Caucasian men (USDHHS, 2007). Most notably, studies have shown that 44% of African Americans with diabetes remain undiagnosed (Graham et al. 2006).

The health disparities gap between African Americans and Caucasians in death rates from all cancers widened from 1975 until the early 1990s. Although, this gap has somewhat narrowed, it still remains bigger than it was prior to 1975 (Ward et al. 2004). Death rates from colorectal cancer, prostate cancer, and breast cancer are responsible for the majority of this disparity (Ward et al. 2004). Overall, an African American male is 1.4 times more likely to die from cancer and an African American female is 1.2 times more likely to die from cancer than their Caucasian counterparts (Ward et al. 2004). African American men are 1.4 times as likely to have lung and prostate cancer, 2.4 times as likely to die from prostate cancer, and twice as likely to have stomach cancer compared to Caucasian men (CDC, 2006).

Although, African American women are 10% less likely to be diagnosed with breast cancer, they are a staggering 36% more likely to die from it compared to Caucasian women (CDC, 2006). African American women are 2.3 times as likely to be diagnosed with stomach cancer, and 2.2 times as likely to die from stomach cancer as Caucasian women (CDC, 2006). It is estimated that 40% of the difference in survival between African American and Caucasian women with breast cancer is explained by the more advanced stage of disease at which African American women are diagnosed (Barroso et al. 2000).

There are multiple factors responsible for the health disparities experienced by the African American population. These factors are summarized in Figure 1 and include

socioeconomic status (education, employment and income), lifestyle behaviors (physical activity and diet), social environment (educational and economic opportunities, racial discrimination, and social support systems), access to health care (such as preventative screening services), and doctor patient communication (CDC, 2005; Matthews, 2002).

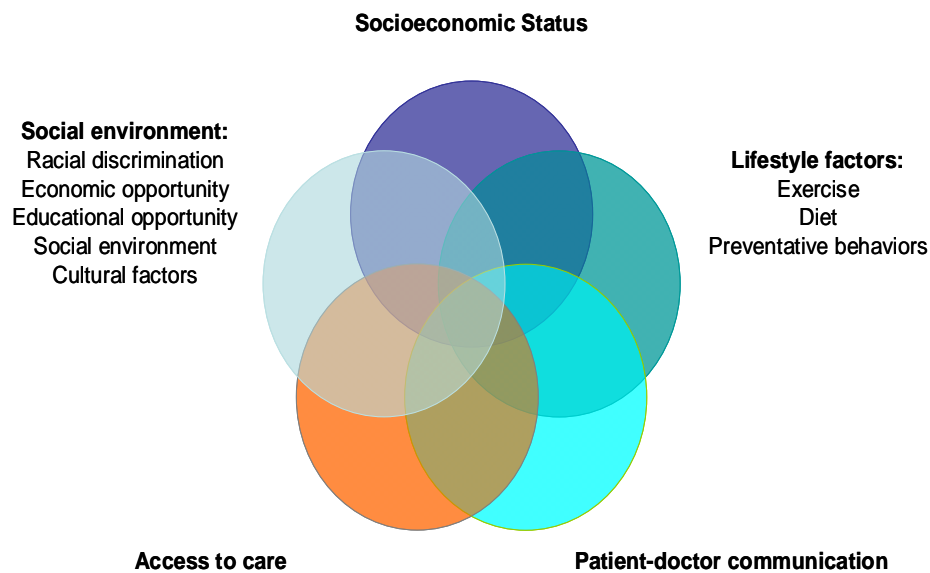


Figure 1. Causes of health disparities

Socioeconomic status (SES) has long been noted to be a cause of health disparities. Both income and wealth are significant predictors of the likelihood to develop a chronic condition; however, SES plays an even greater role in the functional ability of an individual once they have already been diagnosed with a chronic condition. Kington & Smith (1997) looked at the SES and racial and ethnic differences of a sample of 9744 men and women aged 51 to 61. The findings of

this study showed that SES did not play a large role in the prevalence of disease; however, SES played a significant role in the functional health status of individuals once they had been diagnosed with hypertension, diabetes, CVD, and arthritis. SES is associated with smoking, lack of physical activity, and poor diet, all of which are factors that may increase the complications of chronic disease (Kington, R.S. and Smith, J.P. 1997).

Lower SES is related to access to health care. Individuals who are of lower SES are less likely to get the necessary treatment, and are less likely to get treatment at earlier stages of the disease. Within SES, there may be structural barriers such as lack of health insurance, lack of financial support, geographical distance to treatment facilities, and access to transportation that prevent individuals from getting the care they need (Ward et al. 2004). According to Ashton et al. (2003) African Americans use health services at lower rates than Caucasians. Disparities in health care service use are in part caused by limited access to care. In general, when compared to Caucasians, African Americans have lower incomes, less education, lower rates of health insurance coverage, and greater dependence on public health care programs (Ashton et al. 2003). All of these factors interfere with readily available access to services.

Disparities in early detection of cancer are seen in the rate of uptake of recommended screening tests and likelihood to be diagnosed with cancer at a later stage (Ward et al. 2004). African American women are consistently less likely to have a mammogram, and colorectal screening when compared to Caucasian women. Sixty-eight percent of African American women reported having a mammogram within the last two years compared to 72% of Caucasian women. Approximately 15% of African American women have had a Fecal Occult Blood Test compared to 18.3% of Caucasian women. Similarly, 27% of African American women have had an endoscopy compared to 31.3 of Caucasian women (Ward et al. 2004). African American women are more likely to be diagnosed with late stage cancers and less likely

to survive the cancer, than Caucasian women despite the fact that the incidences of all cancers are higher in white women (Ward et al. 2004). The poorer survival rates have been attributed to access to cancer treatment rather than tumor characteristics. African American women with Stage I and II breast cancer were less likely to be treated with surgery than whites even if they have the same insurance and income level. African Americans with cervical cancer are more likely to go undiagnosed and receive no treatment. Caucasians are more likely to receive aggressive treatment for colorectal cancer (Ward et al. 2004).

In addition to SES, and limited access to care health disparities are due to problems with patient doctor communication (Ashton et al. 2003). Even though African Americans may have the same access to care, diagnosis, and level of illness severity; they are less likely to use services that require a doctor's order (e.g. invasive procedures, surgical procedures, and hospitalization). The significance of this finding is that some disparities are present not as a result of poor access to care, but rather as a result of the health care interaction that takes place after an individual gets to the doctor's office (Ashton et al. 2003). A previous study found the presence of a subconscious referral bias when doctors were presented with videotapes of 4 patients whose clinical characteristics were held constant, but gender and race varied. The study found that doctors are somewhat less likely to refer African American women for cardiac catheterization (Schulman et al. 1999).

Another hypothesis that supports that the health care interaction is a contributing factor to health disparities is the communication hypothesis. This hypothesis states that in order for an individual to make informed health care decisions there should be interactive dialogue present between the doctor and patient (Ashton et al. 2003). Such dialogue may be more problematic

when the doctor and patient are of different ethnic and cultural backgrounds. Ashton et al. (2003) hypothesizes that doctors tend to have poorer interpersonal skills with minority patients leading them to provide less information, and utilize a less participatory decision making style in their counseling. A 1988 meta-analysis of the influence of race and ethnicity on doctor-patient communication found that African Americans and Latinos receive poorer care during the physician visit than do Caucasians (Hall et al. 1988). African Americans rated their level of participation during physician visits to be lower than did Caucasian individuals (Kaplan et al. 1995). This research suggests that one step in eliminating health disparities is to improve patient-doctor communication, and facilitate higher levels of patient participation in discussions between minorities and their health professionals.

Lack of information seeking behavior is another factor that widens the health disparities gap. African Americans are less likely to participate in information seeking behaviors (Matthews et al. 2002). Health information seeking behavior involves searching for information about health conditions. Health information seeking behaviors include performing internet searches, reading about health information in books, brochures or magazines, and asking the doctor for more information about health conditions. Health information seeking is an important feature of making well-informed medical decisions. Studies show that individuals who are better informed regarding their illness are better able to maintain a sense of control and cope with the uncertainty of the illness and its treatments (Matthews et al. 2002). Well-informed patients are more likely to be compliant when it comes to following their treatment and management plan, and tend to recover from an illness more quickly and thoroughly than those who are poorly informed (Matthews et al. 2002).

Given the compelling evidence for health disparities in the African American population and the causes of these disparities, it is imperative that public health interventions be tailored to individuals to address these causes in order to close the health disparities gap. Exploring the health locus of control of African Americans can shed light on how to best tailor interventions to the psychosocial needs of the participant in order to encourage physical activity, facilitate information seeking behavior, improve risk perception, and build culturally sensitive communication between medical professionals and patients.

1.2 MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL

1.2.1 DEFINITION OF MHLC

The Multidimensional Health Locus of Control (MHLC) scale is designed to assess the degree to which an individual feels that their actions or other external factors out of their control are responsible for their health status (Figure 2). The MHLC has been used as a predictor of health behavior to explore how to best tailor interventions to target populations. The MHLC consists of three different subscales each of which assesses the three specific factors known to determine health behavior: internality, powerful others, and chance. Internality is the degree to which an individual feels they are in control of their own health or how their personal decisions and actions determine their health status. The Chance subscale is designed to assess the degree to which individuals feel that chance occurrences determine their health status. The Powerful

Others scale is designed to assess the degree to which an individual feels that health professionals, family members, religious figures, and friends influence their health status (Wallston, Wallston & DeVellis, 1978).

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL (MHLC)

Definition: Health locus of control is the degree to which an individual feels that their health is within their own control or within the control of external factors such as chance, luck, and other people.

- Externals: Individuals who feel that their health is the result of outside factors (i.e. health professionals, God, chance events).
- Internals: Individuals who feel that their health is the result of their own actions (i.e. diet, exercise).

Three Dimensions of Health Locus of Control:

- Internality scale: The degree to which an individual feels their health is the result of their actions.

“If I get sick it’s my own behavior that determines how soon I get well again.”

- Chance scale: The degree to which an individual feels their health is the result of fate, luck, and chance events.

“If it’s meant to be I will stay healthy.”

- Powerful others scale: The degree to which an individual feels their health is controlled by health professionals, religion, and family members.

“Whenever I don’t feel well, I should consult a medically trained health professional.”

Figure 2. Multidimensional Health Locus of Control

1.2.2 DEVELOPMENT OF MHLC

The theoretical framework of the MHLC is rooted in Rotter's Social Learning Theory and Rotter's Locus of Control Theory (Wallston, Wallston, DeVellis, 1978). In order to better understand the theoretical framework of the MHLC, it is important to review Rotter's Social Learning Theory and Rotter's Locus of Control Theory.

Rotter's Social Learning Theory

Rotter's Social Learning Theory (SLT) states that an individual's behavior is a function of their behavior potential, their expectations, and the reinforcement value of that behavior (Means, 2007). Behavior potential is the likelihood that an individual will perform a particular behavior in a given situation. For any situation there are a variety of behaviors an individual could engage in, and each behavior has its own specific potential or probability of occurrence. Expectancy is the degree to which an individual feels a particular behavior will lead to a particular outcome. In other words, how strongly does this individual believe that the behavior they engage in will lead to what they expect to happen? Reinforcement value is how much the individual desires a particular outcome. In other words, the reinforcement value is a direct measure of the benefit of the outcome for the individual. SLT is summarized by the following equation:

$$BP = f(E \times RV)$$

Where BP is behavior potential, E is expectancy and RV is reinforcement value.

For example, if an outcome has a low reinforcement value (something that the individual does not strongly desire to happen), and the individual has a low expectancy (they do not strongly expect that this behavior will lead to the desired outcome) the likelihood that this

individual chooses to engage in this behavior is low, or the behavior potential is low. Conversely, if an outcome has a high reinforcement value (something that the individual strongly desires to happen), and the individual has a high expectancy that this particular behavior really will lead to the desired outcome, then the likelihood that this individual chooses to engage in this behavior is high, or the behavior potential is high.

Rotter's Locus of Control Theory

Rotter defined locus of control (LOC) as people's general, cross situational beliefs about what determines whether or not they get reinforced in life (Means, 2007). Individuals with an internal locus of control believe that the outcome of a situation is within their own personal control more than it is in the control of external factors. Hence, an individual with an internal locus of control is more likely to have a higher expectancy that their particular behavior will lead to a particular outcome. Individuals with an external locus of control believe that external factors play a greater role in the outcome of a situation than internal factors such as their own decisions and actions. Therefore, individuals with an external locus of control are more likely to have a lower expectancy that their behavior will lead to a particular outcome. In other words, an individual's behavior outcome could be predicted based on their locus of control, since the degree to which an individual feels that they have control of a situation is related to their expectancy that a particular behavior will lead to a particular outcome.

Rotter believed that SLT could operate on two specific levels. The first level is situation specific. The second level is broader in context, in that an individual's behavior potential could be generalized across situations. Rotter stated that an individual's Locus of Control (LOC) operated on the latter, broader level, context and could be generalized across situations (Means, 2007).

An individual's locus of control (LOC) can be classified along a spectrum of internality and externality. In 1966, Rotter developed the I-E (Internality- Externality) Scale. The I-E scale is a cross-situational scale designed to assess internal vs. external locus of control orientation and has been used in multiple studies worldwide as a predictor of behavior (Means, 2007).

The Health Locus of Control Scale

By the 1970s, Rotter's I-E Scale became widely used as a predictor of behavior in medicine. The Health Locus of Control Scale was developed in 1976 by Kenneth Wallston and Barbara Wallston in order to increase the predictability of LOC in health related situations (Wallston, 1992). It was based on Rotter's belief that health behaviors were closely intertwined with an individual's personal experience in a given situation and that an individual's health locus of control beliefs are not as stable as an individual's generalized LOC beliefs (Wallston, Wallston, Kaplan, & Maides, 1976). Wallston felt that Rotter's I-E scale might not have been the most appropriate measure of LOC since it was designed as a generalized expectancy construct. The HLC was designed to assess internality and externality in a health situation specific manner. The HLC construct differs from the LOC construct in that the LOC construct is thought to be a stable personality trait generalized across various situations, whereas the HLC construct is a situation and experience dependent state that can change for an individual with new experiences and in new situations (Wallston, Wallston, Kaplan, & Maides, 1976).

The original HLC scale was an 11 item Likert scale of five internally worded, and six externally worded items. It was scored such that high scores represented an external belief that one's health status was due to fate, luck, and chance and low scores represented an internal orientation in which one stays or becomes healthy or sick as a result of his or her behavior. Wallston and Wallston showed that the one-dimensional HLC scale in conjunction with a

measure of health value (a measure of how important health status is to an individual) was a better predictor of health related behaviors and outcomes, than the generalized Rotter's I-E scale (Wallston, Wallston et al. 1976; Wallston, Maides, and Wallston 1976; Wallston, 1992).

Multidimensional Health Locus of Control

In 1978, Wallston developed the Multidimensional Health Locus of Control in response to his own findings with the HLC scale consisting of two dimensions, and Levenson's findings which showed that studying internality, fate and chance, and powerful others separately could further improve the scales as predictors of health outcomes (Wallston, Wallston, and De Vellis 1978). Since its development, the MHLC has been widely used in numerous studies and overall validity is dependent on the subscale being utilized, the theoretical context in which it is used, and the statistical analysis conducted to evaluate the data. The MHLC scale is an effective measure that addresses the multidimensional nature of human behavior and has the potential to provide researchers with valuable insights for designing health programs to tailor to these different dimensions, and in turn maximize the impact of such programs (Wallston, 1976; Wallston, 2005).

Since its development, the MHLC has been evaluated in numerous studies of health behavior. Earlier studies conducted in the late 1970s and 1980s showed contradictory results of the MHLC as a predictor of health behavior. Some studies supported that the MHLC was a valuable predictor of health behavior while others did not. Since the 1970s and 1980s the MHLC scales have been assessed in a great diversity of studies. There is now a more substantial body of evidence that the MHLC subscales are a useful predictor of health behavior when studied in those populations who place a high value on their health. For the purposes of the current study

this review will focus on some large scale general health behavior studies as well as the disease specific studies relevant to our analysis.

MHLC and Health Behavior

Norman et al. (1998) performed a large scale analysis of MHLC, health value, and likelihood to participate in health behaviors in 11,632 individuals from the UK. Individuals scoring high on the internality scale were more likely to participate in a higher number of health behaviors. Those who believed that chance and fate played a large role in their health status were less likely to engage in preventative health behaviors. A strong belief in powerful others was found to be related to performance of fewer health behaviors reflecting the belief in the ability of the medical professional to cure illness and protect health.

Bronson et al. (1981) as cited in Wallston & Wallston (1982) found that those individuals scoring high on the internality scale were higher on measures of health behavior, knowledge about health problems, and health plans than low scorers. Fischberg (1979) found a non-statistically significant correlation that internal women were more likely to practice self breast exams than external women. Dishman et al. (1980) showed that internal individuals were more likely to stay in a physical activity program than persons who were external. Grady (1981) as cited in Wallston & Wallston (1982) found that women who agreed to participate in her breast self examination study had higher powerful others and internality scores than those who refused to participate, possibly supporting that those who believe that health can be controlled by powerful others are more likely to participate in health education programs. Kaplan and Cowles (1978) found that internals reduced their cigarette consumption and were more likely to maintain the reduction than externals.

MHLC and Information Seeking

Wallston, Allston, and Maides (1976) found that among college students asked to pretend they had been diagnosed with hypertension, internals were more willing to read a greater volume of hypertension brochures than externals. Toner and Manuck (1979) surveyed individuals undergoing blood pressure screening. After having undergone the screening subjects were allowed to choose from 23 hypertension pamphlets. Internals chose significantly more pamphlets than externals. Sproles (1977) found that among renal dialysis patients, internals were better informed about their condition, were interested in learning more information, and were more willing to attend patient education classes than externals. DeVellis et al. (1980) conducted a nationwide survey of individuals with epilepsy and found that the best single predictor of information seeking behavior was a high powerful others score. Hashimoto and Fukuhara (2004) surveyed 3395 Japanese individuals and found that those who scored low on the powerful others scale were more likely to be active information seekers. The contradictory results of these two studies may be attributed to cultural differences, study population differences, and temporal differences. Hashimoto and Fukuhara (2004) studied a non patient population whereas DeVellis et al. (1980) studied patients with epilepsy. Individuals who have a clinical diagnosis of epilepsy may have different information needs than the general population. Cultural differences between Japanese and Americans may influence information seeking behavior. Lastly, the contradictory results of these two studies may be due to temporal differences. Personal access to health information resources was quite limited in the early 1980s when compared to the 21st century, as this was before the advent of the internet.

MHLC and Adherence to Management Recommendations

Levin and Schulz (1980) found that renal dialysis patients were more likely to follow the recommended diet if they scored high on internality. Goldstein (1980) found that diabetics were more likely to adhere to management recommendations if they scored high on internality and powerful others scales. Hatz (1978) found that high powerful others renal dialysis patients were less likely to gain weight between treatments. Marci (1980) found that high powerful others individuals had a smaller time delay in the time between experiencing chest pain and contacting a health professional.

MHLC and Disease Specific Studies

Burish et al. (1984) concluded that following relaxation training and/or biofeedback, chemotherapy patients with a high external health locus of control experienced less distress and anxiety, lower pulse rates, lower blood pressure, and were less depressed after treatment, suggesting that an external health locus of control may be advantageous in situations where little personal control is possible.

Soler-Vila, Kasl, and Jones (2003) studied psychosocial factors as predictors of breast cancer prognosis in African American and white women and found that MHLC was unrelated to survival prognosis. Nemcek (1989) found that women who strongly believed that health professionals controlled their health were less likely to adhere to recommended guidelines for breast self examination.

Barroso et al. (2000) compared breast cancer beliefs of Caucasian and African American women. African American women were more likely to believe in chance and to depend on powerful others. Perceived susceptibility to cancer, doubts about the value of early diagnosis, and beliefs about the severity of the diagnosis were all significantly related to high powerful

others scores in African American women. African American high powerful others scorers believed that early diagnosis lead to longer time to worry about illness, and that all women could be cured. African American women who scored high on the chance scale were more likely to believe that all women diagnosed with breast cancer will die. Barroso et al. (2000) concluded that African American women were more likely to be external in their health beliefs due to stronger religious beliefs.

Sturmer et al. (2006) performed a prospective cohort analysis of MHLC and chronic disease development in a German study population of men and women aged 40-65. The findings revealed that individuals with a high internal locus of control had a decreased risk of myocardial infarction, most likely related to willingness to participate in preventative health behaviors. Hayes et al. modified the MHLC into a Diabetes Locus of Control scale and administered the measure to African American patients with type 2 diabetes. The resulting findings showed that those individuals who strongly believed chance determined their health status were more likely to have poor glycemic control over a period of 6 months.

Collectively, health locus of control studies have shown that individuals who tend to be more internal in their health beliefs are more likely to participate in preventative health behaviors than those individuals who are external in their health beliefs.

Most studies of MHLC in African Americans have been in patient populations in individuals who have already been diagnosed with a particular health condition. This study will evaluate MHLC, risk perception and health behavior in African Americans in a community setting in order to improve community based prevention efforts.

1.3 THE IMPORTANCE OF ACCURATE RISK PERCEPTION

An individual's risk perception is an important contributor to behavior change. Empirical observations from blood pressure screenings, follow up appointments, and medical check ups of hypertension control, smoking reduction, dieting, and flu vaccination have shown that there is a strong relationship between perceived risk and likelihood to participate in a preventative behavior (Graham, 2006). Graham et al. (2006) states that frameworks of behavior change such as the Health Belief Model, Protection and Motivation Theory, and the Precautionary Adoption Process, concur that perceived vulnerability is the major driving force for protective behaviors.

Keeping the importance of accurate risk perception in mind, studies have shown that most individuals tend to inaccurately estimate their risk as a result of "perceived invulnerability" (Graham et al. 2006). In general individuals estimate their risk to be lower than that of the average person like themselves (Graham et al. 2006). The danger of inaccurate risk perception lies in its effects on preventative behavior. Individuals who underestimate their risk are likely to put off seeking care, less likely to follow medical recommendations, and less likely to engage in preventative behaviors. Individuals are more likely to disregard symptoms and warnings as they regard these warnings to be more applicable to other individuals (Graham et al 2006). On the other side of the spectrum, individuals who overestimate their risk may experience undue burden and excess anxiety. This may lead to avoidance behaviors, in turn interfering with proper adherence to medical recommendations, less frequent visits to the doctor, and putting off seeking care until later stages of disease (Graham et al. 2006). In order to design culturally appropriate community interventions public health professionals must take into account community attitudes and cultural as well as psychosocial factors that determine how an individual chooses to perceive their risk. MHLC scales can be used to study how external and internal locus of control affects

risk perception and may have important implications for how to better tailor risk awareness and education efforts towards the participants of the HBFP.

1.4 MEASURES OF HEALTH BEHAVIOR

In order to determine if a community based intervention project is effective it is important to assess if the target population is improving in the direction of the goals of the intervention. A successful intervention is one in which participants are meeting the goals the intervention aims to accomplish. A previous study used MHLC to evaluate how to better tailor community oriented interventions to patients who had already been diagnosed with diabetes and heart disease (Plescia, 2004). Researchers used the Community Oriented Primary Care model to apply public health techniques in a primary care setting. The goal of the project was to train lay health advisors within the community as “catalysts to promote healthy diet patterns, increased exercise and smoking avoidance and cessation (Plescia, 2004).” MHLC and the Transtheoretical Model of Behavior Change were used to assess how health promotion can be tailored to the needs of the community. The findings of the study revealed that participants 65 years and older with diabetes and hypertension scored higher on powerful others scale than their counterparts. Powerful others were defined as physicians and ministers. These findings were presented to lay health advisors who in turn increased efforts to create partnerships with local churches in for purposes of health promotion.

The goals of the HBFP are to increase and help maintain physical activity, improve risk perception, encourage information seeking behavior, and increase the participation of African

Americans in medical research. The following section is a review of the Transtheoretical Model of Behavior Change, Wilson's model of information seeking behavior, and the Center for Minority Health's Research Recruitment Database, and how these models, and rate of enrollment in research can be used to explore how the HBFP can better tailor its interventions to external and internal individuals.

1.4.1 THE TRANSTHEORETICAL MODEL

The transtheoretical model of behavior change (TTM) attempts to explain how and when people are likely to change their exercise behavior. TTM was originally used to better understand addictive behaviors and was later explored as a framework for exercise behavior change. The TTM has been successfully used to study physical activity behavior change (Marshall and Biddle, 2001). The model treats behavior change as something fluid and changing as opposed to an "all or nothing" behavior (Marshall and Biddle, 2001). It is based on empirical evidence that individuals progress through several stages of change when attempting to change their exercise behaviors and become more physically active. There are five stages that individuals move through as they work towards a more physically active lifestyle. These five stages are: pre-contemplation, contemplation, preparation, action and maintenance. In the pre-contemplation stage individuals have no intention of becoming physically active. In the contemplation stage individuals are thinking about becoming physically active within the next 6 months. In the preparation stage individuals have moved to making plans and small changes in behavior in order to become physically active but have not met the criteria of actually being physically active. In the action stage, individuals have met the criteria to become physically active, but have

not been active for an extended period of time. In the maintenance stage individuals have become physically active and have maintained their level of physical activity for at least 6 months. Traditionally it has been thought that individuals move through the stages of change in a linear fashion, however recent work has shown evidence that individuals may regress and progress through the stages of change in a cyclical fashion (Marshall and Biddle, 2001). Marshall and Biddle's meta- analysis of TTM looked at 71 published studies that support the use of TTM as a valid measure of physical activity behavior change.

Recent work at the CMH has assessed the effectiveness of the family health history session to encourage physical activity behavior change using TTM (Dudley, 2006). Individuals did not progress through the stages of exercise behavior change following the family history session; however, individuals who had an annual income of less than \$20,000, who perceived themselves to be obese, who intended to increase their level of physical activity, who had a moderate risk for any disease, and who perceived themselves to be at high risk for any disease were more likely to progress through the stages of changes than other individuals (Dudley, 2006). The current study will build on previous research to evaluate whether or not likelihood to progress through the stages of exercise behavior change is related to health locus of control.

1.4.2 WILSON'S MODEL OF INFORMATION SEEKING BEHAVIOR

Wilson's 1981 Model of Information Behavior is a theoretical framework that hypothesizes that information needs arise out of the needs perceived by the information seeker. When an individual has a need for information he/she utilizes informal and formal resources in order to satisfy this need. If the individual is not successful at completely satisfying the need for information he then has to repeat the search process (Wilson, 1999).

Wilson's 1996 Model of Information Behavior (Figure 3) is grounded in the 1981 model however, in contrast to the 1981 model it is based on not only literature from the field of information science but has drawn on literature from the fields of psychology, decision making, innovation, health communication, and consumer research (Wilson, 1999). In the 1996 model information seeking behavior is shown to consist of four stages beginning with active attention, passive search, active search and finally ongoing search. Three theories have been incorporated into Wilson's 1996 model which modify the way in which individuals search for information. The first of these theories is the stress/coping theory which leads to the activating mechanism that creates the need to search for information (i.e. heightened risk awareness for a chronic disease); the second is risk/reward theory which explains why individuals choose to use specific resources in their information search (i.e. learning more information about how to prevent a health condition in which the risk is the amount of effort it would take to find the information and the reward is learning how to prevent the health condition), and lastly social learning theory, which states that an individual will participate in information seeking behavior if he/she believes that they can execute this behavior successfully (Wilson, 1999). The MHLC fits into this last theory as its origins are rooted in social learning theory. This study sets out to evaluate whether there are differences between likelihood to progress through the stages of information seeking behavior and MHLC. There are limited studies that have used Wilson's Model of Information Behavior to study information seeking behavior in a community setting. This model is appropriate for the current study as it incorporates social learning theory and health locus of control.

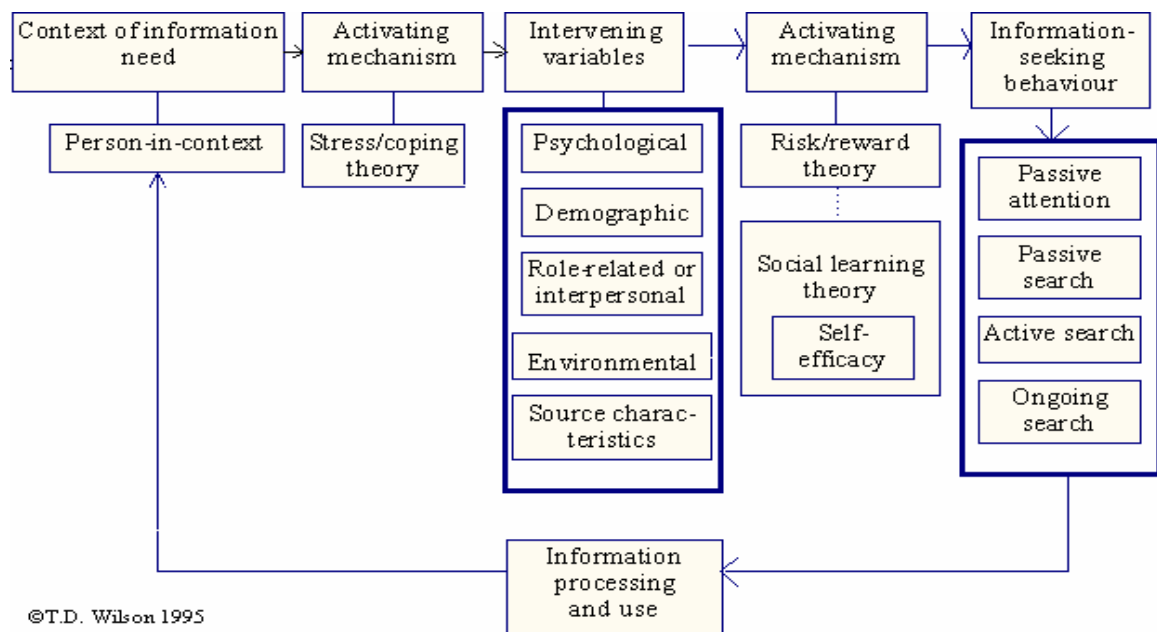


Figure 3. Wilson's Model of Information Behavior

1.4.3 MINORITY RESEARCH RECRUITMENT DATABASE

Current research has shown that African Americans are underrepresented in clinical research studies making the relevance of research results to African Americans of uncertain significance. It is imperative that efforts be put forth to increase African American participation in research studies in order to bridge the health disparities gap. Current literature has shown evidence that most African Americans have never been asked to participate in a research study (Thomas et al. 2001). The Minority Research Recruitment Database was designed to increase enrollment of African Americans in medical research studies in the Pittsburgh area.

There are several barriers to African American enrollment in medical research studies. These barriers can be broken down into 1) the historically rooted barriers experienced by the

African American community, and 2) the barriers perceived by the medical community that prevent them from informing African Americans of studies in the first place. The best known example of mistrust of the medical community is the Tuskegee syphilis experiment (Outlaw, Bourjolly, & Berg, 2000). Other examples include fear of medical treatment, distrust of researchers, and distrust of the government (Mabunda Temple as cited by Outlaw, Bourjolly, & Berg, 2000). The barriers perceived by the health professional that prevent them from informing the participant in the first place include: the concern that clinical trials will be too complex for the patient to understand, the patient may have trouble seeing the value of research, and the patient's fear of the health system (Outlaw, Bourjolly, & Berg, 2000). Another interesting barrier perceived by researchers is that African Americans are "hard to reach" (Thomas et al. 2001).

The Minority Research Recruitment Database was created by the CMH in order to increase participation of African Americans in research studies. Previous CMH thesis work assessed the factors that determined whether or not individuals chose to enroll in the CMH Minority Research Recruitment Database. Approximately 80% of individuals enrolled in the database and 20% declined enrollment when offered the opportunity (Vogel, 2005). The rate of enrollment has stayed consistent with Vogel's 2005 findings with approximately 80% of individuals enrolling in the database. This study will focus on whether or not MHLC is related to willingness to enroll in the Minority Research Recruitment Database.

2.0 SPECIFIC AIMS OF STUDY

The research programs conducted by the CMH were started in order to assess African Americans' response to the family health history. This study is funded by a grant to Stephen B. Thomas from the National Institutes of Health: National Center on Minority Health and Health Disparities Export (NCMHD) which designated the CMH as a Center of Excellence in Partnership, Outreach, Research, and Training (EXPORT). The study received approval by the University of Pittsburgh's Institutional Review Board (IRB) in May 2004, with subsequent renewal in 2005, 2006 and 2007 (Appendix B) and modification in September 2007. Upon the expiration of this grant in September of 2007, the study became funded as the CMH Research Center of Excellence on Minority and Health Disparities @ UPITT also funded by NCHMD. The specific aims of the study are: 1. To determine how knowledge of family health history influences the accuracy of individual risk perception; 2. To determine how knowledge of family health history influences African Americans willingness to participate in clinical research studies; 3. To determine how knowledge of family health history influences "information seeking" behavior; and 4. To determine how the process of completing a family health history affects an individual's level of physical activity. The first two aims and the fourth aim of this study have been addressed by the research of three former genetic counseling students (Murphy, V. 2005; Vogel, K. 2005; Dudley, R. 2006). This thesis will address all four aims of the study.

3.0 METHODS

3.1 HEALTHY BLACK FAMILY PROJECT

The Healthy Black Family Project (HBFP), situated within the Center for Minority Health (CMH), is a multi-disciplinary community demonstration project dedicated to bridging the health disparities gap in the African American community of Pittsburgh, Pennsylvania. The Healthy Black Family Project has implemented interventions targeted at improving physical activity levels, nutrition, mental wellness, smoking cessation, family health history awareness, stress management, and self management of chronic disease within the context of a community-oriented, socially supportive environment.

The specific aim of the HBFP is to reduce the prevalence of hypertension and diabetes in the African American population in Pittsburgh. The HBFP is situated in a geographic area designated by the CMH as the Health Empowerment Zone (Figure 4). This area encompasses the East End neighborhoods that include East Liberty, East Hills, Homewood North, Homewood South, Homewood West, Larimer, Lincoln, and Wilksburg. African Americans make up 79% of citizens in these communities, and 25.7% of this population lives below the poverty line (Hunte et al. 2002). The HBFP was designed to target these communities through public health outreach, education, and evidence-based interventions in order to improve the health of its community members by decreasing the prevalence of common chronic disease.

Zip Code	Neighborhood
15147	Penn Hills
15206	Lincoln, Lemington, Belmar, East Liberty, Larimer, Garfield
15207	Glen Hills
15208	Point Breeze North, Homewood South, Homewood South, Homewood West
15213	Terrace Village, Upper Hill
15219	Crawford Roberts, Terrace Village, Middle Hill, Bedford Dwellings, Upper Hill
15221	Homewood North, East Hills, Wilkinsburg,
15224	Garfield

Figure 4. Health Empowerment Zone

3.2 FAMILY HEALTH HISTORY INITIATIVE

The Family Health History Initiative is one part of the HBFP designed to raise awareness about risks for common disease and educate individuals as to how they can reduce these risks. The self reported family health history is an accurate measure used to identify individuals who may be at increased risk for developing chronic diseases such as hypertension, diabetes, CVD,

and cancer (Scheuner et al. 1997). Graduate genetic counseling students offer the family health history session to all HBFP participants by calling each participant and providing a brief overview of the family health history session. If the participant is interested they set up an appointment with the student to meet at a mutually agreed upon location such as the Kingsley Community Center. During the session the student interviews the participant about their family health history and constructs a diagram of the family tree known as a pedigree. Once the pedigree is complete the participant is provided with a risk assessment, based on Schuener et al. (1997) criteria, for high blood pressure, diabetes, Alzheimer's disease, cardiovascular disease, breast cancer, colon cancer, ovarian cancer, prostate cancer, and lung cancer. Participants are then counseled about how they can decrease their risk for these chronic conditions through diet, exercise, and regular health screenings. At the close of the session the participant is provided with a hand drawn copy of the pedigree. After the completion of the family health history session a resource packet is mailed to the participant's home. The contents of the packet include a computer generated pedigree (produced using Progeny software), a certificate of appreciation, and targeted health information.

3.3 MINORITY RESEARCH RECRUITMENT DATABASE

At the completion of the family health history, the participants were informed about the Minority Research Recruitment Database. Interested individuals sign an informed consent to have their family health history entered into the database. The database is occasionally queried for individuals who would qualify for clinical research studies in the Pittsburgh medical

community based on their family history. Information is then sent to the homes of eligible individuals at which time they can decide as to whether or not they would like to contact the investigators and enroll in the study. Participant information is never disclosed to investigators. The participant has the right to withdraw their family history from the database at any time.

3.4 ASSESSING MHLC, RISK PERCEPTION, AND HEALTH BEHAVIOR

3.4.1 PROCEDURE

Every participant who completed a family health history session was given the option to participate in our research study. At the beginning of each session, the participant was informed that the study consisted of two 10-15 minute surveys and a third follow up survey conducted via telephone. It was explained that the surveys include questions to better understand if the family health history session can improve risk perception for chronic disease, MHLC, and opinions on medical research. If the participant was interested then informed consent was obtained which included a discussion of the specific aims, structure, benefits, and risks of the study.

Once the participant signed the informed consent document, the pre-survey (Appendix D) was administered. The pre-survey consists of questions about demographics, risk perception, physical activity habits, and the MHLC scale. After completion of the pre survey, the student went onto interview the participant about their family health history. Information was gathered for three generations. The participant was asked about their children, siblings, parents, aunts, uncles, and grandparents. Age, health status, any standing diagnoses and age of diagnosis were

recorded on the pedigree. If the family member was deceased, age of death and cause were documented in the pedigree. After construction of the pedigree, the student provided a risk assessment for high blood pressure, diabetes, cardiovascular disease, Alzheimer's disease, and several types of cancer (breast, ovarian, colon, prostate, and lung). Once the risk assessment was complete, and the participant's questions were answered, the post session survey (Appendix E) was administered. The post session survey asks questions regarding risk perception, intent to change physical activity habits, opinions on medical research, and information seeking behavior. Upon completion of the survey the participant was given the opportunity to enroll in the minority research recruitment database. Those individuals that were interested were provided informed consent regarding the specific aims, structure, risks, and benefits of enrollment (Appendix). Lastly, the students asked the participant for permission to contact them in approximately one month for a brief five minute follow up phone survey (Appendix F). The follow up survey consists of questions about the participant's experience with the family history session, changes in family history, information sharing and seeking behaviors, changes in physical activity level, and other lifestyle changes.

3.4.2 QUESTIONNAIRES

Pre- survey questionnaire

Section 1: General Information

Section 1 includes demographic information, their knowledge of genetics, and the respondent's assessment of their weight and health status. In addition, Section 1 asks the participant whether they have a primary care physician and health insurance coverage.

Section 2: Physical Activity Habits

Section 2 provides the participant with the national recommendation on physical activity obtained from the Center for Disease Control (CDC, 2005) and participants stage themselves by level of physical activity or intent to become physically active. This question was based on the Transtheoretical Model of Behavior Change and asked the participants to stage themselves by level of physical activity or intention to begin physical activity. When an individual said that they were physically active they were asked if they were active for more than six months or less than six months. Individuals who indicated that they were not physically active were queried about any plans to start in the next 30 days, in the next 6 months, or if they were not planning on becoming physically active at this time. Those who said they were not physically active were asked if they had increased their physical activity, but not enough to fit the definition. Section 2 asks about exercise frequency, and duration.

Section 3: Risk Perception

Section 3 included questions that determine participants' perception about how much smoking, diet, exercise and family history contribute to an individual's risk for disease. Participants rated their level of concerns for developing any of the most common chronic conditions, and are asked to list any relatives who have had any of these conditions. The rest of the questions in this section assessed the participants perception of risk for common chronic diseases for a woman the same age as them, a man the same age as them, and finally for themselves.

Section 4: Multidimensional Health Locus of Control

In section 4, participants completed the 18 item MHLC scale. The MHLC scale is designed to assess the degree to which an individual feels that they are in control of their own health. The MHLC gives individuals a series of 18 statements and asks them to rate how strongly they agree or disagree with these statements. The MHLC is made up of three different subscales that are designed to assess the three different dimensions of health locus of control that are internality, chance, and powerful others. Once the participant has completed the MHLC their score is calculated and health locus of control can be assessed in these three dimensions.

Post-survey questionnaire

Section 1: Physical Activity Habits

Section 1 determines whether participants think they will increase their level of physical activity as a result of the family health history session.

Section 2: Risk Perception and Health Value Index

Section 2 asks the participant how often (always, sometimes or never) smoking, diet, lack of exercise, and family history contributes to disease risk. This question was used to construct a health value index for each participant. In this section participants indicate their risk perception is for the common chronic diseases based on their family history and how their risk compares to the average individual's (of the same age) risk to develop these same conditions.

Section 3: Opinions on Research

In section 3, participants rated the importance of medical research, whether they had ever participated or been offered the chance to participate in research, and what their general attitudes were towards medical research. Participants were queried about the benefits of medical research

to scientists, community, family and friends, and themselves. Participants were asked if they would be interested in having their name in a research recruitment database and what their expectations were of such a database. If the participant marked that they were not interested, they were asked for their primary reasons for not wanting to be part of the database.

Section 4: Information Seeking Behavior

In section 4, participants were asked if they had plans to share their family history with their doctor and their family. Participants rated how comfortable they were discussing health concerns with family members and their doctor and about any barriers that stood in the way of these discussions. Each participant was asked where they searched for health information, and how frequently they searched for health information. Lastly, participants staged themselves in terms of their level of information seeking behavior (based on Wilson's model). The four levels were as follows: passive attention, passive search, active search, and ongoing search. Participants chose the statement that most closely resembled their level of information seeking behavior from the following options: 1. I am aware of health conditions that run in my family and I do not need to do any more research on these conditions (passive attention). 2. I am aware of the health conditions that run in my family and I read about these conditions when the information is provided for me (passive search). 3. I have done some of my own research on health conditions that concern me (active search). 4. I actively keep up with current research on health conditions that concern me (ongoing search). Participants indicated the frequency of their information seeking behavior (based on a 6 point Likert scale with the options of very frequently, frequently, occasionally, rarely, very rarely, or never).

Follow up survey questionnaire

The follow up survey was designed to assess participants' attitudes towards the family history session and whether or not they had made any lifestyle changes as a result of the family history session. Genetic counseling students conducted the follow up survey by phone. The follow up period ranged from 1 month to 3 months depending on how long it took to get a hold of each individual. Individuals were once again asked to stage their level of physical activity (based on the Transtheoretical model), and their level of information seeking behavior (based on Wilson's model).

3.4.3 PEDIGREE ANALYSIS

The Scheuner et al. criteria (Figure 5) were used to analyze each pedigree and determine the individual's risk for common chronic conditions. Each individual was told that they were low risk, moderate risk, or high risk for hypertension, adult onset diabetes, breast cancer, ovarian cancer, colon cancer, prostate cancer, lung cancer, cardiovascular disease, and Alzheimer's disease. Scheuner's definition of premature onset was used for cardiovascular disease, diabetes, and cancer. The definition for premature onset Alzheimer's disease, diagnosed at age 65 or younger, was established by the Alzheimer's disease association. The definition for premature onset hypertension was established as age 50 or younger based on previous work at the CMH. Each pedigree was analyzed by one genetic counseling student. When questions arose, the other three genetic counseling students were consulted in order to establish a consensus.

High Risk	Moderate Risk	Average Risk
<ol style="list-style-type: none"> 1. Premature disease in a 1st degree relative. 2. Premature disease in a 2nd degree relative (coronary artery disease). 3. Two affected 1st degree relatives. 4. A 1st degree relative with late/unknown onset of disease and an affected 2nd degree relative with premature disease from the same lineage. 5. Two 2nd degree maternal or paternal relatives with at least one having premature onset of disease. 6. Three or more affected maternal or paternal relatives. 7. The presence of a “moderate risk” family history on both sides of the pedigree. 	<ol style="list-style-type: none"> 1. A 1st degree relative with late or unknown disease onset. 2. Two 2nd degree relatives from the same lineage with late or unknown disease onset. 	<ol style="list-style-type: none"> 1. No affected relatives. 2. Only one affected 2nd degree relative from one or both sides of the pedigree. 3. No known family history. 4. Adopted individual with unknown family history.

Note: Premature coronary artery disease: 55 or younger in males; 65 or younger in females. Premature stroke, diabetes, colon cancer, and prostate cancer: 50 or younger Premature breast, ovarian, and endometrial cancer: 50 or younger or premenopausal

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Figure 5. Scheuner et al. (1997) Risk Stratification Criteria

3.4.4 DATA ANALYSIS

Pre-survey, post- survey and follow-up survey data were entered into online versions of each respective survey and retrieved through Perseus Survey Solutions Version 6 ®. Once in Perseus the data were exported into excel data sheets and then analyzed using STATA Version 7® Statistical Software.

First, the health value index was assessed for the study group. The health value index consisted of 4 questions asking how often (never, sometimes, or always) smoking, diet, exercise,

and family history contributed to disease risk. 1 point was assigned for each “never” response, 2 points were assigned for each “sometimes” response and 3 points were assigned for each “always” response. Individuals with a score of 8 or higher were classified into the high health value group and individuals with a score of 8 or lower were classified into the low health value group.

Second, a score was calculated for each participant for the internality, chance, and powerful others subscale (Appendix C: Scoring directions). The median score was then calculated for each subscale. A median split approach was used to split individuals into two categories for each respective subscale. For example, individuals scoring above or equal to the median score on the internality scale were classified as internals (high internals), whereas individuals scoring below the median were classified as externals (low internals). Individuals scoring above or equal to the median score on the chance scale were classified as high chance (those whose HLC was dependent on chance events), and individuals scoring below the median were classified as low chance (those whose HLC was minimally dependent on chance events). Individuals scoring above or equal to the median on the powerful others subscale were classified as high powerful others (those that felt health professionals and family members play a significant role in their health status), whereas individuals scoring below the median were classified as low powerful others (those who do not feel that health professionals and family members play a significant role in the determination of their health status).

Once a subscale score was determined for each participant, MHLC was assessed in conjunction with 1) a risk perception analysis for diabetes, CVD, colon cancer, breast cancer, and ovarian cancer and 2) health behavior analysis for three different outcome measures. These three outcome measures are as follows: level of physical activity, level and frequency of

information seeking behavior, and enrollment status in the CMH Minority Research Recruitment Database.

Risk Perception Analysis

Risk perception was assessed by comparing each participant's objective risk for each condition to their perceived risk for that particular condition. The objective risk for cardiovascular disease, diabetes, hypertension, colon cancer, breast cancer, prostate cancer, and ovarian cancer was determined by carefully reviewing the pedigree using the Scheuner et al. criteria. Individuals were either classified as high risk (greater than 50% chance to develop condition), moderate risk (between 10-50% risk to develop condition) and low risk (less than 10% chance to develop condition). Information regarding individual risk perception for each condition was obtained from the pre-survey questionnaire (filled out prior to the family history session) that asked individuals to list their risk as low, moderate, or high for each respective condition. This data was retrieved from Perseus Survey Solutions and exported to excel spreadsheets. For each individual, accuracy of risk perception was determined for each disease. Individuals were classified as having accurately estimated, overestimated, or underestimated for each disease. Individuals who did not know their perceived risk for a particular health condition or had been previously diagnosed with a particular health condition were excluded from the analysis. Gender was also used as exclusion criteria for respective conditions.

Excel spreadsheets were created with each individual's risk perception accuracy, objective risk, and subscale classification (external vs. internal, low chance vs. high chance, low powerful others vs. high powerful others). A separate analysis was carried out for each disease for all three subscales. Within each disease analysis, individuals were stratified into high,

moderate, and low objective risk categories. Fisher's exact tests were performed to check for differences between individuals who correctly vs. incorrectly estimated and their MHLC scores (external vs. internal, high chance vs. low chance, and high powerful others vs. low powerful others). For example, in the diabetes analysis individuals were first stratified into high, moderate, and low objective risk categories. Within each objective risk category three Fisher's exact tests were performed, one test for each subscale of the MHLC. Since each disease sample was split into three risk categories a bonferroni correction was performed ($\alpha=0.05/3=0.017$). A risk perception analysis was not carried out for prostate cancer and hypertension due to the small sample sizes (prostate cancer $n=12$; hypertension $n= 27$) after exclusion criteria were applied.

Health Behavior Analysis

Physical activity level or intention to be physically active was assessed at time of pre survey during the initial family history session and again on the follow up survey. Level and frequency of information seeking behavior was assessed at time of post survey during the initial family history session and again on the follow up survey. Individuals were given the opportunity to enroll in the database at the initial session. Fisher's exact tests were used to search for differences between internals and externals (across all three MHLC subscales) and likelihood to maintain or increase physical activity, likelihood to maintain or increase level and frequency of information seeking behavior, and likelihood to enroll in minority research recruitment database. Alpha was set at 0.05.

4.0 RESULTS

4.1 PARTICIPANT CHARACTERISTICS

The data reported here are from the 87 participants recruited from the Center for Minority Health Healthy Black Family Project. All personal characteristics were self reported. Table 1 presents the participants' socio-demographic characteristics, general health, knowledge on genetics, and scores on health value index.

Table 1. Characteristics of Study Participants

Participant characteristics (n=87)	n (% of participants)
Sex	
Male	12(14%)
Female	75(86%)
Ethnicity	
African American Only	72(83%)
Multiracial (African American and other)	14(16%)
Caucasian	1(1%)
Age	
≤50	30(34%)
>50	57(66%)
Education	
Grades 9 through 11(some high school)	1(1%)
Grades 12 or GED (high school graduate)	18(21%)
College 1 to 3 years (some college)	37(43%)
College 4 or more years (college graduate)	20(23%)
Graduate level (MS, PhD)	8(9%)
Income	
Less than \$10,000	14(16%)
Between \$10,000 and \$20,000	14(16%)
Between \$20,001 and \$35,000	20(23%)
Between \$35,001 and \$50,000	17(20%)
Between \$50,001 and \$75,000	9(10%)
Greater than \$75,000	2(2%)
General Health	
Good/Very Good/ Excellent	65(75%)
Fair/Poor	19(22%)
Self described weight	
Underweight	2(2%)
Healthy weight	14(16%)
Overweight	56(64%)
Obese	13(15%)
Smoker	
Yes	9 (10%)
No	75 (86%)
Knowledge of Genetics	
Good/Very Good/ Excellent	36 (41%)
Fair/Poor	48(55%)
Health Value Index Score	
High health value (index score ≥8)	78(90%)
Low health value (index score <8)	9(10%)

Note: Percentages in some categories may not add up to 100 due to some participants leaving questions unanswered.

Of all participants, 86 individuals described their race as African American, one individual described their race as Caucasian, and 16% of individuals described themselves as multi racial. The median age for all participants was 55, with an age range of 25 to 84. 66% of individuals were above the age of 50 and 34% were below the age of 50. The sample was mostly female (86%). Of the 87 participants, the majority had some college education (78%). The annual household income for the greater portion (75%) of the sample was less than \$50,000. 75% of participants rated their general health as good, very good, or excellent. More than half (55%) of participants rated their knowledge of genetics as poor or fair, with only 1% of individuals rating their knowledge on genetics as excellent. The majority of the sample (90%) scored high on the health value index indicating that our study population is one that believes smoking, lack of exercise, poor diet, and family history contribute to disease risk at least some of the time.

Table 2 summarizes participants' insurance status and access to health professionals. The majority of participants (91%) have health insurance. Of the 87 participants 63% have one physician they consider their primary care doctor and 35% of participants have more than one primary care physician. Overall, 95% of participants are under the care of at least one primary care physician. 9% of participants have been in a situation where they needed to see a doctor but could not because of the cost. Participants were asked if they had ever been concerned about developing hypertension, CVD, cancer, or Alzheimer's disease. The majority (82%) of participants have talked to their doctor about concerns for developing a disease. Diseases individuals have discussed with their doctor include diabetes, high blood pressure, cardiovascular disease, bone cancer, lung cancer, colon cancer, throat cancer, pancreatic cancer, prostate cancer, Alzheimer's disease, and stroke.

Table 2. Participants' Access to Care

Participant's Insurance and Health Provider Status participants)	n(% of
Health insurance	
Yes	79(91%)
No	6(7%)
Have primary physician	
Yes, only one	55(63%)
Yes, more than one	26(35%)
No	4 (5%)
Did not see a doctor due to cost	
Yes	8(9%)
No	76(87%)
Talked to doctor about concern for developing a disease	
Yes	71(82%)
No	14(16%)

Note: Percentages may not add up to 100, as some questions were left unanswered.

Table 3 summarizes participants' concerns for developing diabetes, hypertension, cardiovascular disease, and cancer and whether or not they have a first degree relative (FDR) or second degree relative (SDR) who has had the condition. Most participants (82%) have been concerned about developing one of the aforementioned diseases at some point in their lifetime. The majority of participants (81%) are moderately to very greatly concerned about their risk for developing these common chronic diseases. Within the concerned group 40% of participants are moderately concerned and 41% of participants are greatly to very greatly concerned about developing one of the common chronic diseases at some point in their lifetime. Of the 87 participants 78% have at least one FDR or SDR that has been diagnosed with the condition they are concerned about.

Table 3. Participants' level of concern for developing chronic disease and family history

Participant characteristics	n(% of participants)
Have you ever been concerned about developing above disease?	
Yes	71(82%)
No	14(16%)
Level of concern 1(low)- 5(high)	
1	2(3%)
2	13(16%)
3	32(40%)
4	13(16%)
5	20(25%)
FDR or SDR with condition?	
Yes	68(78%)
No	13(15%)
Don't know	4(5%)

Note: Percentages may not add up to 100 since some questions were left unanswered.

Table 4 summarizes the 87 participants' objective risk for hypertension (HTN), adult onset diabetes mellitus (AODM), cardiovascular disease (CVD), colon cancer, breast cancer, and ovarian cancer. Individuals were stratified into low, moderate, or high risk categories using Scheuner criteria to evaluate family history. Participants in this study were collectively at increased risk for diabetes, hypertension and cardiovascular disease. A large proportion (66%) of the study population has already been diagnosed with hypertension.

Table 4. Participants' objective risk stratification based on Scheuner et al. criteria

Disease	High risk n(%)	Moderate risk n(%)	Low risk n (%)	Already have it n(%)
AODM	34(39%)	7(8%)	31(36%)	15(17%)
CVD	35(40%)	19(22%)	29(33%)	4(5%)
HTN	19(22%)	4(5%)	7 (8%)	57(66%)
Colon cancer	2(2%)	8(9%)	76(88%)	1(1%)
Breast cancer	9(10%)	1(1%)	76(88%)	1(1%)
Ovarian cancer	1(1%)	1 (1%)	72(96%)	1(1%)

4.2 RISK PERCEPTION ACCURACY

Table 5. Participants' risk perception for chronic disease

Disease	High n (%)	Moderate n(%)	Low n (%)	DK n (%)	AH n (%)
AODM	27(31%)	23(26%)	17(20%)	5(15%)	6(17%)
CVD	32 (37%)	28(32%)	15(17%)	8(4%)	9 (5%)
HTN	10 (12%)	9(10%)	8(9%)	3(3%)	57(66%)
Colon cancer	12(14%)	22(25%)	39(45%)	13(1%)	14(1%)
Breast cancer	6(7%)	36(42%)	32 (37%)	12(1%)	14(1%)
Ovarian cancer	6(8%)	21(24%)	36 (41%)	11 (1%)	13 (1%)

Table 5 summarizes participants risk perception for diabetes, cardiovascular disease, hypertension, colon cancer, breast cancer, and ovarian cancer. The majority of participants (57%) perceived themselves to be at increased risk for diabetes and cardiovascular disease (57%, and 69%, respectively). Of those who perceived themselves to be at increased risk for diabetes 31% perceived to be in the high risk category and 26% perceived their risk to be moderately increased. Of those who perceived themselves to be at increased risk for cardiovascular disease, 37% perceived their risk to be high and 32% perceived their risk to be moderately increased. 66% of the study population has been diagnosed with hypertension. Of the 27 individuals in our study who did not have a diagnosis of hypertension 12% perceived their risk to be high, 10% perceived their risk to be moderately increased, and 9% felt that they were at low risk. The majority of participants perceived their risk for colon cancer to be low (45%) or moderate (25%)

and 14% of participants believed their risk for colon cancer to be high. The majority of women felt their risk for ovarian cancer was low (41%), followed by 24% who felt their risk was moderate, and only 8% who believed their risk to be high. The majority of participants felt that their risk for breast cancer was increased with 42% of women feeling that they were at moderate risk and 7% placing themselves in the high risk category. 37% of women felt their risk for breast cancer was low.

Table 6. Risk perception accuracy

Disease	Correct n(%)	Overestimate n (%)	Underestimate n (%)	Don't know n (%)	Already have n (%)
AODM	26 (30%)	22 (25%)	18 (21%)	6 (7%)	15 (17%)
CVD	32 (37%)	25 (29%)	18 (21%)	8 (9%)	4 (5%)
HTN	14 (16%)	3 (3%)	10 (11%)	2(3%)	58 (67%)
Colon cancer	42 (48%)	30 (35%)	1 (1%)	13 (15%)	1 (1%)
Breast cancer	34 (39%)	33 (38%)	6 (7%)	13 (15%)	1 (1%)
Ovarian cancer	35 (40%)	27 (31%)	1 (1%)	11 (13%)	1(1%)

Participants' risk perception accuracy is summarized in Table 6. Overall, the participants were most accurate at estimating their risk for cancer. 48% of individuals correctly estimated their risk for colon cancer, followed by 35% who overestimated their risk, and only 1% who underestimated their risk. 40% of participants correctly estimated their risk for ovarian and breast cancer. Individuals were more likely to overestimate their risk for both breast (38% of

participants) and ovarian cancer (31% of participants), than to underestimate their risk (7% for breast cancer and 1% for ovarian cancer). Individuals were more likely to correctly estimate their risk for diabetes and cardiovascular disease (31% and 37%, respectively). 21% of individuals underestimated their risk for both diabetes and cardiovascular disease. 24% of individuals overestimated their risk for diabetes and 29% of individuals overestimated their risk for cardiovascular disease. Since 57 individuals had already been diagnosed with hypertension, a small portion of individuals were able to participate in the risk perception study leaving 16% of individuals who correctly estimated their risk, 3% who overestimated their risk and 11% who underestimated their risk. Overall, a significant number of individuals inaccurately estimated their risk for disease or did not know their risk: diabetes (53%), cardiovascular disease (59%), colon cancer (51%), breast cancer (60%) and ovarian cancer (45%).

4.3 MHLC AND RISK PERCEPTION

The statistically significant findings of the risk perception analysis are summarized in Table 7 below. All findings are summarized textually in their respective MHLC disease specific risk perception analysis and tabulated in Appendix A (Tables 12-16).

Table 7. Risk perception analysis: summary of statistically significant results

Disease	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Ovarian Cancer				
Internality Scale				
Low risk				p=0.040
Internals	13(43%)	17(57%)	n/a	
Externals	22(71%)	9(29%)	n/a	
Conclusion: Individuals at low risk for ovarian cancer were more likely to overestimate their risk for ovarian cancer if they were internal (scored high on the internality scale) than if they were external (scored low on the internality scale).				
Diabetes				
Powerful Others Scale				
High risk				p=0.011
High po	10(77%)	n/a	3(23%)	
Low po	5(28%)	n/a	13(72%)	
Conclusion: Individuals at high risk for diabetes were more likely to underestimate their risk if they scored low on the powerful others scale than if they scored high on the powerful others scale.				
Cardiovascular Disease				
Powerful Others Scale				
Moderate				p=0.005
High po	0	6 (100%)	0	
Low po	6(55%)	2 (18%)	3(27%)	
Conclusion: Individuals at moderate risk for CVD were more likely to overestimate their risk for CVD if they scored high on powerful others scale than if they scored low.				

4.3.1 DIABETES

Internality Subscale

Both externals and internals at low risk for diabetes were more likely to overestimate their risk. Of the 29 individuals at low risk for diabetes, 44% of internals and 23% of externals had accurate risk perceptions. 56% of internals and 77% of externals overestimated their risk to develop diabetes. There were no statistically significant differences in accuracy of risk perception for diabetes between low risk externals and internals (p-value= 0.433).

Of the 6 individuals at moderate risk for diabetes, 1 external and no internals correctly estimated their risk. 3 externals overestimated their risk. 1 internal and 1 external underestimated their risk. This sample was too small to perform statistical analysis.

High risk individuals were more likely to estimate their risk correctly regardless of their internality locus of control score. Of the 31 individuals at high risk for diabetes, 50% of internals and 47% of externals correctly estimated their risk. The rest of the study group underestimated their risk. No statistically significant differences in accuracy of risk perception were detected between the externals and internals (p-value= 1.0).

Overall, individuals in the high risk category were more likely to correctly estimate their risk than those individuals in the low or moderate risk categories. There is no evidence to show that degree of internality is related to risk perception for diabetes.

Chance Subscale

Individuals at low risk were more likely to overestimate their risk regardless of their chance HLC score. Of the 29 individuals at low risk for diabetes, 25% high chance scorers and 41% of low chance scorers correctly estimated their risk. 75% of high chance scorers and 59% of

low chance scorers overestimated their risk. There were no statistically significant differences in risk perception accuracy detected between those scoring high and those scoring low on the chance scale ($p=0.449$).

Of the 6 individuals at moderate risk for diabetes, 1 high chance scorer overestimated their risk. Of the low chance scorers, 1 correctly estimated their risk, 3 individuals overestimated their risk, and 2 underestimated their risk. This sample was too small for statistical analysis.

Of the 30 individuals at high risk for diabetes, 62% of individuals who scored high on the chance scale, and 35% of those who scored low on the chance scale correctly estimated their risk. There were no statistically significant differences in risk perception accuracy between those who scored high and those who scored low on the chance scale ($p=0.269$).

Powerful Others Subscale

Low risk individuals were more likely to overestimate their risk regardless of their powerful others scale score. Of the 29 individuals at low risk for diabetes, 33% of those who scored high on the powerful others scale and 35% of those who scored low on the powerful others scale correctly estimated their risk. There were no statistically significant differences in risk perception accuracy detected between the two groups ($p=1.0$).

Of the 6 individuals at moderate risk for diabetes, 2 individuals who scored high on powerful others scale overestimated their risk. Of those who scored low on the powerful others scale, 1 individual was correct in their risk perception, 3 overestimated their risk, and 2 underestimated their risk. This sample was too small for statistical analysis.

Of the 31 individuals who were at high risk for diabetes, 77% of those who scored high on powerful others were more likely to estimate their risk correctly than those who scored low on

powerful others of which only 28% accurately estimated their risk. 23% of those who scored high on powerful others underestimated their risk compared to 73% of those who scored low on powerful others who underestimated their risk. In summary, those who scored low on powerful others were more likely to underestimate their risk for diabetes. This difference was statistically significant with a p-value=0.011 at an alpha of 0.017.

4.3.2 CARDIOVASCULAR DISEASE (CVD)

Of the 87 study participants, 4 had already been diagnosed with cardiovascular disease. 8 individuals did not know their perceived risk for CVD. The final risk perception analysis was performed on a sample of 75 participants.

Internality Scale

Low risk individuals collectively overestimated their risk regardless of their internality score. Of the 25 participants in the low risk category for cardiovascular disease, 30% of internals correctly estimated their risk compared to 40% of externals. 70% of internals overestimated their risk compared to 60% of externals. There were no statistically significant differences in risk perception for CVD noted between externals and internals (p-value= 0.691).

Moderate risk individuals collectively overestimated their risk regardless of their internality score. Of the 17 participants in the moderate risk category, 33% of internals and 40% of externals correctly estimated their risk for CVD. 50% of internals overestimated their risk as did 40% of externals. 3 individuals underestimated their risk for CVD, one of who was an external. There were no statistically significant differences in risk perception for CVD detected in the moderate risk category (p-value=1.000).

The majority of high risk internals and externals correctly estimated their risk. Of the 33 individuals who were high risk for CVD, 53% of internals and 56% of externals accurately estimated their risk. Comparably, 47% of internals and 44% of externals underestimated their risk. No significant differences were detected between externals and internals at high risk for diabetes (p-value=1.000).

Chance Subscale

High and low chance scorers were both more likely to overestimate their risk. Of the 25 individuals in the low risk category for CVD, there were no statistically significant differences in risk perception accuracy detected between those scoring low on the chance scale and those scoring high on the chance scale. 38% of those who scored high on the chance scale and 35% of those who scored low on the chance scale correctly predicted their risk for CVD (p-value=1.0). The rest of the individuals overestimated their risk (63% of internals and 65% of externals).

Of the 17 individuals at moderate risk for CVD, 4 (57%) of the high chance scorers correctly predicted their risk compared to 2 (20%) low chance scorers. 3 low chance scorers and 5 high chance scorers overestimated their risk, and 3 low chance scorers underestimated their risk. There were no statistically significant differences in accuracy of risk perception for CVD detected between high chance scorers and low chance scorers (p-value=0.196).

Of the 32 individuals at high risk for CVD, 44% of high chance scorers and 63% of low chance scorers correctly predicted their risk. There were no statistically significant differences detected between low chance scorers and high chance scorers (p-value=0.479).

Powerful others scale

Of the 25 participants at low risk for CVD, those who scored low on powerful others correctly estimated their risk, whereas those who scored high on powerful others were more likely to incorrectly estimate their risk. 77% of individuals who scored high on powerful others overestimated their risk for CVD, compared to 50% of individuals who scored low on powerful others (p-value=0.226). This difference was not statistically significant.

Of the 17 individuals at moderate risk for CVD, those who scored low on the powerful others scale were more likely to correctly estimate their risk than those who scored high on the powerful others scale. 55% of those who scored low on powerful others correctly estimated their risk compared to 0% of individuals who scored high on powerful others. All of those individuals who scored high on powerful others overestimated their risk for CVD (p-value= 0.005). In summary, this analysis detected a statistically significant difference that shows that those individuals who score low on powerful others are more likely to correctly estimate their risk for CVD than those individuals who score high on powerful others. Although the cell sizes in this study sample are small the chance of making a Type I error is a 0.5%. This means that there is a 0.5% chance that this result could have been observed by chance which means that there is a 99.5% chance that this result is statistically significant.

4.3.3 COLON CANCER

Out of the study participants, 2 had been previously diagnosed with colon cancer, and 12 did not know their perceived risk. Data was analyzed on a total of 73 participants' risk perceptions for colon cancer. Of the 73 participants, 66 were at low risk, 5 were at moderate risk and 2 were at high risk for colon cancer. Statistical analysis was only carried out on the low risk group, since the other two risk category sample size were too small for analysis.

Internality Scale

The majority of low risk individuals correctly estimated their risk regardless of their internality score. Data was analyzed on 66 participants for the internality scale. 56% of internals compared to 60% of externals correctly estimated their risk for colon cancer. 44% of internals and 40% of externals overestimated their risk for colon cancer. There were no statistically significant differences in risk perception accuracy for colon cancer between externals and internals (p-value=0.81).

Chance scale

Data was analyzed on 65 participants for the chance subscale; because one participant did not completely fill out the chance section of the questionnaire. 61% of internals and 54% of externals correctly estimated their risk for colon cancer. No statistically significant differences in risk perception for colon cancer were detected between those individuals who scored low on the chance scale and those who scored high on the chance scale (p=0.622).

Powerful others scale

Of the 66 participants at low risk for colon cancer, low powerful others scorers correctly estimated their risk more frequently than high powerful others scorers. 44% of those scoring high on powerful others and 67% of those scoring low on powerful others correctly estimated their risk for colon cancer. No statistically significant differences in risk perception for colon cancer were detected between those individuals who scored low on the chance scale and those who scored high on the chance scale ($p=0.083$).

4.3.4 OVARIAN CANCER

Of the 87 participants, 75 were women. After excluding those women who had had a total abdominal hysterectomy and those women who did not know their risk perception for ovarian cancer the sample size was 63 women, of which 61 were in the low risk category. For this reason, data analysis was carried out on only those women who were at low risk for ovarian cancer.

Internality Scale

Of the 61 women in the study sample, 71% of externals correctly estimated their risk for ovarian cancer compared to 43% of internals. 57% of women with an internal locus of control overestimated their risk for ovarian cancer compared to 29% of women with an external locus of control. These results were statistically significant at a p-value of 0.040. The bonferonni correction was not necessary in this sample, since the sample size was not truly split amongst three groups. An $\alpha=0.05$ was used.

Chance Scale

56% of low chance scorers and 57% of high chance scorers accurately predicted their risk for ovarian cancer. There were no statistically significant differences in risk perception accuracy for ovarian cancer between low chance and high chance scorers (p-value=0.588).

Powerful Others Scale

Of the 61 women low risk women in the study sample, 67% of low powerful others correctly estimated their risk for ovarian cancer compared to 44% of high powerful others. 56% of those who scored high on powerful others overestimated their risk for ovarian cancer compared to 32% of those who scored low on powerful others. No statistically significant differences in accuracy of risk perception for ovarian cancer were detected (p-value=0.117).

4.3.5 BREAST CANCER

Of the 87 participants in our study in our study, breast cancer risk perception was analyzed on 63 individuals after the sample was filtered through the exclusion criteria.

Internality Scale

Of the 63 individuals who were at low risk for breast cancer, 42% of internals and 53% of externals accurately predicted their risk. Externals were more likely to accurately predict their risk than internals, but this difference was not statistically significant(p-value=0.453).

1 individual was at moderate risk for breast cancer and correctly predicted their risk. 9 individuals were at high risk for breast cancer. Of these individuals 2 externals and 1 internal

correctly estimated their risk, while 4 internals and 2 externals underestimated their risk. There were no statistically significant differences between these two groups (p-value= 0.524).

Chance Subscale

Of the 63 individuals who completed the chance subscale, 47% of high chance scorers and 46% of low chance scorers correctly estimated their risk. There were no statistically significant differences between these two groups (p=1.0)

Powerful others

50% of those who scored high on powerful others and 46% of those who scored low on powerful others correctly estimated their risk for breast cancer. No statistically significant differences were present between these two groups (p-value=0.802).

4.4 MHLC AND HEALTH BEHAVIOR ANALYSIS

A total of 68 individuals completed both the pre- session survey and the 1-3 months follow up survey and were included in the Health Behavior analysis.

4.4.1 PHYSICAL ACTIVITY

Individuals were split up into two groups for analytical purposes. Group 1 consisted of 46 individuals who were physically active at the time of the family history session (individuals who fit the definition of physical activity for more than 6 months or less than 6 months). Group 2 consisted of 22 individuals who were not physically active at the time of the family history session (these were individuals who were contemplating becoming active in either the next 30 days, or the next 6 months in addition to those individuals who were in the pre-contemplation stage and did not have any plans for becoming physically active at the time of the family history session). Data for group 1 was analyzed to determine if locus of control was related to physical activity level maintenance. Data for group 2 was analyzed to determine if locus of control was related to moving through the stages of change of the transtheoretical model, and in turn increasing physical activity behavior change by advancing through one or more stages. Table 8 is a summary of the findings of the MHLC and Physical Activity analysis. There were no statistically significant differences detected across all three MHLC subscales and likelihood to progress through stages of physical activity change.

Table 8. Number of participants who maintained or progressed through the stages of physical activity behavior change and their MHLC subscale classification

Number of participants n (%)		p-value
Internality Scale		
Group 1		p= 0.325
Internals	17 (81%)	
Externals	17 (64%)	
Group 2		p=0.273
Internals	8(100%)	
Externals	4(19%)	
Chance Scale		
Group 1		p= 0.243
Low chance scorers	17 (19%)	
High chance scorers	14(64%)	
Group 2		p= 1.000
Low chance scorers	19 (81%)	
High chance scorers	14(64%)	
Powerful Others Scale		
Group 1		p=0.480
Low powerful others scorers	7(54%)	
High powerful others scorers	15(68%)	
Group 2		p=1.000
Low powerful others scorers	9(82%)	
High powerful others scorers	10(91%)	

Note: Group 1 consisted of individuals who were physically active at start of study.

Group 2 consisted of individuals who were not physically active at start of study.

Of those 46 individuals (68% of study population) who were physically active at the start of the study, 33 (72%) maintained their level of physical activity, whereas 13 (28%) decreased their level of physical activity.

Of those 22 individuals (32%) who were not physically active at the start of the study 86% progressed through the stages of change in working towards increasing their level of physical activity by at least one stage. 6 individuals moved from the pre-contemplation stage to the contemplation stage of becoming physically active within the next 6 months, 10 individuals moved up to or stayed at stage 3 (preparing to become physically active in the next 30 days), and 3 individuals became physically active.

Internality Scale and Physical Activity

Within the physically active group, 17 (81%) of internals maintained their physical activity compared to 17 (64%) of externals. 9 (36%) of externals decreased in their level of physical activity compared to 4(19%) of internals. There was no statistically significant difference detected in maintenance of physical activity between external and internal individuals ($p=0.325$).

Of those individuals who were not physically active to begin with, 8 were internal in their locus of control and 14 were external in their locus of control. 100% of internals ($n=8$) compared to 79% of externals ($n=11$) moved through at least one stage of the transtheoretical model. The majority of individuals who were not physically active to begin with progressed through the stages of changes towards a more physically active lifestyle; however, no statistically significant difference was detected between individuals with an external locus of control and individuals with an internal locus of control ($p=0.273$).

Chance Scale and Physical Activity

Of those individuals in the physically active group, 79% (n=19) of individuals who scored low on the chance scale and 64% (n=14) of individuals who scored high on the chance scale maintained their level of physical activity. There was no statistically significant difference in physical activity maintenance between high and low chance scorers ($p=0.243$).

81% (n=9) of those who scored low on the chance scale and 91% (n=10) of those who scored high on the chance scale progressed through the stages of change and towards increasing their level of physical activity. There was no statistically significant difference between progressing through the stages of change and chance subscale scores ($p=1.000$).

Powerful Others Scale and Physical Activity

Within the physically active group, 54% (n=7) of individuals who scored low on the powerful others scale compared to 68% (n=15) of individuals who scored high on the powerful others scale maintained their level of physical activity. Powerful others score did not play a statistically significant role in likelihood to maintain physical activity ($p=0.480$).

Within the non- physically active group, 82% (n=9) of low powerful others and 91% (n=10) of high powerful others individuals progressed through the stages of change. Powerful others score did not play a statistically significant role in likelihood to advance through the stages of physical activity behavior change ($p\text{-value}=1.0$).

4.4.2 INFORMATION SEEKING

Likelihood to increase level of information seeking behavior was assessed in 66 individuals who were split up into two groups for analytical purposes. Two individuals were not included in this analysis due to not having answered all questions pertinent to the information seeking analysis. The 1st group consisted of individuals who were active or ongoing information seekers. The 2nd group consisted of individuals who were passive searchers or passively attentive to health information. 36 individuals were in the high information seeking group at the start of the study. Of these 36 individuals, 23 maintained their level of information seeking behavior through the duration of the study, whereas 13 individuals decreased into being passive searchers or being passively attentive to health information.

Of the 31 individuals who were either passive searchers or passively attentive to health information, 25 (82%) increased in their level of information seeking behavior, while 6(19%) did not. Table 9 summarizes the number of participants who maintained or increased their level of information seeking behavior and their MHLC subscale scores.

Frequency of information seeking behavior was assessed in 67 individuals by splitting the participants into two groups. The high frequency group consisted of 33 individuals who searched for information either frequently or very frequently. The low frequency group consisted of 34 individuals who searched for information occasionally, rarely, very rarely, or never. 26 (79%) individuals in the high frequency group maintained their level of information seeking behavior throughout the duration of the study. 32 (94%) of individuals in the low frequency group increased their level of information seeking behavior by the end of the study. Table 10 is a summary of those participants who maintained or increased the frequency of their information seeking behavior and their MHLC subscale scores.

Table 9. Number of participants who maintained or increased their level of information seeking behavior and their MHLC subscale classification

Number of participants n (%)		p-value
Internality Scale		
Group 1		p= 0.730
Internals	10 (59%)	
Externals	13 (68%)	
Group 2		p=1.000
Internals	14(78%)	
Externals	11(85%)	
Chance Scale		
Group 1		p= 0.575
Low chance scorers	10(65%)	
High chance scorers	13(63%)	
Group 2		p= 1.000
Low chance scorers	14 (78%)	
High chance scorers	11(85%)	
Powerful Others Scale		
Group 1		p=0.083
Low powerful others scorers	10(50%)	
High powerful others scorers	13(85%)	
Group 2		p=1.000
Low powerful others scorers	11(85%)	
High powerful others scorers	14(78%)	

Note: Group 1 consists of individuals who were in the active or ongoing search at start time of study. Group 2 consists of individuals who were in passive search or passive attention stage at start time of study.

Table 10. Frequency of information seeking behavior and MHLC subscale scores

Number of participants n (%)		p-value
Internality Scale		
Group 1		p= 0.398
Internals	14 (88%)	
Externals	12 (71%)	
Group 2		p=0.513
Internals	19(100%)	
Externals	134(91%)	
Chance Scale		
Group 1		p= 0.195
Low chance scorers	13 (93%)	
High chance scorers	13(68%)	
Group 2		p= 1.000
Low chance scorers	18(95%)	
High chance scorers	18(95%)	
Powerful Others Scale		
Group 1		p=1.000
Low powerful others scorers	14(78%)	
High powerful others scorers	12(80%)	
Group 2		p=1.000
Low powerful others scorers	19(95%)	
High powerful others scorers	13(95%)	

Note: Group 1 refers to those individuals who were either very frequent or frequent searchers of information. Group 2 refers to those individuals who occasionally, rarely, very rarely or never searched for information.

Internality Scale and Information Seeking Behavior

Of the 34 individuals in the high information seeking behavior group, 68% (n=13) of externals and 59% (n=10) of internals maintained their level of information seeking behavior. Internality scale was not a statistically significant predictor of likelihood to increase information seeking behavior (p-value=0.730).

Of the 33 individuals in the high frequency information seeking group, 88% of externals and 71% of internals maintained their frequency of information seeking behavior. Of the 34 individuals in the low frequency information seeking group, 91% of externals and 100% of internals increased their frequency of information seeking. Internality scores were not statistically significant predictors of frequency of information seeking behavior (p-value for high frequency group= 0.398, p-value for low frequency group=0.513).

Chance Scale and Information Seeking Behavior

Of the 36 individuals who were active information seekers, 65% (n=13) of low chance scorers and 63% (n=10) of high chance scorers maintained their level of information seeking behavior (p=0.575).

Of the 31 individuals, who were not active information seekers, 78% (n=14) of those who scored low on the chance scale and 85% (n=11) of those who scored high on the chance scale increased their level of information seeking behavior. Chance scores were not a statistically significant predictor of likelihood to increase information seeking behavior (p=1.0).

Of the 33 individuals in the high frequency information seeking group, 68% (n=13) of externals and 93% (n=13) of internals maintained their frequency of information seeking behavior. Of the 38 individuals in the low frequency information seeking group, 95% (n=18) of

externals and 95% (n=18) of internals increased their frequency of information seeking. Chance scores were not statistically significant predictors of frequency of information seeking behavior (p-value for high frequency group= 0.195, p-value for low frequency group=1.0).

Powerful Others Scale and Information Seeking Behavior

Of the 36 individuals who were in the high information seeking behavior group, 50% (n=10) of those who scored low on powerful others, and 81% (n=13) of those who scored high on powerful others maintained their level of information seeking behavior. Powerful others score was not a statistically significant predictor of likelihood to maintain level of information seeking behavior (p=0.083).

Of the 31 individuals who were in the low information seeking behavior group, 78% (n=14) of those who scored low on powerful others and 85% (n=11) of those who scored high on powerful others increased in their level of information seeking behavior. There was no statistically significant difference detected individuals with high and low powerful others score (p=1.00).

Of the 33 individuals in the high frequency information seeking group, 78% (n=14) of low powerful others and 80% (n=12) of high powerful others maintained their frequency of information seeking behavior. Of the 34 individuals in the low frequency information seeking group, 95% (n=19) of low powerful others and 93% (n=13) of high powerful others increased their frequency of information seeking. Internality scores were not statistically significant predictors of frequency of information seeking behavior (p-value for high frequency group= 1.0, p-value for low frequency group=1.0).

4.4.3 MINORITY RESEARCH RECRUITMENT DATABASE

A total of 68 participants were offered the chance to enroll in the Minority Research Recruitment Database. 54 (79%) individuals enrolled in the database, and 14(21%) individuals declined enrollment. Table 11 is a summary of willingness to enroll in the database and MHLC subscale classifications.

Internality Scale and Database Enrollment

81% (n=30) of externals and 77% (n=24) of internals chose to enroll in the database. Internality score was not a statistically significant predictor of enrollment in the research database (p-value=0.77).

Chance Scale and Database Enrollment

74% (n=25) of low chance scorers and 85% (n=29) of high chance scorers chose to enroll in the database. Chance scores were not a statistically significant predictor of enrollment in the research database (p-value=0.369).

Powerful Others Scale and Database Enrollment

71% (n=27) of individuals who scored low on the powerful others scale and 90% (n=27) of individuals who score high on the powerful others scale chose to enroll in the database. Powerful others subscale score was not a statistically significant predictor of willingness to enroll in the Minority Research Recruitment Database p-value of 0.073.

Table 11. Willingness to enroll in Minority Research Recruitment Database and MHLC subscale scores

Number of participants n (%)	p-value
Internality Scale Internals 24 (77%) Externals 30 (81%)	p= 0.770
Chance Scale Low chance scorers 25 (74%) High chance scorers 29(85%)	p= 0.369
Powerful Others Scale Low powerful others scorers 27(71%) High powerful others scorers 27 (90%)	p=0.073

5.0 DISCUSSION

These data have implications for how to best tailor health intervention efforts to the psychosocial needs of the African American community. This study explored the different dimensions of health locus of control and what role, if any, health locus of control plays in the accuracy of risk perception and health behavior. We used the MHLC scales to evaluate how to improve the effectiveness of the HBFP in promoting physical activity, information seeking behavior, and enrollment in clinical research. The targeted population in this study was African American because they share a greater proportion of the burden of chronic disease than the Caucasian population (Graham et al. 2006). We were interested in determining areas of risk education in need of better tailored interventions. We were interested in evaluating the effectiveness of our current interventions at reaching individuals with differing loci of control, and determining how we could improve our outreach efforts to tailor to the psychosocial needs of our participants.

5.1 RISK PERCEPTION ANALYSIS

Overall, greater than 50% of participants inaccurately estimated or did not know their risk for one or more of the diseases in our study, except for ovarian cancer in which 45% of participants inaccurately estimated their risk. This finding suggests that individuals in our study are inaccurately estimating their risk regardless of their health locus of control. Furthermore,

better tailored risk awareness education interventions, aimed at both externals and internals, are necessary to improve risk perception for diabetes, cardiovascular disease, colon cancer, breast cancer, and ovarian cancer in our study population.

The risk perception analysis findings highlight how interventions can best be tailored to participants' health locus of control in the areas of cardiovascular disease, diabetes, and ovarian cancer, as there were statistically significant differences noted between external and internal individuals.

DIABETES AND POWERFUL OTHERS

Individuals at high risk for diabetes were more likely to underestimate their risk if they were less responsive to the opinions of health professionals regarding their health status. This finding may be explained by the medical distrust present in the African American community as a result of past historical events such as the Tuskegee Syphilis Trial (Outlaw, Bourjolly, & Berg, 2000). Access to medical care did not seem to be a significant problem in our study sample group since 91% reported that they had health insurance and 98% reported that they had at least one primary care physician. Although, access to medical care is not a significant in our study sample, it is a significant contributor to health disparities in the African American population. This finding suggests that in order to increase risk awareness for diabetes in individuals who are less responsive to health professionals we should explore interventions that involve other community members. HBFP participants report that "word of mouth" is one of the more common ways that they receive information about health conditions they find concerning. For the past six years the CMH has worked with local barbershops and beauty salons to train barbers and stylists to be lay health advocates and convey health messages to community members. The HBFP should continue to train barbers and stylists as lay health advocates in order to relay health

messages through the community to better educate community members about diabetes. This intervention takes advantage of “the word of mouth” information medium commonly reported to be used by HBFP participants. A possible individual targeted intervention could be to increase family health history sessions within the barbershop and salon setting. The effectiveness of this intervention can be evaluated by studying risk perception accuracy and MHLC.

Plescia et al. (2004) used the findings of a strong powerful others HLC in his African American study population to educate lay health advisors, who then went on to use these findings by involving ministers and forming partnerships with local churches in order to promote health behavior change. The Witness Project used African American breast cancer survivors to provide information and insight about the importance of early detection and breast self exams to rural African American women in Arkansas. Breast cancer survivors shared their stories and taught self breast exams to women during regularly scheduled church and community services (Barroso et al. 2000). Educating individuals within the community to relay information about diabetes risk, in addition to the use of more targeted one-on-one approaches such as the family health history session is a multi level outreach plan designed to educate both the community and the individual about diabetes.

CVD AND POWERFUL OTHERS

Individuals at moderate risk for cardiovascular disease were more likely to overestimate their risk when they highly valued the opinion of health professionals than those individuals who did not highly value the opinion of health professionals. This finding suggests that individuals are more aware of their increased risk for cardiovascular disease; however, health professionals should still work with these individuals to improve the accuracy of that perception. Efforts should be made by health professionals to decrease burden and anxiety without compromising

accurate risk awareness. Individuals may have feelings of excess burden and anxiety as a result of their increased risk perception. Studies have shown that individuals with increased anxiety may exhibit avoidance behaviors when it comes to preventative screening, diet and exercise (Graham et al. 2006).

One possible explanation for individuals who score high on powerful others and overestimate their risk for cardiovascular disease is poor communication with their health professional. Ashton et al. (2003) suggested that one way health disparities emerge is through doctor-patient interactions due to differences in communication styles when the health professional and patient are of different racial and cultural backgrounds. Studies have shown that physician visits with African Americans tend to be less participatory than those with Caucasian patients (Ashton et al. 2003). A patient's communication behavior can influence the communication of the doctor and vice versa. Four randomized trials have shown that coaching patients in verbal behavior techniques to increase their participation during the physician visit can increase communication behavior and improve health outcomes (Ashton et al. 2003). Ashton and his group have been providing a series of community group forums titled "How to Talk With Your Doctor and Get Your Doctor to Talk With You!" In addition to educating patients, Ashton suggests that doctors need to provide openings and prompts to help the patient do four things: 1. provide a health narrative 2. ask questions, 3. express concerns, and 4. be assertive.

Individuals who tend to score higher on the powerful others scale feel that health professionals are in control of their health and there is little they can do to improve their health status. For this reason we can speculate that high powerful others patients may not be as inquisitive about their risk for heart disease; therefore, may be less likely to ask questions of the health professional. Efforts must be made to empower individuals with the right questions to ask

to clarify their disease risk. This can be done by providing handouts through the HBFP mailings directly to participants' homes. Information on how to communicate with the physician can be included in the HBFP monthly newsletter. The HBFP has been providing participants with Ask Me 3 Literature to teach participants the right questions to ask their doctor. The family health history intervention is an excellent medium by which individuals can clarify their disease risk and learn how to facilitate dialogue with their physician about health concerns. Lastly, efforts should be made to improve patient doctor communication by utilizing verbal behavior coaching techniques to increase patient participation, providing health forums, and educating physicians on how to best communicate information about prevention and self-management to patients of different racial and cultural backgrounds than their own.

OVARIAN CANCER AND INTERNALITY

Women at low risk for ovarian cancer were more likely to correctly estimate their risk if they were external than if they were internal. Women who were classified as internal overestimated their risk. Ovarian cancer is a rare disease that is generally not well understood by the public. It is difficult to detect until its later stages, which in most cases means it has already metastasized. There is no effective ovarian screening available to the general public. The lifetime risk for a woman to develop ovarian cancer is less than 2% (ACS, 2008). Women who are at high risk for ovarian cancer based on family history may choose to have the CA-125 blood test and transvaginal ultrasound on an annual basis. This screening approach has a false positive rate of 50%. Some high risk women may choose to have a prophylactic bilateral salpingo-oophorectomy to remove both ovaries and decrease their risk for ovarian cancer by 95% (ACS, 2008). The negative aspect of the bilateral salpingo-oophorectomy is that it is an invasive

procedure and that the removal of the ovaries may increase the risk for heart disease and osteoporosis in women who have the surgery when they are pre-menopausal.

Because there is no effective general population screening for ovarian cancer at this time, doctor-patient discussion about ovarian cancer is limited to only those individuals who are high risk due to a family history. There has been little public health education regarding ovarian cancer (CDC, 2006). Individuals who are internal are more likely to engage in preventative behaviors because they feel that they have more control over their future health (Norman et al. 1998). We can speculate that women who are internal are more likely to practice self breast exams, get annual mammograms to reduce their risk for breast cancer, and get colonoscopies to reduce their risk for colon cancer. When it comes to ovarian cancer, there may be nothing women can do to feel in control of their risk. Since there is little education in the medical and public health settings, and no effective screening for ovarian cancer, women who are internal may feel like there is little that they themselves can do to reduce their risk for disease. It would then follow that internal women will actually perceive their risk for ovarian cancer to be higher than their actual objective risk. External women may be assessing their risk more correctly than internal women since they are probably more comfortable with the idea that there is little they can do to reduce their risk for ovarian cancer.

Although, it is true that there is no effective prevention strategy for ovarian cancer, our findings emphasize the importance of counseling and educating women regarding their risk to reduce feelings of burden and anxiety. The HBFP family health history initiative provides participants with the opportunity to sit down with a genetic counseling student and receive one-on-one counseling regarding cancer risks, including ovarian cancer risk.

Furthermore, these findings highlight the importance of community-based outreach education for not only ovarian cancer, but cancer in general. Conversations with HBFP participants during the family health history session have revealed that individuals tend to overestimate their family health history risk for cancer when there are multiple cases in the family, regardless of the fact that these cases are most likely sporadic, and unrelated. Furthermore there is literature that supports that individuals tend to overestimate their risk for cancer when there are multiple cases present in the family history (Vernon, 1999). As noted earlier, individuals who tend to overestimate their risk for cancer may feel a heightened sense of anxiety and undue burden. Studies have shown that elevated levels of anxiety may interfere with adhering to recommended screenings and prevention behaviors and lead to avoidance behavior in these individuals (Graham et al. 2006). It is equally important to work with individuals who are overestimating their risk as it is to work with individuals who are unaware of their risk towards a more accurate risk perception. All individuals should be educated about cancer and have a realistic understanding of their risk, as well as what can and cannot be done to reduce their risk. For example, women should be counseled about the high false positive rate of ovarian screening and why it is reserved for high risk women. The family health history initiative is an excellent setting for individuals to discuss their risk for cancer. During the family health history session the genetic counseling student can delineate which families are in fact at high risk for a hereditary cancer syndrome, which families have a clustering of cancer most likely occurring by chance, and those families in which the cancer is most likely due to environmental causes (i.e. lung cancer and cervical cancer). The student is trained to educate the participant about their cancer risk, appropriate screening and prevention strategies, and refer those who are at high risk

for hereditary cancer to genetic counseling. In addition to the family health history, the HBFPP has created monthly cancer forums to educate individuals about cancer risk, and prevention.

Previous work has shown the effectiveness of the family health history session at improving risk perception accuracy for colon cancer and heart disease (Murphy, 2005). Further evaluation is warranted to determine if the effectiveness of the family health history session in improving risk perception for individuals with both an external and internal locus of control. It is the hope of the Healthy Black Family Project that the family health history initiative may serve as an effective tool for improving risk perception not only in the Healthy Black Family Project community here in Pittsburgh, but may one day be used as a model intervention in other community settings nationwide.

The findings of the MHLC and risk perception analysis emphasize the importance of tailoring outreach approaches to health locus of control. These findings suggest that bringing health professionals into the community to facilitate dialogue about disease risk, improving communication between health providers and their patients, working within the community to encourage health screening and prevention behaviors, and using the family health history initiative to improve risk perception accuracy are all important avenues to further explore in health promotion efforts in the areas of cardiovascular disease, diabetes, and ovarian cancer.

5.2 HEALTH BEHAVIOR ANALYSIS

The Health Behavior analysis reveals that individuals are maintaining or working towards increasing their level of physical activity, becoming more active information seekers, and enrolling in the research recruitment database regardless of their health locus of control.

Our findings show that there were no statistically significant differences between externals and internals across all three subscales of the health locus of control and likelihood to maintain or work towards increasing their level of physical activity. The majority of our sample, 46 of 69 individuals or 68%, was physically active for at least 30 days to begin with. The majority (72%) of these individuals maintained their level of physical activity regardless of whether their degree of internality, regardless of their beliefs about the role that fate, luck, chance and health professionals played in their overall well being. The remaining 22 individuals who were not physically active at the start of our study showed similar results. The majority of these participants moved in the direction of working towards increasing their level of physical activity regardless of their degree of internality, their beliefs about chance, and their value of the opinion of health professionals.

Our study similarly found no statistically significant differences between individuals across all three subscales of the MHLC and their likelihood to increase level of information seeking behavior, to increase frequency of information seeking behavior, and to enroll in the Minority Research Recruitment database.

Health locus of control has been shown to be a predictor of health behavior in several large scale studies. Norman et al. (1998) utilized the MHLC to study participation in health behaviors in 11,632 individuals from the UK. The health behaviors studied were exercise, diet, smoking, and alcohol consumption. The results of the study revealed that a strong belief that one's health is under one's control was correlated with performance of a greater number of health behaviors. This result supports prior findings that individuals who score high on the internality scale are more likely to engage in health behaviors. In order to study likelihood to participate in health information seeking behavior, Hashimoto and Fukuhara (2004) administered

the MHLHC to 3395 randomly selected Japanese individuals. The findings of their study revealed that individuals were more likely to participate in health information seeking if they scored low on powerful others scale. In other words, individuals who are less dependent on powerful others were more likely to participate in health information seeking. The results of our study indicate that the majority of HBFP participants participate in health promoting behaviors regardless of their health locus of control scores. One possible explanation for the pattern of behavior change observed in our study is that the HBFP is an effective intervention in that it reaches out to the diverse psychosocial needs of its community population. The Healthy Black Family Project has been able to engage individuals who feel that they have little control over their health, as well as those individuals who feel that the greater part of their health lies within their own hands. Another possible explanation for the pattern of behavior change occurring regardless of health locus of control is that our study is limited by a sample size that is too small to detect differences between external and internal individuals. However, the finding that the majority of the participants in this study increased their level of participation in health promoting behaviors despite their health locus of control score provides preliminary evidence that the HBFP has been successful at targeting individuals with diverse psychosocial needs. Further exploration is necessary to clarify whether or not the HBFP is reaching out to both external and internal individuals.

Obesity and chronic diseases such as diabetes, hypertension, cardiovascular disease, and cancer are, now more than ever, on the rise in the American population with African Americans carrying the greater portion of the disease burden (Graham et al, 2006). Prevention through education is the first line of defense against chronic disease. It is the goal of public health professionals to decrease the burden of chronic disease. Psychosocial barriers often stand in the

way of participation in preventative behaviors such as physical activity, information seeking, and enrollment in clinical research. These psychosocial barriers include feelings of helplessness, lack of control, mistrust of health professionals, and sometimes, too much trust in health professionals (the belief that health professionals can cure all illnesses).

From a public health perspective our study is relevant because our findings suggest that the HBFP breaks through psychosocial barriers, allowing individuals to work to improve their health behaviors regardless of their health locus of control. Furthermore, our study is relevant because it supports that the HBFP can be used as an effective model for community based outreach intervention projects nationwide to decrease the burden of chronic disease in minority populations by educating individuals about their risk, and empowering them with ways to reduce the risk. The Healthy Black Family project has utilized different approaches for disseminating information to individuals with differing levels of health information seeking behaviors, maximizing the role of health professionals in community outreach, and targeting minority involvement in clinical research. Community health outreach programs should implement tailored interventions in order to transcend psychosocial barriers and encourage individuals with differing loci of control to participate in physical activity, information seeking, and medical research.

5.3 STUDY LIMITATIONS

The health behavior analysis may have been limited by the sample size of 68 participants. It is necessary to perform this analysis on a larger sample size to ensure relationships between

MHLC, outcome measures, and risk perception are detected. An adequate sample size would be 125 individuals.

This study had several limitations. One of the limitations is that the study population is not diverse primarily including African Americans. However, this study set out to oversample African Americans as all of the participants of this study were recruited through the Healthy Black Family Project. The implications of the findings of this study are limited to the African American population.

Additionally, this study is limited by sample bias. Since all of the participants were recruited through the Healthy Black Family Project individuals in this study may be highly motivated individuals set on increasing their levels of physical activity, information seeking behavior, and participating in medical research.

In addition to the above form of sample bias, there may be another form of sample bias since only individuals who completed a family health history session were recruited for the purpose of this study. Although, genetic counseling students emphasize that knowledge of family health history is not a prerequisite for participation in the family health history session, those individuals who have little knowledge of their family health history may have opted not to participate. Those individuals who already know their family health history may have opted not to participate. Since these individuals may not have participated in the family health history session it is quite possible that the risk perception analysis may have been skewed to individuals that have moderate knowledge of family history.

Another limitation of this study is that physical activity behaviors and information seeking behaviors were all based on self report. Therefore, it is difficult to know whether or not

individuals actually did increase their level of physical activity and information seeking behavior.

Family health history information was self reported and was not verified by death certificates or medical record therefore participants may have chosen to leave out certain information about their family health history. Self-reported information may have resulted in altered results of the Scheuner criteria-based risk assessment for the risk perception analysis.

Level of activity in the Healthy Black Family Project was not documented. Individuals were considered active if they were a member of the HBFP and had participated in the family health history session.

This study was limited by a short term follow up time period of 1 to 3 months. It would be useful to assess the impact of the HBFP on physical activity and information seeking behaviors at the 1 year time point to determine if individuals maintained or worked to increase their level of physical activity and information seeking behaviors.

Lastly, there was no direct measure of self-efficacy in this study. Self-efficacy is the belief in one's ability to perform a particular behavior. For future studies of MHLC it may be beneficial to include a measure of self-efficacy.

5.4 FUTURE PLANS

This study highlighted the areas of diabetes, cardiovascular disease, and ovarian cancer as those that would benefit from approaches tailored to locus of control for risk awareness

education. Future work should use the MHLC to evaluate the effectiveness of the family health history intervention at improving the accuracy of risk perception for diabetes, cardiovascular disease, and ovarian cancer. This work will help determine the effectiveness of the family health history intervention in educating individuals with differing loci of control about their disease risk.

Further work can be done to explore whether MHLC is related to objective risk and an individual's likelihood to participate in screening health behaviors such as mammography, colonoscopy, and prostate cancer screening. This study can be further expanded to look at changes in diet, smoking cessation, and other health behaviors.

6.0 CONCLUSION

This study evaluated the MHLC in an African American, community based public health outreach intervention program. This study has important clinical and public health implications. We set out to explore the psychosocial needs of the Healthy Black Family Project participants and how our project could best address those needs. We did this by using the MHLC to study differences in risk perception accuracy so that we could highlight which disease areas were in need of better tailored risk education approaches. We also used the MHLC to study physical activity, information seeking behaviors, and enrollment in medical research among our participants to determine how the HBFP can become more successful at targeting individuals with differing loci of control.

Risk perception analysis was performed on a total of 87 participants who completed the MHLC and family health history session. Out of our initial study population of 87 participants 68 also completed the follow up survey 1 to 3 months after the initial family health history session. Participants were asked about their level of physical activity and information seeking behavior at follow up. The outcome measure analysis was performed on the 68 individuals who completed both the initial family history session and the follow up.

Each individual's MHLC questionnaire was scored on three different scales: internality, chance, and powerful others. Individuals were classified as high internals vs. low internals, high chance vs. low chance, and high powerful others vs. low powerful others. Internals are those

individuals who feel that their health is the result of their own actions. High chance scorers are those individuals who feel that their health is the result of chance, luck, and fate. High powerful others scores are those individuals who feel that health professionals, and family members play a large role in their health status.

Based on Scheuner et al. (1997) risk criteria we identified individuals at low, moderate, and high risk for a series of multifactorial chronic diseases. We then compared their risk perception to their objective risk to determine accuracy. Once accuracy was determined we checked for differences on MHLC subscale scores. We identified the areas of diabetes, cardiovascular disease, and ovarian cancer as areas in which participants would benefit from risk education tailored to their locus of control. We suggest that approaches to improve risk perception accuracy be tailored to address individuals with differing loci of control by:

1. Maximizing the role of powerful others;
2. Improving communication between health professionals and their patients;
3. Maximizing the role of community members;
4. Using the family health history intervention as a way to counsel individuals to decrease undue burden and anxiety, without compromising accurate risk perception in individuals who tend to overestimate their risk.

MHLC scores were used to search for relationships between health locus of control and health behaviors such as physical activity, information seeking, and enrollment in research. We found that individuals maintained or were working to increase their level of physical activity, increased their level and frequency of information seeking behavior, and enrolled in the research recruitment database regardless of their internality, beliefs in chance, fate, and luck, and the value they placed on the role of powerful others in their health status. We believe that the pattern of behavior change observed in this exploratory study may preliminary evidence that the HBF

is effective at promoting positive health behavior change in both external and internal individuals. We recommend that the MHLC and Health Behavior analysis be continued for further exploration of HBFP outreach efforts.

The goal of any public health promotion campaign is to improve the overall health and quality of life of its targeted population. There is great psychosocial diversity within a population and it is important to understand this diversity in order for outreach efforts to truly reach out to all kinds of individuals. There are many psychosocial barriers that stand in the way of making changes to health behavior. Individuals may feel helpless and unlucky when it comes to control of their health. These individuals may often be missed by health programs that are targeted to more proactive individuals. Health Locus of Control is thought to be a state, not a trait, and can be influenced by life experiences and well designed health programs. The Healthy Black Family Project is tailored to a diverse group of individuals and is able to reach out to those who may be missed by other health programs. The MHLC is a useful measure to assess the effectiveness of health programs to reach out to individuals with differing loci of control and can help shed light on how to maximize the effectiveness of health programs by tailoring them to the individuals whose health we aim to improve.

APPENDIX A

RISK PERCEPTION ANALYSIS

DATA TABLES

Table 12. Diabetes risk perception and comparison of MHLC subscale scores

Scale	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Internality				
Low risk				p=0.433
Internals	7(44%)	9(56%)	n/a	
Externals	3(23%)	10(77%)	n/a	p= n/a
Moderate risk				
Internals	0	0	1	p= 1.000
Externals	1	3	1	
High risk				p= 1.000
Internals	8(50%)	n/a	8 (50%)	
Externals	7(47%)	n/a	8(53%)	
Chance				
Low risk				p=0.449
High chance	3(25%)	9(75%)	n/a	
Low chance	7(41%)	10(59%)	n/a	p=n/a
Moderate risk				
High chance	0	1	0	p=0.269
Low chance	1	2	2	
High risk				p=0.269
High chance	8(62%)	n/a	5(39%)	
Low chance	6(35%)	n/a	11(65%)	
Powerful Others				
Low risk				p=1.000
High po	5(33%)	10(67%)	n/a	
Low po	5(36%)	9(64%)	n/a	p=n/a
Moderate risk				
High po	0	2	0	p=0.011
Low po	1	1	2	
High risk				p=0.011
High po	10(77%)	n/a	3(23%)	
Low po	5(28%)	n/a	13(72%)	

Table 13. CVD risk perception and comparison of MHLC subscale scores

Scale	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Internality				
Low risk				p=0.691
Internals	3(30%)	7(70%)	n/a	
Externals	6(40%)	9(60%)	n/a	
Moderate risk				p= 1.000
Internals	4(33%)	6(50%)	2(17%)	
Externals	2(40%)	2(40%)	1(20%)	
High risk				p= 1.000
Internals	8(53%)	n/a	7 (47%)	
Externals	10(56%)	n/a	8(44%)	
Chance				
Low risk				p=1.000
High chance	3(38%)	5(63%)	n/a	
Low chance	6(35%)	11(65%)	n/a	
Moderate risk				p=0.196
High chance	4(57%)	3(43%)	0	
Low chance	2(20%)	5(50%)	3(30%)	
High risk				p=0.479
High chance	7(44%)	n/a	9(56%)	
Low chance	10(63%)	n/a	6(38%)	
Powerful Others				
Low risk				p=0.226
High po	3(23%)	10(77%)	n/a	
Low po	6(50%)	6(50%)	n/a	
Moderate risk				p=0.005
High po	0	6 (100%)	0	
Low po	6(55%)	2(18%)	3 (27%)	
High risk				p=1.000
High po	9(56%)	n/a	7(44%)	
Low po	9(53%)	n/a	8(47%)	

Table 14. Colon cancer risk perception and comparison of MHLC subscale scores

Scale	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Internality				
Low risk				p=0.808
Internals	19(56%)	15(49%)	n/a	
Externals	19(60%)	13(40%)	n/a	
Chance				
Low risk				p=0.622
High chance	17(61%)	11(39%)	n/a	
Low chance	20(54%)	17(46%)	n/a	
Powerful Others				
Low risk				p=0.083
High po	12(44%)	15(56%)	n/a	
Low po	26(67%)	13(33%)	n/a	

Table 15. Breast cancer risk perception and comparison of MHLC subscale scores

Scale	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Internality				
Low risk				p=0.453
Internals	13(42%)	18(58%)	n/a	
Externals	17(53%)	15(47%)	n/a	
Moderate risk	Sample size too small for analysis			
High risk	Sample size too small for analysis			
Chance				
Low risk				p=0.794
High chance	12(46%)	14(54%)	n/a	
Low chance	17(47%)	19(56%)	n/a	
Powerful Others				
Low risk				p=0.802
High po	13(50%)	13(50%)	n/a	
Low po	17(46%)	20(54%)	n/a	

Table 16. Ovarian cancer risk perception and comparison of MHLC subscale scores

Scale	Accurate n (%)	Overestimate n(%)	Underestimate n(%)	p-value
Internality				
Low risk				p=0.040
Internals	13(43%)	17(57%)	n/a	
Externals	22(71%)	9(29%)	n/a	
Moderate risk				
Sample size too small for analysis				
High risk				
Sample size too small for analysis				
Chance				
Low risk				p=1.000
High chance	12(57%)	9(43%)	n/a	
Low chance	22(56%)	17(44%)	n/a	
Powerful Others				
Low risk				p=0.117
High po	12(44%)	15(56%)	n/a	
Low po	23(68%)	11(33%)	n/a	

APPENDIX B

IRB APPROVAL LETTER



University of Pittsburgh
Institutional Review Board

3500 Fifth Avenue
Ground Level
Pittsburgh, PA 15213
(412) 383-1480
(412) 383-1508 (fax)

MEMORANDUM

TO: Stephen B. Thomas, PhD

FROM: Richard Guido, MD, Chair *R. Guido*

DATE: September 11, 2007

SUBJECT: IRB #0403125: THE HEALTHY BLACK FAMILY PROJECT: Assessing the Response of African Americans to Family Health Histories

The Institutional Review Board reviewed the recent modifications to your protocol and consent form(s) and find them acceptable for expedited review. These changes, noted in your submission of August 20, 2007, are approved.

Please include the following information in the upper right-hand corner of all pages of the consent form(s), if modifications were made to the consent form(s):

Current Approval Date: March 23, 2007
Modification Approval Date: September 07, 2007
Renewal Date: March 22, 2008
University of Pittsburgh
Institutional Review Board
IRB #0403125

The protocol and consent forms, along with a brief progress report must be resubmitted at least **one month prior** to the renewal date noted above as required by FWA00006790 (University of Pittsburgh), FWA00006735 (University of Pittsburgh Medical Center), FWA00006600 (Children's Hospital of Pittsburgh), FWA00003567 (Magee-Womens Health Corporation), FWA00003338 (University of Pittsburgh Medical Center Cancer Institute).

If this research study is subject to FDA regulation, please forward to the IRB all correspondence from the FDA regarding the conduct of this study.

Please be advised that your research study may be audited periodically by the University of Pittsburgh Research Conduct and Compliance Office.

RG:kh

APPENDIX C

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL AND SCORING INSTRUCTIONS

Form A

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)		4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)					
		SD	MD	D	A	MA	SA
1	If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5	Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am in control of my health.	1	2	3	4	5	6
7	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
8	When I get sick, I am to blame.	1	2	3	4	5	6
9	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10	Health professionals control my health.	1	2	3	4	5	6
11	My good health is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14	Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
17	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

SCORING INSTRUCTIONS FOR THE MHLC SCALES

SUBSCALE	FORM(s)	POSSIBLE RANGE	ITEMS
Internal	A, B, C	6 - 36	1, 6, 8, 12, 13, 17
Chance	A, B, C	6 - 36	2, 4, 9, 11, 15, 16
Powerful Others	A, B	6 - 36	3, 5, 7, 10, 14, 18

APPENDIX D

PRE SURVEY QUESTIONNAIRE

An important aim of genetic counseling is to provide risk information so that individuals and families can make better informed decisions about their health and that of their families. The purpose of this survey is to explore your perceptions of risk for developing certain health conditions. We want to understand whether family health histories (i.e., sharing information about diseases in your family) can help provide you with a more accurate assessment of your risk for developing particular health conditions.

If there is a question that you do not feel comfortable answering, you can skip it and continue on.

Please answer the following questions to the best of your ability.

DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.

The survey should take approximately 10 minutes.

We would like to thank you in advance for your willingness to participate in this survey.

Section 1: General Information

1) What is your age?

___ age in years

2) What is your gender?

1 - Male

2 - Female

3) Are you Hispanic or Latino?

- 1 - Yes
- 2 - No
- 3 - Don't know

3a) Which one or more of the following would you say is your race? **(Check all that apply)**

- 1 - White
- 2 - Black or African American
- 3 - Asian
- 4 - Native Hawaiian or Other Pacific Islander
- 5 - American Indian, Alaska Native
- 6 - Other [specify] _____

4) What was the total household income from all sources last year?

- 1 - Less than \$10,000
- 2 - Between \$10,000 and \$20,000
- 3 - Between \$20,001 and \$35,000
- 4 - Between \$35,001 and \$50,000
- 5 - Between \$50,001 and \$75,000
- 6 - Greater than \$75,000

5) What is the highest grade or year of school you completed?

- 1 - Grades 8 or less (Elementary)
- 2 - Grades 9 through 11 (Some high school)
- 3 - Grade 12 or GED (High school graduate)
- 4 - College 1 year to 3 years (Some college or technical school)
- 5 - College 4 years or more (College graduate or post-graduate)
- 6 - Graduate level (Masters or PhD)

6) How would you rate your knowledge on genetics?

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

7) How would you describe your general health?

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

8) Do you smoke?

- 1 - Yes
- 2 - No

9) How would you describe your weight?

- 1 - Underweight
- 2 - Healthy weight
- 3 - Overweight
- 4 - Obese

10) Do you have one person you think of as your personal doctor or health care provider?

- 1 - Yes, only one
- 2 - Yes, more than one
- 3 - No
- 4 - Don't know / Not sure

11) Was there a time in the past 12 months when you needed to see a doctor but could not because of the cost?

- 1 - Yes
- 2 - No
- 3 - Don't know / Not sure

12) Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare?

- 1 - Yes
- 2 - No
- 3 - Don't know / Not sure

Section 2: Physical Activity Habits

Definition of Physical Activity: The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

11) Based on this definition, are you physically active?

- 1 - Yes, I have been for more than 6 months
- 2 - Yes, I have been for less than 6 months
- 3 - No, but I am planning on starting in the next 30 days
- 4 - No, but I am thinking about starting in the next 6 months
- 5 - No, and I don't plan to start in the next 6 months

12A) If you answered **YES** to question 11, how often do you exercise on average?

- 1 - One time/week
- 2 - Two to three times/week
- 3 - Four or more times/week

12B) If you answered **YES** to question 11, what is the length of your workouts on average?

- 1 - 30 minutes or less
- 2 - 30 – 45 minutes
- 3 - 45 minutes or more

12C) If you answered **NO** to question 11, do you get some physical activity but not enough to fit the definition?

- 1 - Yes
- 2 - No

Section 3: Risk Perception

13) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease?

(Please respond for each item listed)

- 1=Never
- 2= Sometimes
- 3=Always
- 4=Don't know / Not sure

Smoking	_____
Having a poor diet	_____
Lack of exercise	_____
Family history (other family members with a disease)	_____

14) What do you think the chances are of a **healthy woman the same age as you** to develop the following health conditions sometime in her life?

(Please respond for each condition listed)

- 1=Low (<10%)
- 2=Moderate (10-50%)
- 3=High (>50%)
- 4=Don't know / Not sure

Breast cancer	_____
Ovarian cancer	_____
Colon cancer	_____
Heart disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
High Blood Pressure	_____

15) What do you think the chances are of a **healthy man the same age as you** to develop the following health conditions sometime in his life? **(Please respond for each condition listed)**

(Please respond for each condition listed)

1=Low (<10%)

2=Moderate (10-50%)

3=High (>50%)

4=Don't know / Not sure

Breast cancer _____

Colon cancer _____

Prostate cancer _____

Heart disease _____

Lung cancer _____

Diabetes _____

Alzheimer's disease _____

High Blood Pressure _____

16) Have you ever been concerned about your chances for developing any of these health conditions?

1 - Yes

2 - No

16a) If yes, which condition(s)? _____

17) On a scale from 1 (not concerned) – 5 (extremely concerned), how would you rate your concern about developing any of the above health condition(s)? _____

18) Do you have a blood relative (mother, father, sister, brother, uncle, aunt, grandmother, grandfather) who had or has a health condition that you are concerned about developing sometime in your life?

1 - Yes

2 - No

3 - Don't know / Not sure

18a) If **YES**, who had the condition and what was it?

***DO NOT INCLUDE NAMES OF FAMILY MEMBERS, ONLY THE RELATIONSHIP TO YOU**

19) Have you ever talked to a health provider about your concern for developing that particular health condition?

- 1 - Yes
- 2 - No
- 3 - Don't know / Not sure

19a) If yes, which condition (s)? _____

20) At this time, what do you think your chances are of developing any of the following health conditions sometime in your life? **(Please respond for each condition listed)**

- 1=Low (<10%)
- 2=Moderate (10-50%)
- 3=High (>50%)
- 4=Don't know / Not sure
- 5=I already have the condition

Breast cancer	_____
Ovarian cancer (Females Only)	_____
Colon cancer	_____
Prostate cancer (Males Only)	_____
Heart disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
High Blood Pressure	_____

21) At this time, what do you think your chances are of developing any of the following health conditions someday, compared with most individuals your age?

(Please respond for each condition listed)

ML=Much lower

SL=Somewhat lower

S=Same

SH=Somewhat higher

MH=Much higher

DK=Don't know / Not sure

AH=I already have the condition

Breast cancer	_____
Ovarian cancer (Females Only)	_____
Colon cancer	_____
Prostate cancer (Males Only)	_____
Heart disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
High Blood Pressure	_____

Section 4: Multidimensional Health Locus of Control

Form A

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)		4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)					
		SD	MD	D	A	MA	SA
1	If I get sick, it is my own behavior which determines how soon I get well again.	1	2	3	4	5	6
2	No matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	Having regular contact with my physician is the best way for me to avoid illness.	1	2	3	4	5	6
4	Most things that affect my health happen to me by accident.	1	2	3	4	5	6
5	Whenever I don't feel well, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am in control of my health.	1	2	3	4	5	6
7	My family has a lot to do with my becoming sick or staying healthy.	1	2	3	4	5	6
8	When I get sick, I am to blame.	1	2	3	4	5	6
9	Luck plays a big part in determining how soon I will recover from an illness.	1	2	3	4	5	6
10	Health professionals control my health.	1	2	3	4	5	6
11	My good health is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my health is what I myself do.	1	2	3	4	5	6
13	If I take care of myself, I can avoid illness.	1	2	3	4	5	6
14	Whenever I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.	1	2	3	4	5	6
15	No matter what I do, I'm likely to get sick.	1	2	3	4	5	6
16	If it's meant to be, I will stay healthy.	1	2	3	4	5	6
17	If I take the right actions, I can stay healthy.	1	2	3	4	5	6
18	Regarding my health, I can only do what my doctor tells me to do.	1	2	3	4	5	6

APPENDIX E

POST SURVEY QUESTIONNAIRE

We hope that you enjoyed having your family health history done.

We would like to ask you a few more questions about risk to see if the family health history session changed your ideas about what conditions you might be at risk for. In addition, this post-session survey is looking at your opinions regarding participating in research.

If there is a question that you do not feel comfortable answering, you can skip it and continue on.

Please answer the following questions to the best of your ability.

DO NOT PROVIDE ANY NAMES OF FAMILY MEMBERS.

The survey should take approximately 10 minutes.

We would like to thank you in advance for your willingness to participate in this survey.

Section 1: Physical Activity Habits

1) Based on our discussion, do you think that you will increase your physical activity?

1 - Yes

2 - No

Section 2: Risk Perception

2) In your opinion, how often do you believe each of the following factors increases (or contributes to) an individual's chance or risk for developing a disease?

(Please respond for each item listed)

1=Never

2= Sometimes

3=Always

4=Don't know / Not sure

Smoking

Having a poor diet

Lack of exercise

Family history (other family members with a disease)

3) Based on your family health history, what do you think your chances are of developing any of the following health conditions sometime in your life?

(Please respond for each condition listed)

- 1=Low (<10%)
- 2=Moderate (10-50%)
- 3=High (>50%)
- 4=Don't know / Not sure
- 5=I already have the condition

Breast cancer	_____
Ovarian cancer (Females Only)	_____
Colon cancer	_____
Prostate cancer (Males Only)	_____
Heart disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
High Blood Pressure	_____

4) Based on your family health history, what do you think **your chances** are of developing any of the following health conditions **someday**, compared with most individuals your age?

(Please respond for each condition listed)

- ML=Much lower
- SL=Somewhat lower
- S=Same
- SH=Somewhat higher
- MH=Much higher
- DK=Don't know / Not sure
- AH=I already have the condition

Breast cancer	_____
Ovarian cancer (Females Only)	_____
Colon cancer	_____
Prostate cancer (Males Only)	_____
Heart disease	_____
Lung cancer	_____
Diabetes	_____
Alzheimer's disease	_____
High Blood Pressure	_____

Section 3: Opinions on Research

5) How important do you feel that medical research is?

- 1 - Very important
- 2 - Somewhat important
- 3 - Not very important
- 4 - Not important at all
- 5 - Don't know

6) Have you ever participated as a subject in any medical research studies?

- 1 - Yes
- 2 - No
- 3 - Don't know

7) Have you ever been offered the chance to participate in a medical research study, but decided not to participate?

- 1 - Yes
- 2 - No
- 3 - Don't know

8) If you were to describe your general attitude towards medical research involving people, would you say that you feel ...?

- 1 - Very favorable
- 2 - Somewhat favorable
- 3 - Somewhat unfavorable
- 4 - Very unfavorable
- 5 - Neither favorable nor unfavorable
- 6 - Don't know

9) Would the offer of free medical care make you more likely or less likely to agree to participate in research?

- 1 - More likely
- 2 - Less likely
- 3 - No effect
- 4 - Don't know

10) Would the offer of \$500 make you more likely or less likely to agree to participate in research?

- 1 - More likely
- 2 - Less likely
- 3 - Have no effect
- 4 - Don't know

11) Would the offer of free medicine make you more likely or less likely to agree to participate in research?

- 1 - More likely
- 2 - Less likely
- 3 - Have no effect
- 4 - Don't know

12) How much do you think scientists benefit from medical research?

- 1 - A great deal
- 2 - A moderate amount
- 3 - Only a little
- 4 - Not at all
- 5 - Depends

13) How much do you think your community benefits from medical research?

- 1 - A great deal
- 2 - A moderate amount
- 3 - Only a little
- 4 - Not at all
- 5 - Depends

14) How much do you think your family and friends benefit from medical research?

- 1 - A great deal
- 2 - A moderate amount
- 3 - Only a little
- 4 - Not at all
- 5 - Depends

15) How much do you think you benefit from medical research?

- 1 - A great deal
- 2 - A moderate amount
- 3 - Only a little
- 4 - Not at all
- 5 - Depends

16) Do you have an interest in having your name in a database that would allow you to receive information about clinical research studies related to your family health history?

NOTE: Answering YES to this question DOES NOT enter you into any database nor does it sign you up to receive any information.

- 1 - Yes
- 2 - No

16a) If you answered **YES**, what are your expectations? **(Please circle all that apply)**

- 1 - I expect to receive information about *all* of the latest research studies.
- 2 - I expect to receive information about studies that I am eligible for.
- 3 - I expect to be rewarded for participating in research (paid, free health care, etc.)
- 4 - I expect to get the best health care available.
- 5 - Other: _____

16b) If you answered **NO**, what are your primary reasons? **(Please circle all that apply)**

- 1 - I am not interested in participating in research.
- 2 - I am not interested in anything tied to my family/my genetics.
- 3 - I do not want to be part of a database.
- 4 - I do not want to disclose my contact information.
- 5 - Other: _____

17) How would you describe your experience with having your family health history taken? **(Please circle all that apply)**

- 1 - Enjoyable
- 2 - Informative
- 3 - Uncomfortable/Unpleasant
- 4 - Neutral/No opinion

Section 4: Information Seeking Behavior

18) Do you think that you will share the Family Health History with your doctor?

- 1 - Yes
- 2 - No

19) Do you think that you will share the Family Health History with your family?

- 1 - Yes
- 2 - No

20) I am comfortable when it comes to talking to my doctor about health concerns.

- 1 - Agree Strongly
- 2 - Agree Moderately
- 3 - Agree Slightly
- 4 - Disagree Slightly
- 5 - Disagree Moderately
- 6 - Disagree Strongly

21) What are the barriers, if there are any, which stand in the way of you talking to your doctor about health concerns? **(Circle all that apply)**

- 1 - Not enough time during the appointment
- 2 - I am never sure which questions to ask
- 3 - I do not want to talk to my doctor about my health concerns
- 4 - I am afraid I would not understand the information
- 5 - I don't feel there are any barriers
- 6 - Other _____

22) If there are barriers which stand in the way of talking to your doctor about health concerns, what do you think would help you get past those barriers?

23) I am comfortable discussing family history and health concerns with my family members

- 1 - Agree Strongly
- 2 - Agree Moderately
- 3 - Agree Slightly
- 4 - Disagree Slightly
- 5 - Disagree Moderately
- 6 - Disagree Strongly

24) What are the barriers, if there are any, which stand in the way of you talking to your family about health concerns? **(Circle all that apply)**

- 1 - Fear of health conditions
- 2 - My family does not discuss health concerns
- 3 - Difficult to find the time to talk
- 4 - Other_____

25) If there are barriers which stand in the way of talking to your family about health concerns, what do you think would help you get past those barriers?

26) Where do you seek information regarding health conditions you are concerned about?

- 1 - Doctor
- 2 - Library
- 3 - Internet
- 4 - Family and friends
- 5 - Community health fair
- 6 - Other_____

27) Circle the statement that most closely resembles your information seeking behavior.

1 - I am aware of the health conditions that run in my family, but I do not feel the need to do any more research on these conditions.

2 - I am aware of the health conditions that run in my family and I read about these conditions when the information is provided for me.

3 - I have done some of my own research on health conditions that I am concerned about.

4 - I actively keep up with current research on health conditions that I am concerned about.

28) How frequently do you research health conditions that you are concerned about?

1 - Very Frequently

2 - Frequently

3 - Occasionally

4 - Rarely

5 - Very Rarely

6 - Never

**Thank you for taking the time to answer these few questions.
Your participation is greatly appreciated.**

APPENDIX F

FOLLOW UP SURVEY QUESTIONNAIRE

Date: _____

Person Making Phone Call: _____

INTERVIEWER: ASK TO SPEAK WITH THE INDIVIDUAL WHO GAVE US HIS OR HER NAME AND TELEPHONE NUMBER. IF YOU ARE TOLD THAT THE PERSON IS NOT HOME, SCHEDULE A CALL-BACK. WHEN YOU ARE SPEAKING WITH THE INDIVIDUAL, READ...

Hi, my name is _____ and I am calling from the Center for Minority Health at the University of Pittsburgh. About a month ago, you completed a survey and had your family health history (family tree) completed at _____. As you may recall, you agreed to let us contact you for a follow-up questionnaire. I just have a couple of brief questions to ask you. It should take about five minutes. Is it okay to proceed with the questions?

☐ **Yes** ☐ **No** – end interview

If Yes → Proceed to Question 1

If No → Thank you for your time. Have a great day.

1) After having your family health history drawn out, which statement best describes how you felt? **(Circle all that apply)**

- 1 - More Informed
- 2 - More Concerned
- 3 - Same as before
- 4 - Confused
- 5 - Worried

2) Did you tell any one that you had your family health history drawn out?

1 - Yes If Yes → Proceed to Question 2a and 2b

2 - No If No → Proceed to Question 3

2a) Who did you tell about your family health history?

2b) What did you tell them?

3) Has anything about your family health history changed since we met?

1 - Yes

If Yes → Proceed to Question 3a

2 - No

If No → Proceed to Question 4

3a) What has changed about your family health history?

4) Have you contacted any other relatives or researched old records to learn more about your family history?

1 - Yes

2 - No

5) Have you added to or updated any part of your family health history?

1 - Yes

If Yes → Proceed to Question 5a

2 - No

If No → Proceed to Question 6

5a) What part of your family health history have you added to or updated?

6) Did you look over the materials/information we sent you with your family health history?

1 - Yes

If Yes → Proceed to Question 6a

2 - No

If No → Proceed to Question 7

6a) Did you find the materials/information sent to you helpful?

1 - Yes

→ Proceed to Question 6b

2 - No

→ Proceed to Question 7

6b) Would you like any additional information?

1 - Yes

2 - No

7) Have you seen a health care professional since you had your family health history done?

1 - Yes

If Yes → Proceed to Question 7a

2 - No

If No → Proceed to Question 8

7a) Did you show your family health history to the health care professional?

1 - Yes

If Yes → Proceed to Question 7b

2 - No

If No → Proceed to Question 8

7b) What did he or she say about it?

(After response proceed to Question 7c)

7c) Did the health care professional put your family health history in your medical file?

1 - Yes

2 - No

8) In regards to the following statement: “Having my family health history drawn out has made me more comfortable in talking my doctor about health concerns,” would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

9) In regards to the following statement: “Having my family health history drawn out has made me more comfortable in talking to my family about health concerns,” would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

10) Do you have any plans to show your family health history to your family in the next six months?

1 - Yes

2 - No

11) Do you plan to show your family health history to a health care professional (i.e., doctor, nurse, pharmacist, physician assistant, or genetic counselor) in the next six months?

1 - Yes

2 - No

12) During our meeting, you answered a question about your physical activity; I am going to read that question to you again to see if your answer has changed.

I am going to read you the definition of Physical Activity. The national recommendation for physical activity is engaging in moderate physical activity (walking briskly, mowing the lawn, dancing, bicycling) for 30 minutes a day 5 or more days a week OR engaging in vigorous physical activity (jogging, high-impact aerobics, swimming) for 20-30 minutes a day 3 or more days a week.

Based on this definition, which of these statements best describes your level of being physically active? **(Select only one response)**

1 - Yes, I have been physically active for more than 6 months

2 - Yes, I have been physically active for less than 6 months

3 - No, I have not been physically active, but I am planning on starting in the next 30 days

4 - No, I have not been physically active, but I am thinking about starting in the next 6 months

5 - No, I have not been physically active and I don't plan to start in the next 6 months

If Answered 3, 4, or 5 → Proceed to Question 12a

If Answered 1 or 2 → Proceed to Question 12b

12a) Have you increased your physical activity, but not enough to fit the definition?

1 - Yes → Proceed to Question 12b

2 - No → Proceed to Question 12b

12b) Did having the family health history drawn out play a role in increasing your physical activity?

1 - Yes → Proceed to Question 12c

2 - No → Proceed to Question 12c

12c) Do you attend fitness classes at the Kingsley?

1 - Yes → Proceed to Question 12d

2 - No → Proceed to Question 13

12d) What do you feel are the benefits of participating in the fitness classes offered at Kingsley? Would you say... **(Circle all that apply)**

1 - Improving current health

2 - Preventing future health problems (i.e. diabetes, hypertension)

3 - Weight Management

4 - Stress Relief

5 - More Energy

6 - Other_____

13) What kind of physical activity, if any, do you engage in? **(Circle all that apply)**

1 - Walking

2 - Jogging

3 - Aerobics

4 - Bicycling

5 - Housework/yardwork

6 - Swimming

7 - None

8 - Other_____

14) Have you made any other lifestyle changes since we did your family health history?
(Circle all that apply)

1 - Improved Diet

2 - Smoking cessation

3 - Talking to doctor about health concerns

4 - Increased health screening (mammogram, colonoscopy, PSA)

5 - Joined a support group

6 - Other _____

7 - None

If Answered 7 (No changes) → Proceed to Question 14a

If Answered 1 thru 6 → Proceed to Question 15

14a) Do you want to or are you planning on making any changes?

1 - Yes → Proceed to Question 14b

2 - No → Proceed to Question 15

14b) Are there any barriers that prevent you from making changes?

1 - Yes → Proceed to Question 14c

2 - No → Proceed to Question 15

14c) What are the barriers that prevent you from making changes?
(After response proceed to Question 14d)

14d) Is there anything that would help you make the changes you want? (ie: classes, support groups)

15) In regards to the following statement: "Having my family health history drawn out motivated me to increase my knowledge about health conditions that run in my family," would you say that you agree strongly, agree moderately, agree slightly, disagree slightly, disagree moderately, or disagree strongly? **(Select only one response)**

1 - Agree Strongly

2 - Agree Moderately

3 - Agree Slightly

4 - Disagree Slightly

5 - Disagree Moderately

6 - Disagree Strongly

If Answered 1, 2, or 3 → Proceed to Question 15a

If Answered 4, 5, or 6 → Proceed to Question 16

15a) How have you increased your knowledge/understanding? (talked to doctor, family, friends, internet, library, etc.) (After response proceed to Question 15b)

15b) Which of the following statements most closely resembles your information seeking behavior: **(Select only one response)**

1 - I am aware of the health conditions that run in my family, but I do not feel the need to do any more research on these conditions.

2 - I am aware of the health conditions that run in my family and I read about these conditions when the information is provided for me.

3 - I have done some of my own research on health conditions that I am concerned about.

4 - I actively keep up with current research on health conditions that I am concerned about.

16) In regards to the following statement: “How frequently do you research or look for information about health conditions that concern you,” would you say that you look very frequently, frequently, occasionally, rarely, very rarely, or never? **(Select only one response)**

1 - Very Frequently

2 - Frequently

3 - Occasionally

4 - Rarely

5 - Very Rarely

6 - Never

**Thank you for taking the time to answer these few questions.
Your participation is greatly appreciated.**

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