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Using a Family History Intervention to Improve Cancer Risk Perception in a Black Community

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INTRODUCTION

Although Americans have recently experienced an increase in life expectancy and overall health, not everyone is benefiting equally from medical advances and public health Campaigns (Sullivan Commission, 2004; Groman and Ginsburgh, 2004). African Americans (AA) have the highest death rate and shortest survival of any racial and ethnic group in the United States for most cancers, including breast and colorectal cancer, both of which are most effectively treated in early stages (ACS, 2011). In 2011, approximately 169,000 new cancer cases will occur among AA, of which the most commonly diagnosed cancers among men are prostate (PRCA) (40%), lung (15%), and colorectal (CRC) (9%) and among women, breast (BRCA) (34%), lung (13%), and colorectal (11%) (ACS, 2011). The lack of progress at reducing disparities in cancer mortality has been attributed to low screening rates leading to later diagnoses, socioeconomic factors, inaccurate cancer risk perceptions, clinician screening recommendations, and mistrust of the healthcare system (Bloom, 2006; Facion, 2007; Sadler, 2007; Griffith, 2008; Ward, 2008).

Risk perception, a complex cognitive process influenced by a variety of factors and unique to each individual, can be a driving force in an individual's decision to undertake preventive health action (Yoon, 2003; Sivell, 2008; Ward, 2008). Risk perception is a central theoretical construct in recognized models of health behavior change, including but not limited to the Health Belief Model, the Precaution Adoption Model, and the Transactional Model of Stress and Coping (Vernon, 1999; NCI, 2005; Sivell, 2008). An individual's risk

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perception, which derives from threat appraisal, can be most relevant for changing health behaviors (Vernon, 1999).

Research has shown that interventions have been beneficial in improving risk perceptions for BRCA, CRC, and PRCA (Carlos, 2005; DiLorenzo, 2006; Pavic, 2007). Moreover, perceived risk is often a motivator for positive health-related behaviors, particularly with respect to cancer screenings. For example, women are becoming more knowledgeable about breast cancer risk and as a result are more closely adhering to screening guidelines (Powe, 2004; Blumenthal, 2005; Basch, 2006; Pavic, 2007). Blumenthal and colleagues evaluated culturally appropriate media messages related to screening and found that among AA participants these interventions were associated with an increase in BRCA, CRC, and PRCA screenings (Blumenthal, 2005).

Elevated risk perception has been associated with family history (FH) (Watson, 1999; Hopwood, 2003; Warner, 2003). Furthermore, individuals with a FH of a given disorder are more likely to engage in disease prevention behaviors for that disorder (McCaul, 1996; Petersen, 1999; Bloom, 2006). Although research has been inconclusive regarding the relationship between perceived risk, family history, and screening intentions for PRCA and CRC among AA, some studies have shown an association (Bloom, 2006; Katz, 2007; Griffith, 2008; Spain, 2008). Codori et al. found that a strong family history of CRC was associated with better adherence to sigmoidoscopy screening (Codori, 1999; Yoon, 2002; Yoon, 2003). Among AA women with a positive family history of BRCA, participants were more inclined to adhere to mammography and clinical breast examination recommendations (Halbert, 2006; Laing, 2008).

In 2004, the U.S. Surgeon General announced the *Family Health Initiative*, a national campaign to promote the use of FH for disease prevention and health promotion (DSHS, 2004). The use of genetic information, particularly FH, has the potential to identify at-risk individuals and provide opportunities for education, prevention, and early diagnosis. In addition, FH can lay the foundation for accurate risk perception and appropriately identify at-risk individuals for targeted, risk-reducing interventions (Guttmacher, 2004).

One approach to address health disparities among AA is to investigate the process of documenting family histories as an intervention to influence risk perception and motivate at-risk individuals to engage in protective health behaviors. Family history alone has been shown to be a significant risk factor for various cancers. Yoon and colleagues summarized several case-control studies that have shown an increased relative risk associated with one or more affected first-degree relatives among individuals in the general population with a family history of BRCA, CRC, and PRCA (Yoon, 2002). Using FH information to identify AA at increased cancer risk may lead to improved screening in moderate- and high-risk individuals, thereby decreasing the disease burden in this population and contributing to the reduction of health disparities.

The University of Pittsburgh's Graduate School of Public Health Center for Minority Health (CMH) developed the *Family Health History Initiative* in 2003 to explore the utility of family health histories (FHH) as an intervention to improve knowledge of cancer risk. The

development of this initiative has been previously described by Vogel et al. (Vogel, 2007) and is a component of the Healthy Black Family Project (HBFP), a community-based intervention designed to prevent diabetes and cardiovascular disease (Thomas, 2008). Two aims of this initiative were to 1) determine the accuracy of AA participants' risk perceptions for common diseases, including various cancers and 2) understand how participants' perceptions were influenced by FHH interviews. The outcomes of these aims are reported in this paper.

METHODS

Participants

AA participants were recruited from the greater urban Pittsburgh area between May 2004 and June 2008. The study population was drawn from the Health Empowerment Zone (HEZ) in the East End of Pittsburgh, a geographic region defined by urban residential neighborhoods consisting of at least 60% black residents, 20% below the federal poverty line, and considered to be medically underserved (Thomas, 2008). Locations were selected within two predominantly black (72.5% and 97% African American residents) neighborhoods, East Liberty and Homewood-Brushton in the HEZ (Thomas, 2008). Recruitment took place in various community settings, including churches, retirement centers, community health fairs/events, barbershops and beauty salons, and community centers in these neighborhoods. In addition, participants were recruited through word-of-mouth networks (Thomas, 2008; Ford, 2009). Participants were eligible if they were 18 years or older, spoke and read English, and were able to provide informed consent.

The study proceeded in three stages for each participant: 1) a pre-session survey documenting demographics and disease risk perceptions, 2) an interview session recording and assessing each participant's family history, and 3) a post-session survey documenting disease risk perceptions. The pre- and post-session surveys were each designed to take approximately 20 minutes to complete. The interview session was designed to take 30 minutes with time allotted for risk assessment. We compared pre- and post-FHH risk perceptions to the Scheuner risk classification system—high, moderate, and average risk (Scheuner, 1997). All study procedures were reviewed and approved by the Human Subjects Institutional Review Board of the University of Pittsburgh.

Instrumentation

The pre-session survey instrument collected demographic characteristics, including age, gender, self-reported racial/ethnic background, income, education, and general health and insurance status. Participants were asked to evaluate their perceived genetics knowledge, presented as “how would you rate your knowledge on genetics?” with response options coded as excellent, very good, good, fair and poor. Thus, genetic knowledge was self-reported. Additionally, participants were asked about their perceptions on general risk factors for chronic disease including smoking, poor diet, FH, and physical activity. Participants were asked “how often do you believe each of these factors increases or contributes to an individual's chance or risk of developing a disease such as diabetes, heart

disease and cancer?” with response options coded using a Likert-style scale: 1 (Never), 2 (Sometimes), 3 (Always), or 4 (Don’t know/not sure).

The pre- and post- session surveys explored participant’s risk perceptions for nine chronic diseases. The diseases surveyed include heart disease, diabetes, hypertension, Alzheimer’s disease, cancers of the breast, colon, lung, ovary and prostate. Participants were asked the following question: “Based on your FHH, what do you think your chances are of developing any of the following health conditions sometime in your life?” Participants reported their perceived risks using a Likert-style scale: 1 (Low = < 10%), 2 (Moderate = 10–50%), to 3 (High = > 50%). Participants were also given the option to answer “don’t know.” The present analysis is focused on risk perceptions relating to BRCA, CRC, and PRCA due to the prevalence of these cancers among AA and known genetic contributions.

Our survey questions on risk perception were informed by the face validity of existing instruments published in the literature (Hughes, 1996; Hopwood, 2001). We were unable to identify any validated survey to explore risk perceptions among African Americans.

Procedures

Vogel et al. have previously described the FHH sessions, in which participants completed family history interviews with Master’s-level genetic counseling (GC) students (Vogel, 2007). Over the 5 year (2004–2008) recruitment period, a total of 11 genetic counseling students from the Department of Human Genetics in the University of Pittsburgh’s Graduate School of Public Health served as Graduate Research Assistants in the CMH and were dedicated to conducting family health histories. Each student served a two year rotation. In any given year, one to three students were performing FHH in the community. Of these 11 students, eight self-identified as Caucasian, one of mixed race (Caucasian and Asian), one Asian, and one African American. Ten of the 11 students were female and all were between the ages of 22 and 31 (Smith, 2010). Participants constituted a sample of convenience, recruited at community health fairs, barbershop outreach, church events, etc. Counseling students scheduled interviews based upon their workload and the availability of the participant.

The GC students completed appropriate training prior to taking FHH and performing risk assessments. Family health history information was recorded by creating a pedigree using standard pedigree nomenclature (Bennett, 1995; Vogel, 2007). Upon completion of gathering a participant’s FHH, the GC students assessed the participant’s FHH and discussed the participant’s objective risks for various conditions. The students’ risk assessments were based on the guidelines developed by Scheuner and colleagues for stratifying risk based on FH information (Bennett, 1995; Scheuner, 1997).

Data Analysis

We examined the percent distribution of objective risk using the Scheuner guidelines and participants’ risk perceptions pre- and post-FHH. Predictors of change in risk perception post-FHH were examined. Several variables were created to construct the final outcome variable *risk perception change post-FHH*. Initially, a variable was created that determined

the accuracy of pre-FHH risk perception as compared to objective risk. For example, if a person reported average pre-FHH risk, and her/his objective risk was average, then s/he would be categorized as *accurate pre-FHH*. If the person perceived her/his risk as average but the objective risk was high, then s/he would be categorized as *inaccurate pre-FHH*. A similar variable was constructed for *accuracy* and *inaccuracy post-FHH*. These variables were used to construct the final outcome variable. If an individual was *accurate* or *inaccurate* at both pre- and post-FHH, s/he would be categorized as *unchanged*. If the individual was *inaccurate* at pre-, but became *accurate* at post-FHH, or vice versa, s/he would be categorized as *changed*.

Logistic regression was used to examine whether each variable predicted change in risk perception post-FHH. Initial models were unadjusted and examined to determine whether each variable alone significantly predicted risk perception change. Multiple logistic regression was performed to examine whether variables remained significant after including other predictors (> 50 years of age, income, education, self-reported general health, knowledge of genetics, accuracy of risk perception at pre-FHH, perceptions of poor diet, lack of exercise, smoking, and FH, health insurance status, having a healthcare provider, and whether participant had difficulty seeing a doctor in the last 12 months). The mean age for this sample was 52 years; thus, to facilitate statistical analysis, the age category cut-off was 50 years. Interactions were also assessed between accuracy at pre-FHH and the following variables: self-reported health status as fair/poor and risk perceptions related to poor diet, lack of exercise, smoking, and FH.

Exclusion criteria

Participants' responses were excluded from the risk perception analysis for the specified cancer if they reported to have been diagnosed with the condition. A total of 19, 7, and 9 individuals were excluded for BRCA, CRC, and PRCA, respectively, given self-reported diagnoses. Since the majority of participants were female, we excluded males from risk perceptions related to BRCA. Also, we only included male responses to risk perception questions on PRCA. Therefore, the number of participants will vary for each disease. In addition, participants who responded "*don't know*" or had missing responses were excluded from accuracy of risk perception analysis and logistic regression analysis. Participants with missing data on covariates were also excluded from logistic regression analysis.

RESULTS

Demographics, Self-Reported Health, and Perceived Knowledge of Genetics

Individuals who agreed to complete their FHH (n=797) were offered participation in the study, and those who were interested completed pre- and post-session surveys (n=683 or 85%) after informed consent was obtained. Of those who completed the surveys, 665 (83%) participants self-identified as AA and were included in the analyses.

Table I provides a summary of participants' demographic characteristics. Of 665 AA participants, 84% of participants were women and the mean age was 52 years. Seventy-seven percent had at least some college education and 41% had incomes of at least \$35,000.

The majority of individuals reported their general health as good or higher (71%), and almost half perceived their knowledge of genetics as either good, very good, or excellent (49.5%).

Of the 665 participants, 81.4% (n=541) provided risk perception for BRCA (includes all unaffected women), 79.3% (n=528) for CRC (of whom 84.1% or 444 were women), and 14.1% (n=94) for PRCA (includes all unaffected men). Characteristics for participants who provided risk perceptions for BRCA and CRC were similar. Men providing their risk perceptions for PRCA tended to have higher incomes (earning more than \$50,000), to report very good/excellent health status, and to perceive very good/excellent knowledge of genetics.

Perceived Risk Factors

We assessed individuals' perceptions of various risk factors (having a poor diet, lack of exercise, smoking, and FH) associated with the development of a chronic disease (table not presented). The majority of individuals (62% to 75%) perceived that poor diet, lack of exercise, and smoking were always risk factors for chronic disease, in general. In contrast, a smaller percentage (42%) found that having a FH of a disease was always a risk factor.

Objective Cancer Risk

Participants' objective risks, using the Scheuner guidelines for family history for BRCA, CRC, and PRCA, are presented in Table II. For each of these cancers, most participants had an average objective risk, n=462 or 85%, n=591 or 90%, and n=80 or 85%, respectively. Fewer participants were found to have moderate risk (n=42 or 7.8% for BRCA, n=48 or 7.3% for CRC, and n=13 or 13.8% for PRCA) and high risk (n=37 or 6.8% for BRCA, n=16 or 2.4% for CRC, and n=1 or 1.1% for PRCA).

Perceived Cancer Risk

Table II summarizes participants' perceived risks prior to and following the FHH intervention. Prior to the FHH session, most participants perceived themselves to have average or moderate risk to develop BRCA (average=39.7%; moderate=38.8%), CRC (average=44.7%; moderate=29.8%) and PRCA (average=22.3%; moderate=42.6%). We found that 9.2% and 8.9% of participants perceived their BRCA and CRC risk, respectively, as high and one-fifth (19.2%) of males perceived their PRCA risk as high.

Post-FHH average risk perceptions for BRCA (58.0%), CRC (58.8%), and PRCA (35.1%) increased compared to before their FHH (Table II). Fewer participants perceived themselves to be at high risk for BRCA, CRC, and PRCA (8.0%, 5.8%, and 11.7%, respectively).

Accuracy of Cancer Risk Perception

Table III shows perception accuracy pre- and post-FHH. While there were a number of individuals who remained inaccurate and a smaller number who were accurate pre-FHH and inaccurate post-FHH for all three cancers, the majority of participants (292/463 or 63.1% for BRCA; 349/528 or 66.1% for CRC) had accurate risk perceptions post-FHH. For PRCA, fewer participants (32/77 or 41.6%) were accurate post-FHH. Of those who were inaccurate

pre-FHH, we found that 104 (or 43.3%) for BRCA, 103 (or 43.8%) for CRC, and 19 (or 34.5%) for PRCA adopted accurate risk perceptions as a result of the FHH session.

Factors Predictive of Change in Cancer Risk Perceptions Post-Family Health History

Table IV shows the results from logistic regression models. In the initial univariate logistic regression, most variables were not significant predictors of change in risk perception, except for inaccuracy at pre-FHH and self-reported fair/poor health status. Individuals whose risk perceptions changed for BRCA and CRC post-FHH were roughly four times (95% CI 2.63-6.83 for BRCA, 2.85-6.75 for CRC) more likely to change if they were inaccurate at pre-FHH than if they were accurate. Other covariates (demographic characteristics, perceived knowledge of genetics, perception of general risk factors, insurance status, and cost) were adjusted for and results showed that inaccuracy at pre-FHH remained a significant predictor of change in BRCA (OR: 4.63, 95% CI 2.85-7.51) and CRC risk perceptions (OR: 4.28, 95% CI 2.74-6.70) post-FHH. Self-reported fair/poor health status for CRC, which initially was a significant predictor of change in risk perception (OR=1.88, 95% CI 1.22-2.88), was no longer a significant predictor of change after controlling for other covariates (OR: 1.61, 95% CI 0.99-2.62). There were no significant predictors of change in risk perception for PRCA. Interactions between inaccuracy and the following variables: self-reported fair/poor health status and risk perceptions relating to poor diet or having a FH of a disease were not significant.

DISCUSSION

In this community-based study, we evaluated the influence of FHH interviews on AA risk perceptions of BRCA, CRC, and PRCA. We targeted AA because they have higher mortality rates for these cancers than Caucasians in Allegheny County and represent an underserved population (PA DOH, 2002; Thomas, 2008). We examined whether FHH interviews could promote more accurate risk perceptions for cancer. More importantly, we intended to raise awareness about FH as a risk factor for cancer, encourage participants to discuss FH with their family and physicians, and inform participants about appropriate cancer screening guidelines.

We found that study participants appropriately identified smoking, poor diet, physical inactivity, and FH as disease-contributing factors. However, they were less confident about the role of FH. Participants' uncertainties may stem from a lack of understanding and/or healthcare provider communication about FH and disease. Public health campaigns have focused attention on and developed interventions educating AA on the negative effects of smoking, the importance of a healthy diet, and the necessity of engaging in routine physical activity (Royce, 1993; Paschal, 2004; Lewis, 2005; Fu, 2008). It is noteworthy that each of these factors is amenable to behavior change through health promotion and disease prevention efforts. Only with the recent advancements stemming from the Human Genome Project and personalized medicine have national public health initiatives begun to aggressively educate healthcare providers and the public on the relevance of FH not only as a risk factor for disease but also as a potential motivator for adoption of healthy lifestyles (Yoon, 2002; Frezzo, 2003; Guttmacher, 2004; DSHS, 2004).

Prior to the FHH intervention, many of our participants tended to overestimate their cancer risks. Our findings are consistent with past reports that show individuals in the general population often overestimate or misinterpret cancer risks (Watson, 1999; Hopwood, 2003; Bloom, 2006; Odedina, 2008; Spain, 2008). A meta-analysis by Meiser and Halliday evaluated studies that explored risk perception accuracy among individuals undergoing BRCA genetic counseling. They concluded that individuals at risk for BRCA had significantly improved risk perceptions after genetic counseling (Meiser, 2002). Butow and colleagues also had similar observations in their systematic review (Butow, 2003). However, Butow et al. also found that there was a proportion (22–50%) of individuals who still overestimated their risk post-counseling. The majority of studies evaluated by Meiser and Butow focused on BRCA genetic counseling of predominantly Caucasian participants in high risk clinics. Interestingly, we had similar observations in our community-based study with AA participants.

A recent systematic review by Smerecnik et al. focused on the impact of genetic counseling on risk perception accuracy and extended the previous reviews by Meiser and Butow to other genetic conditions including various cancers as well as non-cancerous conditions (Smerecnik, 2009). Similar to Butow et al, they concluded that genetic counseling may have a positive impact on risk perception accuracy (Smerecnik, 2009). Smerecnik reported that some studies observed no effect on risk perception accuracy at all, or only found changes among low-risk individuals. Among those studies that assessed the proportion of individuals who accurately estimated their risk, Smerecnik et al. determined that there was an average increase of approximately 25% (range: 2-55%) of counselees who correctly estimated their risk after counseling; from an average of 42% pre-counseling to an average of 58% post-counseling. However, on average 25% (range 7-55%) continued to overestimate their risks and 19.5% (range: 7-55%) underestimated their risks post-counseling (Smerecnik, 2009). Our findings are consistent with these studies in that the majority of participants in our study had accurate risk perceptions post-FHH for BRCA and CRC; however, we also found that some participants either overestimated or underestimated their risks following the intervention.

Possible explanations for continuing to have inaccurate cancer risk perceptions post-genetic counseling may include inadequacy of the communication process, difficulties by the counseled individual in comprehending or remembering the information given, personal experience with disease, age of participants, media misrepresentation of general cancer risks, and differences in risk presentation format by healthcare providers (Hopwood, 2000; Meiser, 2002; Hopwood, 2003; Smerecnik, 2009). According to Matthews, “many AA have unspoken beliefs or concerns about illness that influence their attitudes and perceptions about cancer” (Matthews, 2000, p. 14). Therefore, cultural beliefs such as *cancer as a taboo topic*, *negative perceptions regarding cancer survivability*, *general anxiety with cancer screening*, and the belief that *focusing on cancer may lead to developing cancer* may have contributed to inaccurate cancer risk perceptions post-FHH among our study participants. Further research is needed to better delineate these associations and to identify solutions for cancer education targeting African Americans.

In our study, AA men were more likely to have inaccurate risk perceptions for PRCA post-FHH (45/77 or 58.4%). Studies have shown that AA men often have inaccurate risk perceptions for PRCA, which suggests a need for interventions designed to educate AA men about the role of FH in determining PRCA risk (Bloom, 2006; Odedina, 2008; Spain, 2008). Documenting a family history, making AA men more aware of their risks, and providing information regarding available screenings and risk-reducing behaviors may improve risk perceptions and screening practices (Scheuner, 1997; Frezzo, 2003; Yoon, 2003).

Study Limitations

A number of limitations apply to this study. First, our participants were self-referred and therefore may not be representative of the AA population in Pittsburgh. The majority of our participants were educated AA women with health insurance coverage. Based on a three-year US Census Bureau estimate (2007-2009) of Pittsburgh's demographic profile, the majority of adults aged 25+ had at least a high-school education (90.6%) and were insured (90.4%) (Pittsburgh Indicators Project, 2011). Although our study participants had similar health insurance coverage (89%), they had less education (78%) compared to the US Census estimate for Pittsburgh residents.

The nature of the HBFP with its focus on lifestyle behavior change and low impact physical activity was attractive to AA women who recruited their family and friends. This is not an unanticipated outcome given that women tend to seek health information for themselves and their families more often than men and are likely to utilize it in health care decisions (Copeland, 2000). The HBFP, specifically the FHH Initiative, provided a non-threatening means for participants to learn about the importance of FH in relation to patterns of chronic disease.

Another limitation of the study is that knowledge of genetics was assessed by self-report and not with the use of a validated instrument. Therefore, participants may have over or under estimated their knowledge of genetics. Additionally, although the interview team informed all potential participants that knowledge of their FHH was not a prerequisite to participate in the study, some individuals may have refused due to lack of knowledge about the types of disease and causes of death among their family members.

Vogel et al. described other challenges to enrollment including inability to quantify the number of potential participants and difficulty in contacting those who indicated interest in participation (Vogel, 2007). Another limitation is that our data rely on participant recall rather than medical documentation, which may lead to inaccurate classification of objective risk.

Research Recommendations

In the future, we plan to explore risk perception recall and whether participants' perceptions change over time. We plan to expand our study to explore participants' communications of FH information with family members and healthcare providers as well as the impact of the intervention on participants' willingness to engage in healthy behaviors and cancer screenings. We may also consider community venues that exclusively serve men (e.g., barbershops, fraternities, and sporting events) as a means to increase male participation in

the FHH Initiative. Finally, the study design can be strengthened by use of a validated instrument on knowledge of genetics as a means to increase the reliability and validity of changes in knowledge before and after the FHH interview over time.

Implications for Genetic Counseling Practice

We explored the use of FHH as an intervention and its influence on participants' perceptions of risk. We learned that for many a FHH intervention in a non-clinical setting can lead to accurate cancer risk perceptions. According to Etchegary et al. (2007),

“In the context of genetic counseling, at risk people may hold beliefs about their own risk derived largely from the pattern of disease expression in their families. These beliefs can be used to negate or exaggerate their actual risk, and as such, may preclude the systematic processing of risk information discussed during counseling or the acceptance of risk-reducing protective behaviors. Indeed, family history of illness is a powerful influence on personal genetic-risk perception...” (Etchegary, 2007, pg. 421).

An interesting and remarkable outcome of this initiative is how well the FHH intervention resonated with AA participants. It is possible that techniques utilized by genetic counselors assimilate traditions of black oral history. The FHH intervention lends itself to cultural values that are based in the AA community and oral history traditions (Banks-Wallace, 2002). It is noteworthy that our approach provided genetic counseling students, the majority of whom were not African American, the opportunity to learn about these cultural values and to have a deeper understanding of the lives of study participants in a manner not often experienced by genetic counselors trained and practicing in traditional clinical settings alone.

Genetic counselors are increasingly interacting with individuals of diverse racial and cultural backgrounds. Moreover, gaps in effective communication continue to be pervasive in health care and contribute to disparities in health. As stated by Thomas et al. (2004),

“Efforts to eliminate health disparities must be informed by the influence of culture on the attitudes, beliefs, and practices of not only minority populations but also public health policymakers and the health professionals responsible for the delivery of medical services and public health interventions designed to close the health gap” (p. 2050)).

Therefore, genetic counselors can engage in this effort by not only understanding their own racial and cultural identities, but pursuing education and training opportunities that promote awareness of the cultural attitudes, beliefs and practices of the clients they serve (Ota Wang, 2001).

The successful recruitment of African American study participants in our study was made possible by working in partnership with credible, opinion leaders with shared values of the target community and operating out of trusted venues such as black barbershops, beauty salons, community centers and black churches. This combination of working with trusted leaders and recruiting in community settings facilitated our ability to communicate key

messages on health, family history, and preventive screening. Most importantly these messages were reinforced by active participation in the Healthy Black Family Project.

Conclusions

As the dialogues and public health education campaigns continue, the public will become more aware of FH as a risk factor which may positively influence health behaviors. A detailed FHH can be useful in identifying individuals in the general population who may be at increased risk to develop cancer and targeted for personalized prevention strategies.

Today, practicing genetic counselors have great challenges to overcome in serving patient populations, and have adapted by diversifying their skills to provide nontraditional counseling, including phone-and web-based, telemedicine, and contract services. Similarly, genetic counseling training programs could benefit from developing strategies to provide experiences for GC students to be engaged in the community by partnering with community-based organizations serving underserved communities. Additionally, practicing genetic counselors can benefit from continuing education and training opportunities that enrich their understanding of the diverse cultural beliefs, attitudes, and values of our patient populations. This approach is in concert with the vision and mission of genetic counselors to integrate genetics and genomics to improve health outcomes and to provide quality genetic services and education (NSGC, 2011). The HBFP Family Health History Initiative demonstrated the feasibility of launching such a program outside of the clinical environment.

Many AA participants commented that the experience of documenting the FHH and seeing the information on paper “opened their eyes.” As stated by Dr. David Satcher, “the greatest opportunities for reducing health disparities are in empowering individuals to make informed healthcare decisions and in providing the skills, education, and care necessary to improve health” (Satcher, 2000). Family health histories may serve as the bridge between patients and providers by incorporating cultural traditions to improve health communication and increase uptake of preventive measures, in order to reduce disease burden.

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Table 1

Demographic data of family health history participants (n = 665)

	All participants	
	n	%
Male	104	15.6
Female	561	84.4
Age		
50	282	42.4
>50	383	57.6
Mean Age (SD)	52.38 (13.37)	
Income		
\$20,000	185	27.8
\$20,001 to \$35,000	159	23.8
\$35,001 to \$50,000	119	17.9
\$50,001 to \$75,000	154	23.2
Missing	49	7.4
Education		
High School Education	149	22.4
Some College (to 3 years)	303	45.6
College Graduate or Post Graduate Education	208	31.3
Missing	5	0.8
Self-Reported General Health		
Excellent/Very Good	128	19.3
Good	345	51.9
Fair/Poor	185	27.8
Missing	7	1.1
Knowledge of Genetics		
Excellent/Very Good	72	10.8
Good	258	38.8
Fair/Poor	320	48.1
Missing	15	2.3
Have Health Insurance		
No	65	9.8
Yes	593	89.2
Don't Know / Not Answered	7	1.1
Have a Healthcare Provider		
No	35	5.3
Yes, only 1	395	59.4
Yes, >1	226	34
Don't Know / Not Answered	9	1.4

	All participants	
	n	%
Needed to see MD in past 12 months but could not because of cost		
No	566	85.1
Yes	92	13.8
Don't Know / Not Answered	7	1.1

Of the 665 participants, 81.4% (n = 541) provided risk perception for BRCA (includes all unaffected women), 79.3% (n = 528) for CRC (of whom 84.1% or 444 were women), and 14.1% (n = 94) for PRCA (includes all unaffected men). Characteristics of participants who provided risk perceptions for BRCA and CRC were similar. Men providing their risk perceptions for PRCA tended to have higher incomes (earning more than \$50,000), to report very good/excellent health status, and to perceive themselves as having very good/excellent knowledge of genetics.

Table 2

Objective and perceived cancer risk based on Family Health History (FHH)

	Objective disease risk based on FHH		Perceived disease risk, before FHH		Perceived disease risk, after FHH		Difference from Pre to Post	
	n	%	n	%	n	%	%	
Breast Cancer (n = 541)								
Average	462	85.4	215	39.7	314	58	18.3	
Moderate	42	7.8	210	38.8	153	28.3	-10.5	
High	37	6.8	50	9.2	43	8	-1.2	
Don't Know	-	-	47	8.7	19	3.5	-5.2	
Missing	-	-	19	3.5	12	2.2	-1.3	
Colon Cancer (n = 655)								
Average	591	90.2	293	44.7	385	58.8	14.1	
Moderate	48	7.3	195	29.8	178	27.2	-2.6	
High	16	2.4	58	8.9	38	5.8	-3.1	
Don't Know	-	-	79	12.1	33	5	-7.1	
Missing	-	-	30	4.6	21	3.2	-1.4	
Prostate Cancer (n = 94)								
Average	80	85.1	21	22.3	33	35.1	12.8	
Moderate	13	13.8	40	42.6	40	42.6	0	
High	1	1.1	18	19.2	11	11.7	-7.5	
Don't Know	-	-	7	7.5	5	5.3	-2.2	
Missing	-	-	8	8.5	5	5.3	-3.2	

Table 3

Accuracy of risk perceptions pre- and post-family health history using objective disease risk

Disease risk	n	%
Breast Cancer (n = 463)		
Inaccurate Pre and Inaccurate Post	136	29.40%
Accurate Pre and Accurate Post	188	40.60%
Inaccurate Pre and Accurate Post	104	22.50%
Accurate Pre and Inaccurate Post	35	7.60%
% Accurate Post/Total (104 + 188/463)		63.10%
% Accurate Post/Total Inaccurate Pre (104/136 + 104)		43.30%
Colon Cancer (n = 528)		
Inaccurate Pre and Inaccurate Post	132	25.00%
Accurate Pre and Accurate Post	246	46.60%
Inaccurate Pre and Accurate Post	103	19.50%
Accurate Pre and Inaccurate Post	47	8.90%
% Accurate Post/Total (47 + 246/528)		66.10%
% Accurate Post/Total Inaccurate Pre (103/132 + 103)		43.80%
Prostate Cancer (n = 77)		
Inaccurate Pre and Inaccurate Post	36	46.80%
Accurate Pre and Accurate Post	13	16.90%
Inaccurate Pre and Accurate Post	19	24.70%
Accurate Pre and Inaccurate Post	9	11.70%
% Accurate Post/Total (13 + 19/77)		41.50%
% Accurate Post/Total Inaccurate Pre (19/36 + 19)		34.50%

Individuals were excluded if they had missing responses, responded “don’t know,” or had the specified cancer(s). In addition, female participants were only included for the breast cancer analysis and male participants were only included for prostate cancer analysis.

Table 4

Factors associated with change in risk perception: results from unadjusted and adjusted multiple regression

Variable	Unadjusted		Adjusted ^a	
	Odds Ratio	95% CI	Odds Ratio	95% CI
Breast Cancer (n = 410)				
Inaccurate Risk Perception Pre-Family History	4.27	2.63–6.83	4.63	2.85–7.51
Fair/Poor Self-Reported Health	1.03	0.64–1.65	0.9	0.53–1.54
Having a Family History Always Increases Risk for Disease	0.92	0.61–1.41	0.82	0.50–1.34
Poor Diet Always Increases Risk for Disease	0.77	0.49–1.22	0.71	0.38–1.33
Colon Cancer (n = 470)				
Inaccurate Risk Perception Pre-Family History	4.39	2.85–6.75	4.28	2.74–6.70
Fair/Poor Self-Reported Health	1.88	1.22–2.88	1.61	0.99–2.62
Having a Family History Always Increases Risk for Disease	1.05	0.71–1.58	0.9	0.57–1.44
Poor Diet Always Increases Risk for Disease	1.25	0.80–1.96	1.45	0.78–2.70
Prostate Cancer (n = 72)				
Inaccurate Risk Perception Pre-Family History	0.73	0.26–2.05	0.9	0.24–3.34
Fair/Poor Self-Reported Health	2.06	0.72–5.89	1.39	0.36–5.33
Having a Family History Always Increases Risk for Disease	0.35	0.10–1.19	0.29	0.07–1.26
Poor Diet Always Increases Risk for Disease	0.38	0.14–1.02	0.22	0.04–1.39

BOLD indicates significance

^a Adjusted for the following covariates: inaccuracy at pre-FH, >50 years of age, income, education, self-report of fair/poor health, perception that smoking, poor diet, lack of exercise, or having a family history of disease is always a risk factor, having one or more healthcare providers, having health insurance, and needed to see MD in past 12 months but could not because of cost