

The Use of Family Health Histories to Address Health Disparities in an African American Community

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African Americans continue to suffer from health disparities. The Center for Minority Health (CMH) within the University of Pittsburgh has the mission to eliminate racial and ethnic health disparities. CMH has designed and implemented the Family Health History (FHH) Initiative. The FHH Initiative places genetic-counseling graduate students in the African American community to provide risk assessments and emphasize the importance of family history as it pertains to disease prevention. The FHH Initiative also allows participants to enroll into the Minority Research Recruitment Database (MRRD). This enables CMH to alert individuals to available research participation opportunities. In the first year of this program, 225 African Americans completed their family health histories. More than 60% of individuals enrolled in the MRRD. The authors report their initial successes and challenges of an initiative that incorporates awareness of family history information, proper screening guidelines, behavior-modification recommendations, and support for participation in clinical research.

Keywords: *genetic counseling; African American; Black; minority; minority health; health disparities; minority recruitment; community outreach; genetics; clinical trials; family history; public health*

In November 2004, the U.S. Surgeon General announced the Family History Initiative to increase awareness about the importance of family history and to provide a tool that collects and organizes family history information. The Web-based tool (www.hhs.gov/familyhistory) allows individuals to organize and store their family history information and highlights diseases with known evidence-based medical treatments and prevention guidelines. These conditions include multifactorial diseases such as cancers of the breast, ovary, and colon; stroke; type 2 diabetes; and coronary artery disease (Guttmacher, Collins, & Carmona, 2004). Prior to the Surgeon General's program, a similar effort began in Pittsburgh, Pennsylvania through the Center for Minority Health (CMH). This program is known as the Family Health History Initiative (FHH Initiative). However, the Center's effort is unique as it uses family history as an intervention strategy designed to eliminate health disparities.

Based in the University of Pittsburgh's Graduate School of Public Health, the CMH has the mission of eliminating racial and ethnic health disparities, a goal articulated in the Healthy People 2010 initiative. Healthy People 2010 is a nationwide health-promotion and disease-prevention agenda launched by the Department of Health and Human Services (Marwick, 2000). As part of the effort to end racial and ethnic health disparities, CMH developed the FHH Initiative. The first component of the FHH Initiative is to provide family history

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risk assessments for African American residents of greater Pittsburgh. The second component allows participants to have their family history information entered into a database that enables CMH to periodically send them information on clinical trials for which they may be eligible to enroll. The aim of this article is to report on the successes and challenges encountered during the first year of the FHH Initiative.

BACKGROUND

Racial and Ethnic Health Disparities

The goal of eliminating racial and ethnic health disparities is important because African Americans have poorer health status and less access to health care than Caucasians. In the United States, race and ethnicity foretell discrepancies in health status. In 2002, the four leading causes of death for African Americans were heart disease, cancer, stroke, and diabetes. Examining mortality rates, incidence rates, and survival rates of

these diseases reveals significant differences between African Americans and Caucasians (Centers for Disease Control and Prevention [CDC] & National Center for Health Statistics [NCHS], 2004; Moreno-John et al., 2004; Williams, 1999). In addition, conditions such as breast cancer and osteoporosis have a lower incidence within minority populations but have significantly higher rates of morbidity and mortality (Moreno-John et al., 2004).

Many reasons have been postulated as to why African Americans have poorer health than Caucasians. African Americans tend to be of lower socioeconomic status, which is closely linked to poor health. After adjusting for socioeconomic status, however, racial disparities persist (Williams, 1999; Wyatt et al., 2003). Another explanation is that African Americans are more likely to have greater exposures to psychosocial risk factors (i.e., unemployment and stress) as well as environmental risk factors (i.e., poor diet and high-risk behaviors). This population is also less likely to have health insurance, less likely to receive medical care, more likely to receive medical care of poorer quality, and less likely to have access to continuous and preventive care (Freeman, 1998; Hunte, Bangs, & Thompson, 2002; Williams, 1999; Wyatt et al., 2003). Racism and discrimination are considered to be at the root of many of these factors (Williams, 1999).

Disparities in Research Participation

Directly linked to health disparities is the fact that minorities have historically been underrepresented in clinical trials (Meinert, Blehar, Peindl, Neal-Barnett, & Wisner, 2003; Moreno-John et al., 2004). Several causes have been reported in the literature. For example, some clinical trials do not collect data on race and ethnicity, whereas others choose to not report it. When this data is collected, the proportion of minority participants is often less than their proportion within the general population. There are some areas of research in which the minority enrollment rate is especially lacking, such as cancer research, HIV/AIDS clinical trials, women's health clinical trials, and psychiatric research (Moreno-John et al., 2004).

Given the wide range of racial health disparities, low minority participation in clinical research is a problem. By including ethnic minorities in clinical research, we are providing individuals access to new and high-quality health care, increasing our ability to generalize research, learning of any potential difference in the pathobiology of the disease, and assessing any race-related differences in drug responses (Moreno-John et al., 2004; Outlaw,

Bourjolly, & Barg, 2000). By increasing participation in clinical research, it is possible to reduce health disparities. Given this, there are downsides to clinical trials that need to be well-communicated to participants. Many clinical trials involve risks including unpleasant or possibly life-threatening side effects. In addition, the experimental treatment may not be effective for the participant. There needs to be a careful balance between increasing minority participation in clinical trials while maintaining the rights and safety of participants.

The African American population is reportedly hesitant to become involved in clinical research (Corbie-Smith, Thomas, & St. George, 2002). Possible explanations for the limited involvement in research include socioeconomic constraints, language and literacy barriers, misunderstanding of research, fear of deportation, lack of access to medical care, physician concerns about referring patients, difficulty in recruiting minorities, researcher and physician biases, and most important, mistrust of the scientific community (Daunt, 2003; Freimuth et al., 2001; Gamble, 1993; Moreno-John et al., 2004).

Increasing minority recruitment can be challenging. African American participants need to have a better understanding of research. Trust needs to be established between African Americans and researchers as well as the health care community. Attitudes and opinions of researchers need to be addressed because they can act as barriers toward recruitment. In an attempt to address some of these issues, all participants of the FHH Initiative were invited to enroll into the Minority Research Recruitment Database.

The Importance of Family History—The Basis of the FHH Initiative

Many of the diseases that African Americans and other minorities are at increased risk for developing are multifactorial chronic diseases that result from multiple gene and environmental interactions (Frezzo, Rubinstein, Dunham, & Ormond, 2003; Guttmacher et al., 2004). Although these interactions are complex, the family health history, or *pedigree*, is a valuable method of capturing the relationship between genetic susceptibilities, common behaviors, and shared environment (CDC, 2003; Guttmacher et al., 2004; Yoon et al., 2002).

The pedigree has long been the cornerstone of clinical genetics. It aids in making a diagnosis, determining risk, and assessing the need for patient education and psychosocial support (Frezzo et al., 2003; Yoon, Scheuner, & Khoury, 2003). In recent years, genetic medicine has entered the realm of primary care because the importance of family history as a risk factor for multifactorial diseases has been established (Frezzo et al., 2003).

Approximately 45% of families have a positive family history of one or more common chronic diseases (Hunt, Gwinn, & Adams, 2003). The pedigree can be useful in predicting the risk of many of these conditions, including heart disease; cancers of the breast, colon, and ovary; osteoporosis; asthma; type 2 diabetes; and suicide (Erasmus et al., 2001; Genomics and Chronic Disease Summit, 2002; Guttmacher et al., 2004; Hunt et al., 2003; Yoon et al., 2002). Generally, family history of a common chronic disease is associated with relative risks ranging from two to five times greater than those of the general population (Scheuner, Wang, Raffel, Larabell, & Rolter, 1997; Yoon et al., 2002). Therefore, the pedigree has the potential to be a cost-effective, noninvasive, population-based screening tool for genetic risk of common diseases (Frezzo et al., 2003).

Applying the Health Belief Model to the FHH Initiative

The health belief model (HBM) is one of the most widely recognized conceptual frameworks of health behavior. According to the HBM, individuals will take action to prevent, to screen for, or to control ill-health conditions if they (a) regard themselves as susceptible to the condition, (b) believe it would have potentially serious consequences, (c) believe that a course of action available to them would be beneficial in reducing their susceptibility to or the severity of the condition, and (d) believe that the anticipated barriers to (or costs of) taking the action are outweighed by its benefits. Although the HBM was originally designed to help explain health-related behaviors, it can also be a useful framework for designing behavior-change strategies (Janz, Champion, & Strecher, 2002; National Cancer Institute, 2005).

Given the framework of the HBM, the FHH Initiative may prove to be an effective tool in using family history to increase risk-reduction behaviors. The goal of the FHH Initiative is to raise awareness of disease susceptibility by using family history as well as to convey courses of action, such as risk reduction strategies, that are both physically and financially accessible.

Genetic Counseling Graduate Students' Role in the FHH Initiative

In the FHH Initiative, genetic counseling graduate students provide health information. The profession of genetic counseling was defined by the American Society of Human Genetics in 1975 as

a communication process which deals with the human problems associated with the occurrence or

risk of occurrence of a genetic disorder in a family. The process involves an attempt by one or more appropriately trained persons to help the individual or family to: (1) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available management, (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, (3) understand the alternatives for dealing with the risk of recurrence, (4) choose a course of action which seems to them appropriate in view of the risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (Ad Hoc committee on Genetic Counseling, 1975)

Given this broad definition, which encompasses all aspects of genetic counseling, the role of a genetic counselor can expand to the public health setting and be used to educate individuals regarding risk reduction for common diseases.

► STRATEGIES

Genetic counseling graduate students from the University of Pittsburgh helped to shape the FHH Initiative in CMH. The genetic counseling graduate students provided health information within the community. Human genetics professors and the CMH director, also a professor in behavioral and community health sciences, oversee graduate students involved in the project. In addition, the graduate students are able to conduct thesis research through their partnership with CMH.

Recruitment

The project began with a coalition of well-respected institutions within the African American community. The first location that was contacted was a predominantly African American church with approximately 7,000 members. Contact was initiated through the associate director of CMH, who is an active member of both the church and its Health and Wellness Ministry (HWM). The relationship with the church was established by introducing the FHH Initiative to members of the HWM and completing family health histories with interested members. Once members became familiar with the process, they helped to develop a plan to expand the program to the congregation.

Beginning at the first Sunday service and continuing thereafter, sign-up sheets were available in the church's

fellowship hall for interested congregants. Members of the HWM helped to recruit participants and often shared their own experiences with interested individuals. Once individuals expressed interest by signing up, they were contacted to set up an appointment for a family health history session. By going through the Health and Wellness Ministry and maintaining a continued presence in the church, there was success in attracting participants.

Following the initial success at this first location, the graduate students established contacts with other African American churches, retirement centers, health facilities, health fairs/community events, and barber-shops/salons using this strategy. The graduate students would make contact with an organization leader (i.e., pastor, director, barbershop owner). If he or she expressed interest, the graduate student would record that individual's family health history. This process allowed the organizational leader to experience the family health history interview process and assist with recruitment efforts.

Family Health History Sessions

Graduate students met with participants for 30- to 60-minute, one-on-one sessions. Participants were asked to complete a brief questionnaire in addition to the family health history. The questionnaire was designed to gather demographic information as well as information related to specific thesis research topics. If the participant agreed, he or she underwent an informed consent process to participate in the optional questionnaire.

Following the completion of the questionnaire, the individual's detailed pedigree was recorded by hand. The graduate students inquired about age, health status, health history, ages of death, and causes of death for the participants and their family members. The graduate students asked directed questions, with a focus on multifactorial conditions such as cancer, heart disease, and diabetes. On completing the pedigree, the graduate student would provide a general risk assessment, focusing on diseases that the individual may be at increased risk for developing, based on family history. The graduate student then provided the individual with information on appropriate behavior modifications, such as increased screening, smoking cessation, increased exercise, and improved diet, which might reduce their risk. The importance of sharing this information with family members and their health care providers was emphasized. Finally, the participant was given a form if they wished to disclose their contact information in addition to any written feedback.

Individuals who completed their family health history had the opportunity to enroll into the Minority

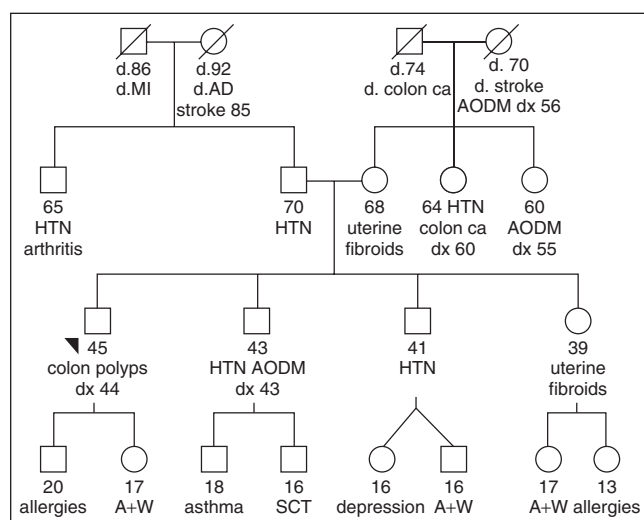


FIGURE 1 Computer-Generated Family Health History

Research Recruitment Database, a database created by CMH with the aim to increase minority recruitment into clinical trials. After participants gave consent to enroll, their pedigrees were entered into the database. When CMH became aware of a recruiting clinical research study, the graduate students queried the database for participants who met the inclusion criteria. Eligible individuals were mailed information about the details of the study so they could choose to contact the investigators if they were interested. CMH maintains all participants' contact information in the database and does not disclose it directly to study investigators.

Follow-Up

Following this initial one-on-one session, the graduate student created a computer-generated version of the pedigree (see Figure 1). This document was mailed to the participant along with targeted health education materials, such as locations for free cancer screenings, as well as a certificate of appreciation. With the participants' permission, the graduate student would call them approximately one month following the initial interview to ask follow-up questions. The questions were aimed at assessing whether participants had gathered additional family health information; shared that information with family, friends, or physicians; and made any behavior modifications. In addition, this follow-up phone call allowed participants to ask any additional questions that may have arisen since the first encounter.

CMH maintains contact with all participants. When CMH receives information about a recruiting research

TABLE 1

Location of Recruitment for 225 Family Health Histories

Location	%
Church	56%
Community event/health fair	30%
Referral	6%
Retirement center	4%
Barbershop/salon	2%
Health facility	2%

study, information is sent to appropriate individuals in the database. In coordination with the Surgeon General's initiative, a letter was mailed to participants during Thanksgiving 2004 to remind them to share their family health histories with family members. In March 2005, an appreciation dinner was held to thank participants for their participation in the FHH Initiative.

RESULTS

Successes

Two hundred and twenty-five family health histories were completed in the first year of this program (see Table 1). Participants were recruited from more than 20 locations, most of which were either churches, community events, or health fairs. The majority of the participants attended the session alone, although a few participants brought family members. Participants provided information to develop a three- to four-generation pedigree. The average pedigree included 30 to 40 family members. The most common conditions reported included hypertension, diabetes, cancers, heart disease, stroke, mental illness, and substance abuse.

In addition to completing a family health history, many participants were supportive of the Minority Research Recruitment Database. Of all participants, more than 60% have enrolled into the database during the first year. Approximately 25 participants were sent information regarding research studies, including studies related to breast cancer, prostate cancer, weight management, Crohn's disease, and diabetes.

Nearly all participants agreed to the follow-up phone call. We reached more than 90% of these individuals by phone. We do not report on the follow-up data collected in this article.

Of the 225 participants who completed the family health history, demographic information is available for 168 of these participants (see Table 2). Participants were mostly women (78%), were educated (81%), had

TABLE 2
Demographics of Family Health History Participants

	%	n
Age		168
18-35	18%	
36-50	41%	
51-65	31%	
66-plus	10%	
Gender		168
Male	22%	
Female	78%	
Race		168
African American only	91%	
African American and other	9%	
Income		162
< \$10,000	7%	
\$10,001-\$20,000	19%	
\$20,001-\$35,000	22%	
\$35,001-\$50,000	19%	
\$50,001-\$75,000	14%	
> \$75,0001	19%	
Highest level of education		166
Eighth grade or less	<1%	
Some high school	4%	
Completed high school	14%	
1 to 3 years of college	39%	
4-plus years of college	20%	
Graduate school	22%	
Insurance coverage		167
Have coverage	89%	
Do not have coverage	11%	
Primary physician (PCP)		166
No PCP	10%	
One PCP	61%	
More than one PCP	29%	
Self-reported overall health		168
Poor	2%	
Fair	20%	
Good	49%	
Very good	23%	
Excellent	6%	

health insurance (89%), and had a primary care physician (90%). There was a range of ages, incomes, and self-reported health conditions of participants.

Participants received the opportunity to share comments regarding their experiences with the FHH Initiative. Participants felt that this process was informative and not invasive. The following are some examples of their shared experiences:

The family health project was very informative and brought to light more about my family history and my chances of developing health problems. You are doing a great thing for our community.

This was an enjoyable experience. It will encourage me to have some specific information gathering conversations with family members. The questioning phase was very positive and not the least bit intense.

The interviewer was excellent, warm, receptive, and knowledgeable. She was open to my concerns and many questions. She is culturally sensitive.

This has been a very good experience. Thank you for bringing this service to my church family.

Challenges

Although the program did appeal to many individuals within its first year, there was resistance by many individuals. Data was not collected on the potential number of individuals who declined to participate, yet there were a significant proportion of individuals who did not sign up at the recruitment sites. To improve recruitment, organization leaders periodically spoke to potential participants regarding their experience with the FHH Initiative to regain interest. Following the leader's mention of the FHH Initiative, there was consistently a remarkable difference in the number of individuals requesting information on the initiative.

Another challenge was the failure to reach individuals after they initially requested to be contacted to receive more information. We attempted to increase outreach by contacting individuals during the evenings and weekends, which improved recruitment. However, we were unable to contact approximately half of the total number of individuals who signed up to receive information. Similarly, we often had to make attempts to recontact individuals to reschedule their appointments. This worked for some participants, yet there were some individuals who never rescheduled.

DISCUSSION

Although African Americans are commonly perceived as being wary of health professionals and medical research, this initiative was successful in attracting participants to engage in a health-promotion activity and enabling participants to enroll into the Minority Research Recruitment Database.

At this time, we are not able to assess whether this program is achieving its aims. However, the FHH Initiative has been successful in recruiting African

American participants. Participants expressed that they enjoyed the one-on-one sessions and found the family health history information to be important. By building these trusting relationships as part of the development of this initiative, our project will hopefully allow future research on this initiative to be conducted more easily. Moreover, the positive response from participants reinforced the notion that genetic counselors are appropriate health professionals to deliver this information. The role of a genetic counselor can extend beyond genetic diseases in a clinical setting to a public-health setting that deals with multifactorial diseases.

The goal of this article was to report our initial observations during the first year of the FHH Initiative. We found that this program attracted participants of various ages and socioeconomic levels. Although the majority of participants were educated women, we will expand our efforts to recruit men. One explanation for the larger proportion of female participants is that this program attracts individuals who are interested in the health information of their family. Women more often play a key role in health-care-seeking behavior, both for themselves and their family members. In general, they are more experienced and knowledgeable health care consumers in comparison to men (Copeland & Scholle, 2000). Another explanation is the higher proportion of women compared to men in many of the recruitment locations. With respect to education status, more than 80% of participants had at least some college education. This may be a result of individuals with higher education being more likely to seek out health-promotion activities. Alternatively, it is possible that the recruitment sites were comprised of mostly well-educated individuals. Further research is necessary to explain the demographic distributions.

Although those who have participated reported having a good experience, many potential participants did not participate. We found that some individuals who expressed interest did not complete a family health history session, whereas others did not express initial interest. Given that the majority of our participants were well-educated women, it is possible that the initiative may not appeal to everyone. Future efforts will be made to increase the appeal of the FHH Initiative to a wider audience, particularly men and less educated individuals.

Limitations and Future Directions

Research on the outcomes of the FHH Initiative has yet to be completed. As more individuals participate and further research is conducted, future publications will report the FHH Initiative's effectiveness in (a) increasing awareness of the importance of family

history, (b) promoting risk-reduction health behaviors, and (c) increasing minority recruitment in research. Much of the data collected during the follow-up phone call will aid in these assessments.

Once the benefits of this initiative have been established, aspects of the program may be applied to a vast range of health professionals. For example, if we find that individuals who participate in this program are more likely to pursue proper cancer screenings, then medical providers can learn to take pedigrees as a means to provide proper screening recommendations for which patients may be more likely to respond. Similarly, if this program is effective in recruiting minorities into clinical research, researchers may consider creating similar databases that would encourage minority recruitment. As this initiative is evaluated, implications for public policy changes may become evident.

Data will continue to be collected as long as this initiative continues. The hope is to find that this program is increasing awareness of family history information, positively influencing health promotion behaviors, and increasing minority participation in research. One ongoing limitation to our research includes that the study population is self-selected and may not be representative of the general African American population. Moreover, the family health history information provided by participants was self-reported.

CONCLUSION

Because racial and ethnic health disparities persist, public health professionals and researchers should make attempts to better engage minority communities. At the same time, it is important to raise awareness of health risks, particularly those involving one's family history. Having a family history of a condition may pose a significant threat to the health of an individual, a threat that could be ignored. Genetic counselors are individuals who specialize in risk assessment based on family history information and are qualified health professionals who can address these risk factors. By raising African Americans' awareness of the importance of family history and helping people to develop more accurate risk perceptions, individuals are more likely to engage in health-behavior modifications that will decrease health risks and therefore decrease health disparities.

In addition, there are still great barriers between minorities and participation in clinical trials. It is important to include a representative sample of the racial and ethnic distribution in our population so that new drugs and treatments can be created to be more

effective for a wider target audience who will eventually use these drugs. Therefore, it is important for public health professionals to make all individuals aware of the importance of research participation while providing the opportunities for appropriate individuals to participate.

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