Feature Article

Using Family Health History for Chronic Disease Prevention in the Age of Genomics: Translation to Health Education Practice

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ABSTRACT

Advances in the field of human genomics have important implications for the prevention of chronic disease. In response to these advancements, public health professionals—including health educators—must become competent in the principles underlying the interface between genomics and the use of family health history. Family health history captures the familial nature and incidence of chronic diseases and provides valuable insights on the risk for chronic diseases within the context of shared genes, environments, and behavior. The purpose of this article is to review family health history research as an important tool for assessing chronic disease risk; to provide information regarding its use in health education practice as a potential preventive tool; and to discuss the ethical, legal, and social implications of such use.

INTRODUCTION

Advances in the field of human genomics and their associated health implications call for an increased understanding and capacity among public health professionals to integrate this knowledge into existing and future health programs and prevention strategies. Unlike genetics, which is viewed as the study of single genes, genomics is the study of functions and interactions of all genes with each other and the environment.[1] In April 2003, the sequencing of the human genome—the detailed mapping of the chemical building blocks of DNA—was announced.[2] This achievement instilled hope among many that individualized information will ultimately lead to the design of "new effective therapeutic and preventive strategies."[3(p69)] The Centers for Disease Control and Prevention (CDC) have responded to this scientific progress by encouraging awareness among health educators and practicing public health professionals, as well as competency in facilitating the education of agency staff, administrators, volunteers, community groups, and other interested personnel in the effective use of genomics in health education and public health.[2,3] To ensure competency, the CDC has developed web-based training tools on the importance and relevance of genomic advancements to the practice of public health.[4]

Personalized genomics, or the sequencing of one's own genome for determining individual risk for disease, is presently limited by cost and is subject to further research.[5] As such, it may not be an affordable option for most individuals until years from now.[5] Although genetic tests for certain cancers and diseases are available and may be covered at varying degrees by health insurance, not all possible genetic changes that mark the risk for developing cancer and certain chronic diseases have been discovered, nor are all these detected by current laboratory methods. In the meantime, family health history, or the health background of individuals sharing a common ancestry, can serve as a "genomic tool,"[6] providing information on potential disease susceptibility within the context of shared genes, environment, and behaviors.[7,8] Although additional studies are needed to establish the effectiveness of fam-

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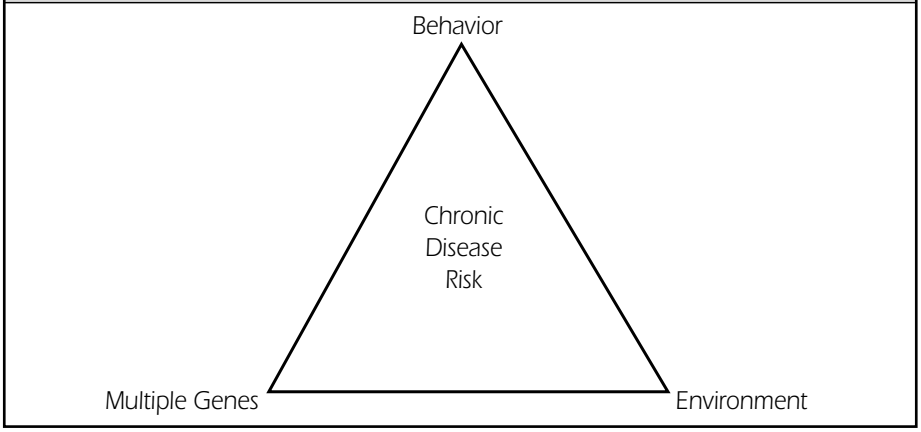
Figure 1. Relationship between Modifiable and Unmodifiable Risk Factors of Chronic Disease



ily health history as an intervention tool for changing modifiable risk factors,[9,10] a growing body of research suggests that risk communication based on family health history information can influence the adoption of a healthy lifestyle, particularly among at-risk groups. By encouraging the use of the family health history, health educators can help individuals and families take an active role in managing their own health by moderating risks for such chronic conditions as heart disease, diabetes, stroke, and cancer.

The purpose of this article is to (1) review evidence of family health history as an important tool for assessing chronic disease risk and for motivating behavior change, (2) review ethical and legal implications for using family health history in health education practice, and (3) provide recommendations for the application of family health history in health education practice. These recommendations are based on genomic and family health history research indicating that chronic diseases result from the complex interaction between genes, behavior, and environment.

Family Health History as a Risk Factor for Chronic Disease

Chronic illnesses such as heart disease, cancer, stroke, and lower respiratory diseases collectively remain the leading cause of death among Americans.[11] These conditions arise from complex interactions between multiple genes, environmental factors, and personal behaviors.[2] Few diseases (e.g., Huntington's and Tay-Sachs) can be attributed to mutations in single genes without any interactions with the environment.[2] These inherited single-gene disorders account for only 5% of the total disease burden in the population,[12] whereas chronic diseases, as a result of multiple gene/environment influences, account for a majority of the disease burden.

Family health history offers evidence for multiple gene, behavior, and environmental interactions. It is recognized as an independent predictor and important risk factor for disease. Researchers have demonstrated that individuals who have family members with a particular chronic disease are at greater risk of developing the disease themselves compared to the general population. For example, several studies have linked a positive family health history with coronary heart disease (CHD).[13] One classic study—the Health Family Tree Study conducted among 122,155 Utah families—revealed that 14% of the families had CHD as part of their family health history. These families accounted for 72% of the early CHD cases (men less than 55 years of age and women less than 65 years of age) and 48% of all CHD cases that were reported among study participants.[14]

Similarly, numerous studies have found family health history to be a risk factor for Type 2 diabetes.[15] For example, research has shown 2.3 times greater risk of diabetes among Pima Indians who had at least one parent affected with the disease,[16] and the same heightened rate among individuals in the United Kingdom who had an immediate family member with the disease.[17] In addition, the risk for developing diabetes was nearly triple for residents of Augsburg, Germany, who had a maternal or paternal history of diabetes (2.8 and 2.7 times higher risk, respectively).[18] As Kardia and colleagues[13] concluded from their review of Type 2 diabetes research, "[M]ost studies reported a two-fold to six-fold increase in the risk of Type 2 diabetes with a positive family health history compared with a negative family history."[15(p154)]

In their extensive review of the literature regarding the predictive power of family health history on asthma, Burke et al.[19] asserted that such a history is a significant risk factor for developing the disease, suggesting that the risk could quadruple with the presence of asthma in a first-degree relative.[19]

In addition, many studies have found that the risk for certain cancers (e.g., ovarian, breast, colorectal, prostate) is higher among those with a positive family health history.[20] A meta-analysis of studies related to family health history and ovarian cancer has shown that sisters and daughters with a history of the cancer had a significantly higher risk of developing the disease.[21] In a meta-analysis of 74 published studies on the relationship between family health history and breast cancer, the risk of such cancer increased among individuals under the age of 50 who had a first-degree or second-degree relative diagnosed before the age of 50.[22] Similarly, researchers have found that the likelihood of recurrence of melanoma is significantly greater if individuals have a family health history of melanoma and/or dysplastic nevi.[23] Researchers have also concluded that individuals with a family health history of osteoporosis are at greater risk for the disease.[24] In summary, a vast amount of research provides strong evidence linking a positive family health history with the eventual development of chronic disease.

Awareness of one's risk for a particular disease may help motivate preventive

behavior. For example, researchers have demonstrated that women who have a family health history of breast cancer are more likely to participate in prevention activities (e.g., mammography).[25] This conclusion was drawn from a meta-analysis of 19 separate studies demonstrating that heightened perceptions of breast cancer risk were positively associated with breast cancer screening.[25] A similar result was obtained in evaluating men who had a family health history of prostate cancer. Jacobsen et al[26] assessed a sample of 83 men who had a first-degree relative with the cancer. The study showed that these men tended to perceive themselves as more vulnerable to the cancer and were therefore more likely to have had regular prostate-specific antigen (PSA) tests. Similarly, Azzarello, Dessureault, and Jacobsen[27] studied 100 unaffected first-degree relatives of melanoma patients to determine whether family health history of the disease motivated sun-protective behavior (e.g., sunscreen, shade, protective clothing). Their findings revealed that sun-protective behavior and self-efficacy were positively correlated with the perceived risk for melanoma, suggesting that the adoption of sun-protective behavior can be strengthened by communicating risk information.

Results of studies on risk awareness and the adoption of preventive behavior are inconclusive. For instance, knowledge alone of an elevated risk of breast cancer may not necessarily lead to increased breast cancer screening. In one study, only 33% of patients indicated that they had a mammogram screening because they were aware of their family health history. In that study, the most commonly reported reason for screening was "physician recommendation," while family health history was perceived as "part of a routine check-up." Yet, in another sample of women with a family health history of breast cancer, 93% had undergone a mammogram in the previous 2 years.[28] It appears that perception of risk due to family health history accounts for preventive behavior in some women, but not all. Audrain-McGovern and colleagues[29] concluded that counseling women with a family health history of breast cancer regarding their risk "has a small and short-term effect on risk comprehension, a small effect on breast cancer screening, psychological benefits for some women and unintended negative effects on screening for others." (p183)

Other studies report that individuals are no more likely to change their harmful behaviors when they perceive risk for a particular disease or actually have a family health history of that disease.[30,31] For example, a randomized, controlled trial revealed a two- to three-fold increased risk of lung cancer among participants who received both counseling and risk assessment through genetic testing as compared to those who received counseling alone.[32] Although positive changes were observed in perception of risk and beliefs regarding quitting, smokers that received both genetic testing and counseling were no more likely to quit smoking despite an increased number of attempts than those who received counseling alone. Findings from these studies show that awareness of one's risk for disease as assessed from a family health history (and/or confirmed by genetic testing) may not necessarily motivate behavior change.

However, some studies have shown that behavior change is more likely in settings in which the affected individual believes that the personal risk for a particular disease could be significantly minimized by adopting specific preventive measures. For instance, McCusker et al.[33] concluded from their research of more than 3,000 respondents—of which almost half reported a family health history of heart disease—that the regular use of aspirin and monitoring of cholesterol levels were more likely to be performed by study participants with moderate to high risk for heart disease. Marteau et al[9(p1056)] concluded that among people who are made aware of their family health history and risk for disease, "behavioral change may be more likely if people are persuaded that changing their behavior can reduce the risk of an adverse health outcome and they are given access to evidence-based interventions." These researchers also warned that individuals who do not show an increased risk of disease should not develop a "false sense of reassurance" or "feel invulnerable" to the impact of risk behaviors. Although none of these highlighted studies have ever placed in question the preventive and clinical value of the family health history, conflicting results on risk awareness and behavior change require further research to demonstrate the effectiveness of family health history and genetic risk stratification in changing behavior and preventing chronic disease.[9,34]

Public health efforts to influence modifiable risk factors that contribute to chronic disease have not been fully successful, as evidenced by the large numbers of Americans who remain overweight and inactive and who continue to smoke.[8,35] New approaches are needed to achieve better results. Profiling one's risk for chronic disease through the use of family health history can provide a cost-effective means of communicating risk. While the relationship between family health history and chronic disease has long been understood, the use of family health history as a health promotion and disease prevention tool has yet to be widely and systematically implemented among the American public. Its use in health education practice provides a fresh approach to modifying risk factors with the potential of increasing the adoption of preventive behaviors among individuals, groups, and communities.[10]

Ethical and Legal Considerations on the Use of Family Health History Information

The use of family health history presents actual and still-untapped benefits for health promotion and disease prevention at various settings: clinical practice for direct individual and family care; the public health level in terms of program planning, implementation, and evaluation for at-risk populations; and in the field of teaching, training, and research. Family health history, by its very nature, is more than individual health data. It is a record of diseases and conditions expressed among generations of biologically related individuals. Such data includes the familial occurrence and potential genetic predisposition for disease

within the context of behaviors predominant in a group setting that contribute and/or hasten the development of disease. Hence, family health history can contain sensitive, personal identifiable information such as names, birthdates, ages, race, contact information, relationships, and the number of pregnancies and children.[36] Without a doubt, the breadth of information from an extensive and accurate family health history carries important predictive genetic information[37] as well as the preventive value of early screening, risk stratification, effective interventions, and surveillance, particularly for at-risk individuals and their families.[6,38] For this reason, an extensive family history is routinely obtained and verified even before genetic testing is carried out.

From an ethical and legal perspective, such benefits of use have to be sensitively weighed against other ethical principles such as the participant's rights to "nonmaleficence, justice, and autonomy."[39] Information obtained from a family health history—whether volunteered by an individual, collected during a doctor's visit, given out in evaluating insurance coverage, or used in health education and research—is vulnerable to ethical and legal issues, especially since health information is not completely private.[40,41] The challenges posed by the use of such information are heightened by advances in internet technology and the potential for even wider information sharing. Moreover, in the process of collecting and storing this information, the assent of family members mentioned in a family tree is not usually obtained, nor are they informed that such data exist.[36]

At the core of several ethical and legal issues is whether ownership, access, and use of health history information could result in more than the minimal risk to the index subject and/or other individuals. Such harm could potentially come from misuse and breach of confidentiality and misunderstanding of predictive genetic information, which could then lead to unfavorable discrimination[42] as well as embarrassment and shame.[43] If disclosure of information generally constitutes the "duty to warn," it is to be carefully considered against the right to withhold information. The key factor is the "potential for harm," where either disclosure or nondisclosure of information carries more than the minimal risk of injury to either the subject and/or the relatives. Such risk from disclosure may be in the form of being denied employment, adequate insurance coverage, education, or loans; breakdown in trust and confidentiality in professional relationships; or injury brought about by misconceptions, shame, insult, and reproach within families and society. Nondisclosure, however, could delay health care for both participants and affected relatives; limit benefits of intervention programs tailored for at-risk individuals and families at the public health level; or restrict knowledge that could be optimally gained from health histories through research, teaching, and training.

Balancing the rights of the individual with those of other family members and of the public (in terms of access and use of extracted health information) presents a dilemma. Health educators as well as other public health professionals and researchers face seemingly conflicting obligations even to members of the same family: either respect the privacy of an individual's health records or use the information to carry out screening and other preventive strategies directed at all at-risk family members.[38,44] To illustrate, the father of a woman participating in a twin study filed and won a legal suit against Virginia Commonwealth University for violation of his privacy rights when his medical information was brought out in the course of collecting the woman's family health history.[13]

Such scenarios become even more complex when personal consent and the roles of third parties are factored in. Are third parties such as schools, employers, and insurance companies entitled access to personal health and possibly genetic information? How much health and medical information does an individual consent to that is deemed reasonable for third-party use? These questions underlie the potential for misunderstanding predictive genetic information that could result in unfavorable discrimination and/or loss of privileges. For example, Schmitz and Wiesing[37] quoted the case of a German teacher who, during a required medical examination for a permanent government job, had to disclose that her father had Huntington's disease. Although she is healthy and capable of carrying out the job responsibilities, she was denied the opportunity to hold such a position based on her 50% chance of inheriting the disease.[37]

Currently, health information provided by the patient, including that which may pertain to other biologically related members of the family, is considered individual property.[38] This is basic in a patient-physician relationship, in which the patient's right to privacy and autonomy are foremost. Any information provided by the patient to the physician is considered confidential unless there are significant reasons for disclosure. Reducing the ethical and legal risks in the use of family health history calls for respecting privacy in the process of collecting and verifying health information, even in situations in which a family member has expressed refusal to disclose data.[45] This is sound practice even in the broader health education/public health use of family health history, in which individuals and families are encouraged to compile, store, and regularly update their own family health information. Interviews and questions in collecting family health information may be prefaced with an emphasis on the protection of personal information and on the voluntary decision of respondents to not include information they feel might be damaging to a family member.[46]

As the extracted health information pertains not only to an individual but also to a group of relatives, health educators should recommend that family health history information be shared with one's physicians. Participants should be provided information on how the data will be used and with whom it will be shared. Experts strongly advise treating the information with the utmost level of confidentiality and security currently applied to all personal health information.[47] Such safeguards should likewise guide the

collection, sharing, and use of data within families, with a cautious eye on the risks to personal privacy and confidentiality. In research and publication, risks to confidentiality posed by the use of family health history are addressed through informed consent, data coding, and certificates of confidentiality.[48] Each family member's permission is sought using an informed consent that emphasizes the voluntary nature of the process and clearly articulates the relevance, benefits, extent, and risks of assent; the responsibilities of both parties; the choice to either retain or omit information; and the intended use of data, such as in preventive, clinical, research, or public health settings.[47] This, however, may present a challenge in situations where participants are not competent to provide consent or where significant psychological impact to the participant and/or other family members presents more than minimal harm.[43] In teaching and training, keeping case studies anonymous to the extent possible, despite limitations, is the current practice.[49]

There are still differing perspectives on how stringent or flexible the standards should be on the collection, storage, access, and use of health information. Some researchers continue to emphasize an even higher level of security and confidentiality regarding the use of family health history, even if its applications are not necessarily confined to the field of genomic medicine. Others, however, argue for greater accessibility in the interest of the greater public good and the potential for clinical benefits that can be made available given current consent guidelines. As family health history is a source of predictive genetic information with the potential for misuse and hence, discriminatory action, Schmitz and Wiesing[37] called for the same level of scrutiny and rules of consent on the use of family health histories as presently applied to genetic tests. Both medical ethicists are emphatic on the prohibition of the use of family health histories and genetic tests where there is significant risk on the participant's right to consent or refuse, as in preemployment examinations.[37] Chen et al.[48] believe in preserving participant autonomy, arguing that family members participating in research "own" the manner in which they perceive their family health information and should therefore have a choice as to how it is used and disclosed.

In contrast, Parker and Lucassen[38] proposed a different framework, a "joint account model" in which access to family health information is allowable as long as there is no risk of serious harm to the patient and relatives. In such a structure, information is family or group-owned. As such, these researchers do not find it necessary to obtain consent from all family members, arguing that the benefits of access outweigh the reasons for requiring assent from each and every member included in a family health history record—an effort that they view as "disproportionate" and fundamentally impractical.[36] They add, however, that the process still requires clear agreement between index subject, family members, and interested parties on how the information will be used, discussing the potential risks as well as the limits of assent with regard to the collection, use, and disclosure of information. In terms of research, obtaining consent from each and every family member may not be feasible and could delay critical diagnosis and treatment for affected family member(s) without necessarily changing the inherent risk from the disease.[50]

Specific applications of family health history remain subject to issues that also confront predictive genetic testing. There are still numerous ethical and legal questions that need to be clarified, such as: Who owns the data?[38] If family history is family-owned information, how does group possession of data bear on the personal right to privacy? What uses and degree of access does the participant consent to? As such, who has the obligation to store and share the information? Who has the right to access the data? Even more basic questions arise: Is obtaining and/or evaluating an index subject's family history that eventually results in the disclosure of other members' health information a breach of these relatives' privacy? By the same token, does disclosure of an individual's genetic information to other family members for purposes of prevention or early treatment constitute a breach of privacy? An exhaustive discussion of these ethical and legal concerns is beyond the scope of this article.

In sum, although laws are in place in the United States that address issues of discrimination emanating from the use of health information, there remains ethical and legal ambiguity on the use of family health history for designing health education programs directed at identified at-risk populations, as well as for clinical practice, teaching, research, and publications. Health educators should encourage the participation of the public and all stakeholders in reviewing and/or composing guidelines on the ethical and legal use of family health histories.[46] For instance, legal policies and measures are needed that address concerns associated with the use and sharing of family health histories with third parties in particular. Creation of such policies should be founded on real rather than theoretical threats to privacy and confidentiality in multiple settings.[47] In addition, given the diverse family structures and ethnic composition of American society, further studies are needed on how family dynamics and cultural factors impact legal and ethical perspectives as well as health decisions, especially among at-risk populations.

Family Health History in Health Education Practice

Whereas the primary focus of health education practice is on influencing modifiable risk factors that contribute to disease, little attention is placed on nonmodifiable risk factors. Genomics has helped to explain chronic disease as the result of interactions between modifiable risk factors (behavior and environment) and nonmodifiable ones (multiple genes). Family health history provides health educators with a way to assess these important interactions and the inherited risks for chronic disease. Unfortunately, this family record remains underutilized as a prevention tool,[34] with inadequate attention given to its implications for public health.[51] Even among health care providers who

request limited family health history, such information is rarely used for determining disease risk and motivating preventive behaviors such as early detection. Based on a direct observation of physicians, Acheson, Wiesner, Zyzanski, Goodwin, and Stange[52] reported that family health history was taken in only half (51%) of visits by new patients and in only 22% of visits by established patients. In addition, even among patients of family practitioners, only 40% had some family health history information in their office medical records such as history of colon or breast cancer or alcoholism, while only 11% had a pedigree diagram.[52] Newly practicing physicians were more likely to visit longer with patients to collect family health history information.

Data collected from the 2004 HealthStyles Survey of 6,175 respondents across the United States showed that 96.3% of respondents considered knowing about their family health history as important, but only 29.8% were actively collecting health information to determine said history.[53] Public health educators, especially those who are competent in genomics, would be uniquely qualified to bring the use of family health history to the forefront of practice by (1) encouraging individuals and families to share the collected information with their physicians for further analysis and interpretation, and (2) using it to promote health in the home, school, worksite, and community.[2] In essence, the family health history screening results not only help assess one's individual risk for disease but can also help highlight the role of confirmatory procedures such as genetic testing. Such assistance from health educators can help physicians overcome the common obstacles to using family health history, including insufficient time to obtain, organize, and analyze family health history information; anxiety about lack of expertise in obtaining and organizing such information; and worries regarding potential discrimination in employment or insurance.[41]

Obtaining valid and reliable family health history tools for use is another obstacle for both individuals and health professionals. Several comprehensive family health history tools are available in both print and electronic format and can provide individuals and families with a clearer picture of disease risk (Table 1). Guttmacher et al.[41] noted that "almost every patient today has access to a free, well-proven, personalized genomic tool that . . . can serve as the cornerstone for individualized disease prevention."(p1) We recommend in particular the U.S. Surgeon General instrument (*My Family Health Portrait*), the American Medical Association instrument, and the Utah Health Family Tree. Each of these tools is pedigree-based and available in hard copy for use among health educators, consumers, and health care providers. Some electronic family health history instruments are interactive, providing immediate feedback about disease risk upon completion. Other instruments assist individuals in constructing a family tree (pedigree) that is meant to be printed and shared with their health care provider. In either case, health educators can be instrumental in assisting individuals in locating family health history tools, completing instruments, and sharing the information with their health care provider.

More sophisticated family health history instruments will require that individuals be prepared with information about their family's health history. Health educators can assist by helping individuals identify which family members they should collect information from and what information is important to collect for these relatives. For example, in order to determine risk, family health history information should be collected on individuals, their first-degree relatives (such as children, siblings, and parents), and their second-degree relatives (such as grandparents, aunts/uncles, and nieces/nephews).[34] First-degree relatives provide a clearer picture of risk because they share about half of their genes as compared to second-degree relatives, who share less of the same genetic material.[34] Information on family members and relatives should include (1) major medical conditions and causes of death, (2) age at onset of disease and age at time of death, (3) ethnic background, and (4) associated modifiable risk factors such as being overweight, having a poor diet, smoking, or heavy drinking.[54] Health educators should instruct that obtaining this type of family health history information will require asking questions of family members, talking to relatives at family gatherings, drawing a family tree, writing information down, and looking at vital statistics like death certificates and family medical records.[54]

Health educators can likewise assist individuals in overcoming barriers to the use of family health histories such as the time and energy required in collecting and verifying information. To minimize such challenges, the Surgeon General declared Thanksgiving Day as a National Family History Day to encourage relatives to discuss and write down family health problems as they gather on this holiday.[54] The Surgeon General's Family Health History Initiative also provides health professionals with a number of useful resources, including recommendations for community health promotion (Table 2).

Health educators can act locally to support this initiative by advising that collecting, updating, and sharing family health history information can be as easy as keeping track of a child's immunization records.[10] In fact, family health information and immunization records can be kept together and updated regularly. Another barrier for some is that it might not be possible to determine one's biological family health history. In such cases, health educators should encourage the collection of family health history information based on the guardian family. As noted above, this is because family health history not only accounts for genetic risks of chronic disease but also measures risks associated with important ecological determinants.

Health educators must emphasize that optimal use of family health history information requires collecting information personally and sharing the findings with a health care provider for interpretation and recommendation. Placing this responsibility on the health care provider has been less beneficial in some instances, as the collected information is rarely used for determining

Table 1. A Comparison of Family Health History Tools for Consumers and Providers

Tool	Web address	Focused on consumers (C) or providers (P)?	Hard-copy tool available?	Pedigree based?	Specific disease focus?
U.S. Surgeon General (My Family Health Portrait)*	www.hhs.gov/familyhistory/	C	✓	✓	✓
Utah Health Family Tree*	www.health.utah.gov/genomics	C	✓	✓	
American Medical Association*	www.ama-assn.org/ama/pub/category/2380.html	P	✓	✓	
American Society of Human Genetics	www.ashg.org/genetics/ashg/educ/007.shtml	C		✓	
National Society of Genetic Counselors	www.nsgc.org/consumer/familytree/index.asp	C		✓	
Genetic Alliance	www.geneticalliance.org	C		✓	
Genetics in Primary Care	www.genetests.org	P	✓		
March of Dimes	www.marchofdimes.com/pnhec/4439_1109.asp#FamilyHealthHistoryForm	C	✓		
American Academy of Family Physicians	www.aafp.org/x33092.xml	C	✓		
Genetic Risk Easy Assessment Tool (GREAT)	https://family.case.edu	C		✓	✓
JamesLink	www.jamesline.com/go/jameslink	C			✓
Generational Health	www.generationalhealth.com	C		✓	
The Heart of Diabetes Family History Tree	www.s2mw.com/aha/fht/index.aspx	C		✓	✓

Sources: Portions of the table adapted from Benkendorf J, Bodurtha J, Schreiber A, Bodkin C. Integrating genetics into clinical practice using family history-based tools: a developing initiative. Poster session presented at the annual meeting of the National Coalition for Health Professional Education in Genetics, Bethesda, MD; January 2005. Other information obtained from the Utah State Health Department Chronic Disease Genomics Program.
*Recommended

disease risk or motivating preventive behaviors that include early detection.[52] Certainly a standardized and consistent approach to collecting and applying family health history information for health promotion and disease prevention will likely enhance patient care, as would having periodic health history updates and keeping "portable" family health history records in the event of changes in physician or transfer of care.

When considering the application of family health history to population-based program planning, stratifying risk to focus specifically on high-risk individuals can prove to be more cost-effective than targeting the general population.[55] This can be done by health educators during a community assessment process using family health history information and Scheuner's classification system to classify populations according to their risk. As such, resources and intervention activities can be directed to segments of the population that need them the most. In Scheuner's classification system, the degree of risk for chronic disease based on family health history is classified into three different categories: high risk, moderate risk, and average risk.[56] Risk classification is determined by using a comprehensive family health history instrument that assesses variables such as the number of relatives with a particular disease; age at disease onset; and the relationship of the point person to the family member, such as first- or second-degree relative (Table 3).

Stratification of disease risk through family health history can assist health educators in tailoring interventions according to the unique needs, dynamics, and resources of individuals and families. For example, Hunt et al.[57] suggest that family health history is a useful tool for identifying a small subset of families at greatest risk for cardiovascular disease who might benefit from screening and more intensive interventions. This was demonstrated through a study using the Health Family Tree questionnaire among Utah high school students enrolled in mandatory health education classes.[58] The Health Family Tree questionnaire was used to collect medical history as well as certain lifestyle factors and diseases over three generations. Family risk scores were determined and the results were distributed to each participating family. Following the initial assessment, family-based interventions were offered, often in the home, specifically to those families identified as being at high risk for certain diseases. Behavior-change classes were also made available. This research was initiated in part because 14% of the Utah population contributed to 72% of early coronary deaths. The cost-effectiveness of collecting family health history information was demonstrated by the fact that the cost of the intervention for each high-risk family was roughly $27. Costs included data analysis, the production and mailing of reports, and in-kind donations from state and county health departments.[58]

Table 2. Family History: Community Health Promotion Ideas

1. Use information from the Resource Packet for Health Professionals to develop family history materials (e.g., fact sheets, videos, PowerPoint presentations) specific to your community.
2. Distribute reproducible materials from the Resource Packet for Health Professionals to local doctor's offices, hospitals, and clinics.
3. Convene community presentations and discussions at churches, libraries, schools, hospitals, health fairs, worksites, etc.
4. Create an exhibit and distribute materials at conferences, sporting events, and health-related activities.
5. Partner with local photography studios to include family history in their promotional materials.
6. Sponsor a poster contest for students.
7. Develop continuing education modules for health department personnel.
8. Partner with ongoing national health promotion campaigns such as CDC's "5 A Day" and VERB initiatives, or with local campaigns in your community.
9. Write articles for local newspapers and include personal stories about people in your community who have used knowledge about family history to protect their health.
10. Identify a local champion that can help you promote family history.
11. Bundle the "learn about your family history" message with other national messages to eat healthy, increase physical activity, and avoid smoking.
12. Add the following links to your website:
    a. U.S. Surgeon General's Family History Initiative: www.hhs.gov/familyhistory
    b. CDC's Family History for the General Public: www.cdc.gov/genomics/public/famhistMain.htm

Source: U.S. Department of Health and Human Services, The Surgeon General's Family History Initiative, 2005.

CONCLUSION

There is a great deal of evidence linking family health history and chronic disease. More recently, advances in the field of human genomics have helped to better explain the nonmodifiable and modifiable risk factors that contribute to chronic disease within the context of shared genes, behaviors, and environment. Because it facilitates the assessment of these gene–environment interactions, the family health history serves as an important tool for health educators and other health professionals to promote a healthy lifestyle and stratify risk. However, the family health history remains underutilized in public health practice.

In light of the growing evidence suggesting the utility of family health history, health educators should ensure that they are able to assist individuals and families in (1) using a reliable and valid family health history instrument, (2) collecting health information, especially from family members, and recognizing information that is important, (3) overcoming barriers to collecting and using family health information, and (4) sharing family health history information with their health care provider. Beyond these important implications for individual health improvement, health educators should strongly consider the application of family health history to guide program planning and implementation. Assessing family health history among populations provides health educators with a method of stratifying disease risk and personalizing interventions. Additionally, future research is needed to (1) test the acceptance and viability of family health history among at-risk populations, (2) enhance family health history assessments for the basic home environment, and (3) enhance family health history assessments to include behaviors of the participants, thus providing a more comprehensive family health history profile.

Since the family health history is a record of diseases and conditions within generations of biologically related individuals, it is important that health educators be sensitive to the ethical and legal implications of its use in health education and public health. Such health histories can contain sensitive information that should be treated with the highest ethical standards. Health educators therefore have a responsibility to facilitate the creation of policies and guidelines that address the use and sharing of family health history information, especially with third parties.

In the age of genomics, family health history represents an underutilized tool that can be easily instituted in new or existing health education programming. Indeed, many family health history tools are currently available and can be accessed electronically. Health educators who take advantage of these tools can enhance their practice and potentially improve health outcomes among target populations.

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Table 3. Family History Risk Stratification

High Risk	Moderate Risk	Average Risk
1. Premature disease* in a first-degree relative.	1. A first-degree relative with late or unknown disease onset.	1. No affected relatives.
2. Premature disease in a second-degree relative (coronary artery disease only).	2. Two second-degree relatives from the same lineage with late or unknown disease onset.	2. Only one affected second-degree relative from one or both sides of the pedigree.
3. Two affected first-degree relatives.		3. No known family history.
4. A first-degree relative with late/unknown onset of disease and an affected second-degree relative with premature disease from the same lineage.		4. Adopted individual with unknown family history.
5. Two second-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 "moderate risk" family history on both sides of the pedigree.		

Source: Scheuner MT, Wang S, Raffel LJ, Larabell SK, Rotter JI. Family history: a comprehensive genetic risk assessment method for the chronic conditions of adulthood. *Am J Med Genet*. 1997;71:315-324.
*Conditions defined as "premature disease" include the following: coronary artery disease onset ≤55 years of age in males and ≤65 years in females; stroke, noninsulin-dependent diabetes, or colon/prostate cancer onset ≤50 years; breast, ovarian, or endometrial cancer onset premenopausal or ≤50 years.

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