Enhancing the Collection, Discussion and Use of Family Health History by Consumers, Nurses and Other Health Care Providers

Because Family Health History Matters

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KEYWORDS

• Family health history • Genetics • Genomics • Personalized medicine

KEY POINTS

- The family health history is a powerful tool that can be used by health care providers to identify common diseases and rare diseases prevalent in families.
- Information from a patient's family health history can draw the attention of providers to red flags commonly associated with genetic risks and can be used to develop personalized preventive health care plans.
- Data highlighted in this report suggest the need for more targeted efforts by nurses and other health care providers to increase public awareness of the importance of family health history and to promote discussion about family health history among individuals and families. Data also suggest the need for similar efforts by leaders in the clinical and academic arena to review, reinforce, and reaffirm the value, importance, and relevance of the family health history among nurses and other health care providers in the practice setting.

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INTRODUCTION

Advances being made by genetic and genomic scientists domestically and abroad are impacting all facets of health care. Knowledge gleaned from genetic research is increasing the understanding of diseases that result from single-gene errors (eg, cystic fibrosis, sickle cell anemia, Huntington's disease, hereditary hemochromatosis, Tay-Sachs disease, glaucoma, Marfan syndrome, phenylketonuria). Knowledge gleaned from genomic research is, likewise, increasing the understanding of diseases caused by genetic mutations, lifestyle, and environmental factors (eg, heart disease, high blood pressure, Alzheimer's disease, Parkinson's disease, arthritis, diabetes, breast and colon cancer, and obesity/overweight). As a direct result, progress is being made relative to the identification of biomarkers of pathogenesis and the development of genetically based tools for use in the personalized assessment of health status and disease risk. Yet, in this era of genetics, genomics, and personalized health care, it is suggested that newly developed high-tech genetically based options do not completely overshadow low-tech tools currently used to assess a patient's health status and to evaluate their risk of both common and rare diseases. Rather they are reported to give them new meaning and power.

The family health history (FHH), often touted as the first genetic test administered in the health care setting, has been described by leaders in the field as "the most powerful genetic/genomic tool available to clinicians in general and specialized practice."[1–4] The FHH has long been used by nurses and other health care providers in clinical practice to determine if an individual, their family members, or their future generations are at an increased risk of heritable disease development (**Box 1**).[5,6] The FHH can reveal common diseases and rare diseases prevalent in families. The FHH can draw attention to red flags commonly associated with genetic risks, such as family history of multiple affected family members with the same disease or disorder; 2 or more generations of family members affected by the same disease; combinations of diseases within a family (eg, breast and ovarian cancer, heart disease and diabetes, diabetes and peripheral vascular disease); early onset of disease within a family (ie, onset of disease within a family 10–20 years before people are typically diagnosed); disease in the less-often-affected sex (eg, breast cancer in a male, persistent stuttering in a female); consecutive miscarriages, stillbirths, or sudden infant deaths; ethnic predisposition to genetic disorders (eg, sickle cell anemia or lactose intolerance in individuals of African ancestry, cystic fibrosis in whites of Northern European descent, BRCA 1/2 mutations and Tay-Sachs disease in individuals of Ashkenazi Jewish ancestry); and consanguinity (ie, children resulting from relationships between blood relatives who would be at an increased risk of having an autosomal recessive condition).[7,8] The FHH can similarly be used to identify social, environmental, and cultural factors that may impact an individual's health.

Several of reports in the peer-reviewed literature over the last decade address issues relevant to FHH. Included among them are reports that describe the origin and evolution of FHH[5,9–13]; reports that highlight the utility of FHH for identifying persons at risk of heritable disease development[14–19]; reports that describe patterns of communication and documentation of FHH common among diverse population groups[20–26]; and reports that delineate factors impacting the quality, quantity, and use of FHH in clinical practice.[27–29] Despite the expanding body of evidence substantiating the power of FHH as a genetic/genomic tool, the value of FHH for the assessment of disease risk, the importance of FHH to provision of health care in clinical practice, and the institution of national FHH campaigns by the Office of the United States Surgeon General[30] and the Centers for Disease Control and Prevention,[31]