Families SHARE, an educational genomics workbook

8 July 2021

Credit: Pixabay/CC0 Public Domain

Researchers at the National Human Genome Research Institute (NHGRI), part of the National Institutes of Health (NIH), have developed the Families Sharing Health Assessment and Risk Evaluation (SHARE) workbook, which helps people use their family history to assess their risk for heart disease, diabetes, breast cancer and colorectal cancer.

Since 2012, Laura Koehly, Ph.D., and her research team have measured the accessibility and usability of the workbook by working with communities and continually updating the workbook to address issues. Koehly is the chief of the Social and Behavioral Research Branch at NHGRI and senior author of the study. In a recent study in the journal *Public Health Genomics*, the researchers published data gathered from questions on the efficacy of the workbook that they posed to African American communities.

Through the Families SHARE workbook, researchers seek to provide a tool that encourages people to have discussions about their family health history and helps them understand how their family history is associated with their risk for heritable diseases. The workbook also provides feedback on the ways people can reduce their risk for diseases, such as changing their behavior and seeking clinical care.

African Americans experience a disproportionately high number of chronic diseases compared to other racial and ethnic groups in the United States. African American families are also exposed to social and environmental health risks that are known to contribute to higher diabetes and heart disease rates.

"One big issue is that many available genomics resources don't reach a vast number of people," said Koehly. "For this study, we wanted to evaluate if the Families SHARE workbook could bridge that gap and whether it is well-adapted as a tool for low-income African American families."

The research team collected data from African American adults living in two low-income neighborhoods in Baltimore and Washington, D.C. During a baseline survey, the researchers captured data about the individuals' family health history and health status.

The researchers gave the participants Families SHARE workbooks, which included:

- Personalized family trees associated with heart disease, diabetes, breast cancer and colorectal cancer.
- Definitions of each disease and associated risk factors.
- A worksheet that explains how clinicians assess increased risk based on family health history.
- A set of additional tools to remind participants to make healthy lifestyle choices based on their level of disease risk, and to remind them to update their family health history.

Six weeks after receiving the workbook, participants noted a sense of ownership over their family health history. Ninety-eight percent of participants reported that they could assess their own disease risk when using the workbook, and 70% of the people had shared the workbook with their family members and also tried to assess the family members' disease risk. Three-quarters of the participants felt motivated to share it with others, like healthcare providers, in the future.

"It was incredibly valuable to see the start of a dialogue between family members about their health history," said Kayla de la Haye, Ph.D., associate professor of preventive medicine at the University of Southern California and corresponding author on the study.

Based on discussions during focus groups with participants, the researchers plan to include community education programs in future iterations of the workbook.

"Our participants are telling us that they want advocates to help them use and understand the workbook in a community setting. They want a support system where community members can come together to learn from one another," Koehly said. "Our future efforts will take these suggestions into account."

Apart from the workbook for African Americans, the researchers are also working with domestic and international communities to design other versions of the workbook for diverse groups.

More information: Kayla de la Haye et al, Formative Evaluation of the Families SHARE Disease Risk Tool among Low-Income African Americans, *Public Health Genomics* (2021). DOI: 10.1159/000517309

Provided by NIH/National Human Genome Research Institute