Enabling Precision Health and Medicine: Increasing Awareness and Accessibility of Family Health History (FHH) Collection

Duke BASS
CONNECTIONS

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Bass Connections in Information, Society & Culture

Introduction

What is FHH?

A collection of health information about a patient and their family members (both living and deceased). With this information, health providers can identify patients at increased disease risks, and recommend appropriate screenings and/or lifestyle changes to minimize risks or identify disease at an early stage.

Project Goals:

A continuation of a study conducted in 2017, this project aims to

- 1. Create an online resource that educates people about how to collect and share their FHH
- Provide information about the cultural considerations behind FHH associated with religion, race, ethnicity, and age

Our ultimate goal is to increase awareness and accessibility of FHH collection methods through consolidation of FHH information that is transformed into a website.

Methods

Literature Review Topics

- How to collect FHH from family members and share this information with providers
- Young adults and FHH
- Cultural considerations of FHH across religion, race, ethnicity, and age

Website Development

- 1. Organize and compile information obtained from the literature review.
- 2. Convert this information into a more accessible format in terms of readability.
 - a. Goal: 8th grade readability level.
- 3. Compile a list of helpful tips and suggestions for FHx collection.
- 4. Compile a list of resources on FHH, collection tools, and video explanations.
- 5. Develop a set of Q&A responses for commonly asked questions related to FHH.

Results 1: Resource Consolidation

How to Collect FHH

- Share your purpose.
- Provide different ways to answer questions.
- Be mindful of how you word your questions.
- Be a respectful listener.
- Respect their privacy...

Young Adults & FHH:

- Known barriers to FHH collection among young adults include
 - (1) not knowing which questions to ask about
 FHH
 - (2) not knowing how to obtain their FHH
 - (3) lack of information about the exact cause of death for one or more relatives
- Young adults may not perceive that FHH is important to collect.
 - This is concerning because many life-long health behaviors are made during adolescence and young adulthood.
 - Poor health behaviors and lack of FHH knowledge may cause one to habitually push back provider visits that could potentially help with earlier disease detection.



Cultural Considerations

- Patients come from different backgrounds that may affect their perception and actions towards FHH collection.
 - Latinx patients may benefit from culturally-trained provider and interpreter services may increase their ability to understand the significance of FHH.
 - Chinese Americans may be hesitant to discuss FHH with physicians because disease discussion, especially about mental illness, is a traditionally sensitive topic.
- It is important for patients and providers to be knowledgeable of cultural intricacies and its effects on FHH knowledge and collection.

Discussion

- Our literature review validated that young adults and certain racial, ethnic, or religious groups are hesitant to collect FHH despite potential health benefits.
- 2. Our website is a first step in **creating culturally competent FHH resources**that address diverse age groups and educational backgrounds.
 - a. These resources could educate individuals or families about collecting and sharing FHH with healthcare providers.

Framework for Future Research:

- 1. Conduct research on utilizing website intervention on select focus groups
- 2. Determine the efficacy of interventions on increasing understanding, awareness, and perceived utility of FHH collection by taking into consideration
 - a. Age (targeting young adults)
 - b. Gender
 - c. Cultural background
- 3. Increase efficacy of providers in navigating FHH collection with patient populations of diverse cultural backgrounds.
- 4. Compare experimental group of providers with and without access to culturally-sensitive website materials.
- 5. Determine resulting change in patient behaviors or attitudes towards FHH.

Results 2: Website Development

Website Elements:

- 1. About Us
- 2. Overview of FHH
- 3. How to Collect & Use FHH
- 4. Cultural Considerations of FHH
- 5. Online FHH Tools
- 6. FAQs
- 7. Other Resources
- 8. Glossary

