

Does It Run in the Family? Toolkit: Improving Well-Educated Elders Ability to Facilitate Conversations about Family Health History

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Abstract

The role of elders imparting family health history (FHH) information to younger generations has not been well established in the literature, and even less attention has been given to their interaction with various FHH tools that can potentially assist them in collecting and organizing such information. This study sought to address this gap by assessing the impact of the customizable *Does it Run in the Family? toolkit* on elders' ability to facilitate conversations about FHH and share the information with health care providers. The overall findings suggest that well-educated, relatively affluent elders, when provided the opportunity to be educated in the use of the toolkit, were willing to embrace and use it to acquire FHH information that could possibly influence health care decisions.

Keywords: Family health history. *Does it Run in The Family? toolkit*, Elders

Introduction

In the age of genomic medicine, there has been a proliferation in the number of tools created to assist health care providers, families and communities to engage in a more systematic process of gathering and using Family Health History (FHH) information. FHH is defined as a description of the genetic relationships and medical history of a family¹.

This valuable information is used to help health care professionals assess risk factors associated with hereditary diseases and determine who may benefit from genetic testing, prevention, and early intervention approaches^{1,2}.

FHH tools exist in many different formats. There are paper family history tools, e.g., the American Medical Association's *Adult Family History Form*. There also exist computer-based tools for drawing pedigrees (diagrams using standard symbols and terms), such as *Progeny*, *Genosketch*. There are family history documentation tools that can be downloaded from the internet, e.g. the U.S. Surgeon General's *My Family Health Portrait* and The Cleveland Clinic's *My Family*. "Electronic medical records are increasingly integrated into medical practice and vary in the way information is obtained" ¹(p. 277).

Rich et.al¹ suggest that the ideal tool, in order to be helpful to patients, must be easy to use. That is, it must be understandable and appropriate for the person's "age, gender, ethnicity, and health condition". Additionally, they suggest that to encourage its use the tool should be available in multiple formats (paper and computer input) to better accommodate patient preferences. Given the variations in office information systems and record keeping, family history tools should be compatible with multiple clinical information system applications¹ (p. 278). The Genetic Alliance offers a downloadable, customizable tool, the *Does It Run in the Family? toolkit* for helping families make discussions of Family Health History a routine part of their interaction with one another. These tools offer the promise of encouraging and empowering individuals and communities to be more proactive in gathering and sharing FHH with health care providers by offering them the knowledge of how this can be done, removing the social stigma often attached to certain diseases and informing them of both. This paper seeks to explore this premise in relationship to Genetic Alliance's *Does it Run in the Family? toolkit* and older adults.

Background: Why Elders and the Does it Run in the Family? toolkit

The Genetic Alliance collaborated with community partners in the Community Centered Family Health History (CCFHH) Project, a national initiative to create an inclusive, accessible, customizable FHH tool that would facilitate conversations about health among family members and lead to healthy lifestyle choices. The CCFHH project focused specifically on developing a nonmedical tool (*Does It Run in the Family? toolkit*) that captures genetic, lifestyle, and environmental factors associated with increased risks of developing hereditary diseases³.

The product of the CCFHH Project, the *Does It Run in the Family? toolkit*, is designed to fit the unique context in which conversations about family health history take place. The CCFHH Project valued diversity factors (e.g. geography, culture, race, ethnicity, age, gender, sexual orientation, disability or other health condition, class, culture, literacy, language, groups that have a common interest or cause, etc.) that potentially influence health outcomes within and across groups of people³.

Consideration of these factors led Genetic Alliance to collaborate with community partners across the country for the CCFHH project. Seven communities, including Iona College⁴, customized and measured the utility of the *Does It Run in the Family? toolkit*⁵. The toolkit consists of two booklets – "A Guide to Family Health History" and "A Guide to Understanding Genetics and Health" –that explain the importance of knowing and talking about health within the family as well as basics about how conditions are passed down through generations. These booklets provide suggestions and resources to help people talk about the health conditions affecting their families and how to use that information to maintain and improve health.

This current study was developed in collaboration with Stanford Geriatric Education Center (SGEC) at the Stanford University School of Medicine and Genetic Alliance. It was undertaken to assess the impact of the *Does It Run in the Family? toolkit* on older adults' ability to initiate and facilitate conversations about family FHH and to test the hypothesis that if elders initiated conversations about FHH, then family members of different generations would be likely to participate in discussions and share FHH information with their health care providers. This study also expanded on the observations of the authors who beta tested the customizable FHH tool with college students and their families as part of the CCFHH Project.

The SGEC, Genetic Alliance and Iona College partnership emerged as an outgrowth of participation in a year-long Faculty Development Program in Ethnogeriatrics, involving one of the Principal Investigators who proposed to examine the impact of the customizable tool with older adults as facilitators of FHH conversations. A major underlying assumption of this endeavor was that the CCFHH Project would validate the positive contributions that elders make towards promoting health and well-being in the family, despite their own aging process⁶.

Methods

Participants

Participants were a self-selected group of well-educated and somewhat affluent older adults who expressed an interest in FHH. The sample consisted of 30 elders, age 55 or older, capable of reading and providing written consent, and with a willingness to voluntarily participate in the study.

Elders were recruited from two major organizations with large older adult constituencies and by word of mouth. The first, LIRIC (Learning in Retirement at Iona College), is a group of retired, mainly professional people who remain active through affiliation with the learning community of the college by participating in college events and promoting a lecture series in the spring drawing upon Iona faculty expertise. Although membership in LIRIC is open to elders of diverse backgrounds, most active members are Caucasian Americans. The second is Sister to Sister International, Inc., a non-profit advocacy organization founded in 1996 in Westchester County to empower women and families of color by enhancing health literacy. Among other health literacy initiatives, Sister to Sister International, Inc. sponsors an annual Healthy Weekend Extravaganza to promote health literacy throughout the County. This organization's membership is comprised of predominantly professional and retired women of African, African American, and Caribbean descent.

Participants were invited to take part in the study during a formal presentation made at a general membership meeting of each organization. Time was set aside at a monthly meeting for the Principal Investigators to meet with interested elders either individually or in small groups to complete the baseline survey (described below), answer questions, and distribute the toolkit. Participants who were referred by word of mouth were met with on an individual basis to complete the baseline and follow-up surveys. Principal Investigators asked participants to read the booklets and engage family members of different generations in conversations about FHH during a defined time interval between February and April 2012.

Participants signed consent forms confirming their participation was strictly voluntary. They were offered a \$5.00 gift card to either Dunkin Donuts or Starbucks as a token of appreciation for completing the study and follow-up survey.

Principal Investigators monitored the project during the implementation phase by monthly telephone calls to remind participants about the specifics regarding the timeline and determine their progress towards reading and sharing information contained in the booklets with family members. In early May the Principal Investigators revisited the scheduled monthly meetings of the participating organizations to procure follow-up surveys and give participants the gift card of their choice. Participants were informed that a summary report would be made available to their respective participating organizations.

Survey Instruments

The Iona College research team was granted permission by Genetic Alliance to use any and all family health history materials for the current study involving older adults. Baseline and follow-up surveys were adapted from those used in the CCFHH national project with students, which had been adapted from a CDC evaluation of a direct-to-consumer marketing campaign run by Myriad Genetics. The surveys solicited information on health behaviors relevant to FHH, such as trust and decision making with the health care provider, quality of the health care provider, awareness and knowledge of FHH, and lifestyle and health behaviors. The follow-up survey mirrored the baseline survey, with additional questions regarding intentions to use the tool during future health visits^{3,5}. The questions in both the baseline and follow-up surveys used a 4-point scale.

The main outcome measures for the survey of older adults included: reading about FHH, talking with family members and providers, and sharing materials about FHH with family members. Participants were asked their thoughts on the importance of these activities. Several questions asked participants whether and how often they used the materials, and how they used the materials with family members.

Finally, demographic information and information about participants' health status was obtained, including whether they had health insurance, whether they had a relationship with a health provider, and whether they had collected FHH in the past⁵.

Demographic Profile

Of the thirty participants that took part in this study 13 (43%) were between 55 and 64 years of age, 7 (23%) were between 65 and 74 years of age, 8 (27%) were between 75 and 84 years of age, and 2 (7%) were between 85 and 94 years of age.

When asked, 13 (43%) of the study participants reported that they were Black, 14 (47%) reported that they were Caucasian, 1 (3%) claimed to be Latino, and 2 (7%) claimed to be of Other Racial heritage. Thus, the race distribution of participants is almost evenly divided between Blacks and Caucasians.

The educational accomplishments of the two predominant groups of participants are summarized in Table 1 and show that both Black and Caucasian participants are well educated, with more than three quarters of the sample from both races having earned college degrees. The somewhat better financial position of the black subgroup (Table 2) may well be explained by the larger percentage of earned graduate degrees in this group.

Eight Black (61.5%) compared to six Caucasian (43.0%) participants reported incomes over \$81,000.

Table 1

Educational Accomplishments of Participants by Race/Ethnicity				
Educational Accomplishment	Frequency		Percent By Race/Ethnicity	
	Black	Caucasian	Black	Caucasian
No High School Diploma	1	0	7.5	0.0
Some College – No Degree	1	3	7.5	21.5
Undergraduate Degree	0	3	0.0	21.5
Some Graduate Education – No Graduate Degree	0	1	0.0	7.0
Graduate Degree	11	7	84.5	50.0
Total by Race/Ethnicity	13	14		

Table 2

Annual Household Income of Participants by Race/Ethnicity				
Annual Household Income	Frequency		Percent	
	Black	Caucasian	Black	Caucasian
Less than \$30,000	0	1	0.0	7.0
\$31,000 - \$40,000	1	3	7.5	21.0
\$41,000 – \$50,000	0	1	0.0	7.0
\$51,000 - \$60,000	1	0	7.5	0.0
\$61,000 - \$70,000	1	1	7.5	7.0
\$71,000 - \$80,000	2	2	15.0	14.0
Over \$81,000	8	6	61.5	43.0
Total by Race/Ethnicity	13	14		

Results

Participants were asked to rate their family's knowledge and personal knowledge about genetics and health on a scale of 1 to 10 (1= nothing at all to 10 = quite a lot), both before and after participation in the study. The mean rating for the participant's perception of their family's knowledge about genetics and health increased from 5.9 before participation to 6.4 after participation. The mean rating for the participant's perception of their personal knowledge about genetics and health increased from 7.1 before participation to 7.7 after participation. Although neither of the differences were statistically significant, there were small reported increases in knowledge after using the customized FHH tool.

When asked to rate their perceptions of comfort (1 = uncomfortable to 10 = very comfortable) among family members discussing FHH, there was no significant difference in the mean of 7.0 before and the mean of 6.9 after participation in the study.

The same was found to be true in the assessment of family members’ agreement about the importance of FHH (1 = unimportant to 10 = very important). Mean before was 6.6 and mean after was 7.2.

A comparison of the perceived level of comfort among family members when discussing FHH before and after using the tool shows a decrease in the number of participants in the two oldest age categories that felt their family members were very comfortable with discussions of FHH. There were other small fluctuations throughout the table, but they were not as clear as with older age groups.(Table 3).

Table 3

Level of comfort among family members about discussing Family Health History					
Age		Very Uncomfortable	Uncomfortable	Comfortable	Very Comfortable
55 - 64	Before	0	1	4	1
	After	0	0	4	2
65 - 74	Before	0	1	3	1
	After	0	1	2	2
75 - 84	Before	0	1	2	2
	After	1	2	2	0
85 - 94	Before	1	2	3	2
	After	1	2	4	1
Total	Before	1	5	12	6
	After	2	5	12	5

It is at this point that it must be noted that participants’ non-response to questions becomes an issue. The total number of respondents does not agree with the total number of study participants for some questions perceived to be of a personal nature. While there is not much difference in the perceived level of comfort overall, there are changes at the extreme ends of the spectrum when data is filtered by race/ethnicity for Black and Caucasian participants. The number of families in which the level was rated as very comfortable increased for Blacks while falling for Caucasians (Table 4).

Table 4

Level of comfort among family members about discussing Family Health History					
Race/Ethnicity		Very Uncomfortable	Uncomfortable	Comfortable	Very Comfortable
Black	Before	1	3	7	1
	After	0	3	5	4
Caucasian	Before	0	1	6	3
	After	2	0	7	1
Total	Before	1	4	13	4
	After	2	3	12	5

While there was an overall increase in the reported frequency in which participants discussed family health history with their health care providers, it was observed that these gains occurred primarily in those 74 years of age or younger. The only age group which failed to demonstrate any positive movement in terms of increased discussion with health care providers was the 85 – 94 years of age group. (Table 5).

Table 5

Age		Talk about family health history with health care provider			
		Rarely or Never	Sometimes	Often	Usually or Always
55 - 64	Before	0	6	4	2
	After	0	3	5	4
65 - 74	Before	1	5	1	0
	After	1	2	2	2
75 - 84	Before	1	4	1	2
	After	3	0	4	1
85 - 94	Before	0	2	0	0
	After	2	0	0	0
Total	Before	2	17	6	5
	After	6	5	11	7

In Table 6 we observe that the Black Race/Ethnic group was most likely to increase the frequency of discussions about family health history with health care providers after participation in the project. While there was some increase in the number of Caucasians that discussed FHH with their health care providers after participation in the study, the number of Caucasians that rarely or never talk to their health care providers about family health history more than doubled after participation in the study.

Table 6

Race/Ethnicity		Talk about family health history with health care provider			
		Rarely or Never	Sometimes	Often	Usually or Always
Black	Before	1	7	4	1
	After	1	2	6	4
Caucasian	Before	2	8	2	2
	After	5	3	4	2
Latino	Before	0	1	0	0
	After	1	0	0	0
Other	Before	0	1	0	1
	After	0	0	1	1
Total	Before	3	17	6	4
	After	7	5	11	7

Discussion

We sought to determine whether the *Does It Run in the Family?* toolkit promoted intergenerational FHH conversations. Small differences were observed when comparisons were made between subgroups in the study. Although there was no deliberate attempt to exclude any racial/ethnic groups, the opportunity to explore Black and Caucasian participants' interaction with the toolkit became evident due to the profound impact of recruitment methods on the findings. First, we recognize that the small sample size of this study limits our ability to generalize findings. For example, Table 2 shows the race distribution of participants as 43% Black, 47% Caucasian, and 3% Latino. These figures are substantially different from those reported in the U.S. Census Bureau Quick Facts⁷: 62.6% White, 17.1% Latino, and 13.2% Black. Thus, the authors acknowledge that the sample is not representative of the general population along racial lines.

Second, in Table 3 it was reported that 71% of the participants had earned a graduate degree and 13% had earned an undergraduate degree. This is substantially higher than the 28.5% of the population having earned a Bachelor's degree reported by the U.S. Census Bureau⁷ for the years 2008 – 2012. Again our sample demonstrates a substantial deviation from the national parameter.

Third, Table 4 illustrates yet another demographic by which the sample in this study seems to differ from national norms, Household Income. 84.5 % of Blacks and 64.0% of Caucasians reported annual household incomes higher than the median annual household income of \$53,046 reported by the U.S. Census Bureau⁷.

Despite these limitations, we believe the unique aspects of this sample provide a glimpse into how subgroups of older adults of similar educational and socio-economic backgrounds benefitted from using the *Does It Run in the Family? toolkit*. For example, both subgroups reported increases in knowledge after using the toolkit. This finding is consistent with the literature showing a significant correlation between education, income and positive health outcomes for older adults⁸. However, when asked about level of comfort among family members discussing FHH, more Black than Caucasian participants rated this item “very comfortable.” In this study, that comfort among Black participants may also be attributed to having been recruited from a mission-driven organization with a specific focus on health literacy and advocacy. It is likely that the high level of comfort discussing health concerns as part of their mission was expressed in their response to this question.

Small differences were also observed between Blacks and Caucasians when asked whether they shared FHH with health care providers. Black participants tended to trend toward more frequent communication with healthcare providers, whereas there was no obvious trending among Caucasian participants. This finding is not consistent with what is usually presented in the literature about Blacks’ mistrust and underutilization of provider resources⁹, but might be based on the mission of the health advocacy organization from which Black participants were recruited. Overall, for these two major subgroups of highly educated, affluent elders, the customizable *Does It Run in the Family? toolkit* was considered to be of benefit.

Importance of these findings:

- 1) Family Health History tools are additional resources that allow older, affluent, well-educated adults a structured way of passing along health history either in written form or through stories, making information available to younger generations and health care practitioners.
- 2) Appropriate use of existing tools can help to create a record of information that potentially guides health care decision-making, interventions, as well as prevention practices.
- 3) The ability to capture the context in which FHH stories naturally occur using a platform like the *Does it Run in the Family? toolkit* also supports intergenerational connectivity across the lifespan while positively impacting health outcomes for all family members.

Implications

The potential implications of this study for genetic counselors are as follows:

1. Genetic counselors should recognize that some well-educated, affluent, older adults of diverse backgrounds are willing to participate in conversations about FHH and likely have lots of knowledge/important information about family health that would be useful for their children, grandchildren and for the genetic counselor to know.
2. Genetic counselors should involve well-educated, affluent elders in conversations about family health where appropriate.
3. Genetic counselors should advise individuals to consult with their older family members about the reasons that brought them to their genetic counseling visit.
4. Genetic counselors should promote the use of family health history tools including the customizable, internet-accessible *Does It Run in the Family? toolkit* to empower diverse elders to impart and gather family health history information in collaboration with other family members.

Future Research

Follow-up research is needed to gain a greater understanding of the differences that exist between and within racial/ethnic groups using the *Does It Run in the Family? toolkit*. Follow-up research focusing on cultural differences among diverse elders would also shed light on the usefulness of the *Does It Run in the Family? toolkit* in facilitating conversations about FHH in relation to a user’s educational level and socio-economic background.

Future research might further clarify why perceived family comfort levels went down for Caucasians and up for Blacks in this study.

Future research comparing the effectiveness of the *Does It Run in the Family?* toolkit for different educational achievement levels holding age-range constant may shed light on its usefulness.

Conclusion

The current study explores well-educated, affluent, older adults' interactions with the *Does It Run in the Family?* toolkit as a collaborative effort between Stanford Geriatric Education Center (SGEC) at the Stanford University School of Medicine, Genetic Alliance, and Iona College. The goal was to empower elders to initiate and share conversations about FHH. Overall findings seem to suggest that given the opportunity to be educated in the use of the *Does It Run in the Family?* toolkit, these older adults were willing to embrace and use it toward acquiring additional information that could possibly influence health outcomes for themselves and family members.

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