J Community Genet (2013) 4:251–261
DOI 10.1007/s12687-013-0138-0

ORIGINAL ARTICLE

"You don't have to keep everything on paper": African American women's use of family health history tools

Tess Thompson · Joann Seo · Julia Griffith · Melanie Baxter · Aimee James · Kimberly A. Kaphingst

Received: 28 September 2012 / Accepted: 27 January 2013 / Published online: 9 February 2013

Abstract Little is known about African American women's collection of family health history (FHH) information and use of FHH tools. Most FHH research has investigated tools that use a biomedical paradigm, but other kinds of tools, such as those that include information about family social context, have been developed for use in diverse populations. Using mixed methods, we interviewed 32 African American women about behavioral steps to collecting FHH, family communication about health, and reactions to a biomedical FHH tool. Participants chose one of two FHH tools to take home. A follow-up call three weeks later assessed tool use. Many participants expressed support for writing down FHH information, but at baseline few had done so; most participants who had collected FHH information had done so verbally. Participants reacted positively to the biomedical FHH tool used during the interview, with many saying it allowed them to see patterns in their FHH. At follow-up, 67 % reported using their FHH tool, primarily to promote discussion among family members; only 32 % used the tool to write down FHH information. Although participants thought collecting FHH information was important and had positive reactions to both tools, the majority did not use the tools to write down information and instead collected FHH informally. These findings underline the importance of separating the components of FHH collection behaviors to analyze the steps used in FHH creation. Practitioners should consider additional methods of encouraging patients to create written FHHs in order to share the information with health care providers.

Keywords Family health history · Family communication · Racial/ethnic minorities · Cancer

T. Thompson (✉) · J. Seo · J. Griffith · K. A. Kaphingst
Health Communication Research Laboratory,
Washington University in St. Louis, 700 Rosedale Avenue,
St. Louis, MO 63112, USA
e-mail: tessthompson@wustl.edu

M. Baxter
Siteman Cancer Center, Washington University School of Medicine,
St. Louis, MO, USA

A. James
Division of Public Health Sciences, Washington University School of Medicine, St. Louis, MO, USA

K. A. Kaphingst
Division of Public Health Sciences, Washington University School of Medicine, St. Louis, MO, USA

Introduction

Many evidence-based guidelines for disease prevention and screening use family history information to guide clinical interventions and recommendations (Carmona and Wattendorf 2005). In cancer screening, for example, family history informs screening guidelines for several common cancers (American Cancer Society 2012). Stratifying risk based on family history usually requires information about first- and second-degree relatives, including the specific type of disease and age of onset (Hampel et al. 2004; Tyler and Snyder 2006; Scheuner et al. 1997; Valdez et al. 2010). Because family history can affect risk for multiple diseases, this information can inform multiple prevention or screening recommendations (Guttmacher et al. 2004; Yoon et al. 2009; Cree et al. 2009; Audrain-McGovern et al. 2003).

Evidence suggests, however, that family history information is underutilized in clinical practice. Although patients are interested in talking to primary care physicians about disease risk (Buchanan et al. 2005), primary care physicians often do not collect enough family history information for risk stratification or tailored disease prevention and control recommendations (Schroy et al. 2002; Acton et al. 2000; Grover et al. 2004; Sweet et al. 2002). In addition, although the majority of respondents to one nationwide U.S. survey believed that

knowing their family health history (FHH) information was important for their own health, few adults reported collecting health information from family members in order to create a family health history (Yoon et al. 2004). Factors that may affect the collection of FHH information include gender, as well as personal history of chronic disease (Yoon et al. 2004). A survey of community health center patients found that people reporting a family history of cancer were more likely to report talking frequently with family members about FHH information (Kaphingst et al. 2012).

Identifying optimal methods for encouraging patients' collection of FHH information is a critical step toward increasing the use of this information in clinical practice (Berg et al. 2009). FHH tools, which offer systematic approaches to capturing and documenting family history (Qureshi et al. 2009), hold promise in helping individuals collect and retain this information. A number of initiatives have been launched in the USA and elsewhere to educate the public about the importance of collecting and recording FHH information (Guttmacher et al. 2004; Dunlop and Barlow-Stewart 2009), often promoting the use of one or more FHH tools to be completed by patients prior to a provider visit (Yoon et al. 2002; Acheson 2003; Rich et al. 2004; Fuller et al. 2010). However, prior research has generally considered completion of a FHH tool as a binary outcome; few studies have examined the various behavioral steps required to complete a written FHH record using one of these tools (e.g., discussing FHH with different family members, selecting a FHH tool, recording the information in a FHH). Understanding whether and how individuals complete each of these steps is critical to informing intervention approaches to encourage the completion of a FHH record.

In addition, the best paradigms for FHH tools have not been systematically investigated. More than 75 different FHH tools have been created for public use (Wang et al. 2011), but few have been evaluated for use in clinical (Wang et al. 2011; Reid et al. 2009) or population-based settings (Petruccio et al. 2008). Most FHH tools are based on a biomedical paradigm, focusing only on the collection of information about disease diagnoses of relatives (Qureshi et al. 2005; Feero et al. 2008). The U.S. Surgeon General's FHH tool, *My Family Health Portrait* (MFHP), is one such tool that has been widely promoted in the USA as a means of helping people collect FHH information (U.S. Surgeon General's Office 2011). Tools using a biomedical approach, however, may be difficult for lay individuals without specialized genetics knowledge or with limited health literacy (Wang et al. 2011; Kelly and Sweet 2007), due in part to unfamiliar terms and concepts (Clarke 2009; Fuller et al. 2010; Wallace et al. 2009). Some researchers have investigated alternate paradigms for FHH tools, such as tools that collect information about the social context of the family in addition to disease history information. One such tool is *Does It Run in the Family*?, which was developed as part of a larger culturally competent intervention encouraging the collection of FHH information (Petruccio et al. 2008). Although preliminary evaluation research has shown the acceptability of this FHH tool in six diverse communities in the U.S. (Petruccio et al. 2008; O'Leary et al. 2009), the majority of participants in one intervention still did not create a written FHH pedigree (Petruccio et al. 2008).

Research on users' reactions to and use of biomedical FHH tools is limited. One study of the Health Heritage FHH tool found that only 30 % of participants completed a 1st and 2nd-degree family history (Cohn et al. 2010). The U.S. National Human Genome Research Institute has implemented demonstration projects to promote FHH collection using the MFHP tool in various communities (Wallace et al. 2009; Murray et al. 2007; National Human Genome Research 2011). In the two weeks following the completion of MFHP during an educational session, 75 % of urban Appalachian participants reported sharing their FHH with a family member or significant other; many (78 %) planned to share the FHH information with their health care providers (Wallace et al. 2009).

In addition to the need for research on the behavioral steps to complete a written FHH record and to examine the underlying biomedical paradigm, more investigation of collection of FHH by non-White individuals is needed. Despite persistent health disparities between Whites and many other racial and ethnic groups in the USA (American Cancer Society 2011), most research on collection of FHH information and use of FHH tools has included mainly white participants (O'Neill et al. 2009; Acheson et al. 2010; Wideroff et al. 2010; Cohn et al. 2010). One study of African Americans participating in a FHH and genetics intervention suggests that pledging to collect FHH information might be an effective strategy for promoting the collection of such information in this population (Butty et al. 2012). In addition, FHH interventions with tailored health education materials may foster discussion of FHH information in diverse families (O'Leary et al. 2009).

This mixed-methods study was designed to address these research gaps by examining different behavioral steps needed to collect FHH information and comparing different paradigms for FHH tools among an underserved racial/ethnic group in the United States. We examined how African American women viewed FHH collection, how they perceived and used FHH tools, and whether reactions to and use of tools differed between those with and without a personal history of cancer. This study population was chosen because previous research indicated that women and people with a family history of cancer may be more likely to collect or discuss FHH information (Yoon et al. 2004; Kaphingst et al. 2012).

Methods

Design overview

A mixed-methods baseline interview was used to collect primarily qualitative data, but it also included some quantitative, closed-ended items. The in-person interview, which lasted approximately 90 min, had five parts: (a) closed-ended questions about past FHH collection and related beliefs; (b) semi-structured, open-ended questions about family communication about health and collection of FHH information; (c) completion of the *My Family Health Portrait* (MFHP) online tool (U.S. Surgeon General's Office 2011) and response to open-ended questions about the tool; (d) closed-ended questions about immediate reactions to the MFHP online tool and participant characteristics; and (e) selection of a paper-based FHH tool to take home (either a printed version of MFHP or *Does It Run in the Family*? (Genetic Alliance 2009)).

Participants were interviewed by telephone 3 weeks after baseline to assess short-term use of their selected FHH tool. Follow-up interviews used a combination of open-ended and closed-ended questions.

Participants

From January 2011 to July 2011, we recruited 32 African American women from two databases composed of people who had volunteered to participate in studies about health. In this purposeful sample, half of the participants (16) had a past diagnosis of cancer and half (16) did not. This sample size was chosen because best practice recommendations for qualitative individual interviews suggest that saturation (the point at which researchers no longer discover new themes or ideas) can occur with sample sizes as small as 10 (Willis 2005; Beatty and Willis 2007). To reach saturation, we therefore planned to enroll 15–16 participants per group.

Participants were 21 years of age or older, had at least basic English skills, and had not seen a genetic counselor. Potential participants were contacted by phone, and interested women who met eligibility criteria were invited to participate.

Two participants (one with a history of cancer and one without) were lost to follow up, a retention rate of 94 %. This study was approved by the Human Research Protection Office at Washington University in St. Louis.

Interventions

We selected two FHH tools for this study that focused on multiple diseases, were publicly available, had lower print and document health literacy demands (Wang et al. 2011), and had prior usability data. For use during the baseline interview, we chose the online version of the Surgeon General's biomedical MFHP tool because it could be started based on participants' current knowledge of their FHH. Participants were asked to use the MFHP tool to enter FHH information during the baseline interview and create a family history diagram. This tool collects basic biomedical information such as relatives' names, relationship to the participant, diseases (with age at diagnosis), and (if applicable) date of death. An interviewer was present but did not assist participants in completing the tool, except to ask them to create a FHH diagram for viewing as part of the interview. During the interview, one participant had difficulty navigating the online tool and switched to a print version.

At the end of the baseline interview, participants selected either the paper version of MFHP or *Does It Run in the Family*? to take home. The paper version of MFHP collects the same information as the online version, but participants complete a simple grid. *Does It Run in the Family*? includes suggestions and sample questions for talking with family members about diseases and health behaviors, as well as stories about people who have gathered health information from their families and instructions for creating a FHH chart. *Does It Run in the Family*? was designed to be customizable, and we used culturally appropriate photographs to create a customized version for African American women in our community.

Measures

Baseline interview measures

Open-ended items

Open-ended questions explored participants' prior collection of FHH information and their reactions to the MFHP tool.

Collection of FHH information was explored through questions such as "Is there someone in your family who keeps track of information about diseases that run in the family?" and "For your family, what would be the most useful way to keep track of information about diseases that run in the family? How would you share this information?"

Reactions to the MFHP tool were explored through questions such as "How well do you feel that this chart summarizes your family?" and "How useful does it seem to write down this type of information about your family?"

Closed-ended items

Perceptions of the importance of FHH were assessed by three, 3-point Likert scale items adapted from Orom et al. (2007) (e.g., "How important do you think knowledge of your family's health history is to your personal health?").

Prior FHH collection was assessed by two yes/no items ("Have you ever actively collected health information from your relatives for purposes of developing a family health history?" (Yoon et al. 2004) and "If yes, did you write down the family health history information?").

Reactions to the FHH tool: Five seven-point Likert scale items, ranging from 1 ("strongly disagree") to 7 ("strongly agree") assessed ease of use, ease of understanding, perceived fit between the tool and the participant's family, helpfulness in talking to family members about cancer, and interest in further using the tool (for example, "Would you agree or disagree that this tool was easy to use to fill out your family health history?").

Cancer screening history was assessed by items asking whether participants had had a Pap test, mammogram, colonoscopy, sigmoidoscopy, or fecal occult blood test, as well as the screening intervals for those tests (Vernon et al. 2004).

Health literacy was assessed with one 5-point Likert scale item: "How confident are you filling out medical forms by yourself?" (Chew et al. 2008).

Demographic information collected included education level, age, marital status, and household composition.

Follow-up interview measures

Open-ended items

During the 3-week follow-up interview, participants were asked open-ended questions about using the FHH tool and discussing FHH since the baseline interview. Our initial follow-up interview questions did not distinguish between *using the tool* and *using the tool to write down FHH information*, but based on initial participant responses in which people reported using the tool but not writing down FHH information, the interview guide was revised after the first two participants to differentiate between *using the tool to prompt discussion* and *using the tool to create a written family health history.*

Close-ended items

Participants who reported using the FHH tool were asked to rate time spent, satisfaction, and experience with the tool using three 7-point Likert items (for example, "Would you say that you were satisfied using the tool to fill out information about your family health history?").

Analysis

Baseline interviews were audio recorded and tapes were transcribed verbatim. We checked all transcripts against the tapes for accuracy. Four trained student coders were responsible for qualitative coding using Atlas.ti. Each transcript was coded for content by two independent coders, using directed thematic analysis (Miles and Huberman 1994; Coffey and Atkinson 1996; Sandelowski 1995; Miles 1983). Coders first independently reviewed the transcripts using a preliminary codebook developed from on prior literature. The research team then discussed these themes and refined the codebook with additional deductively developed codes. Coders independently coded all transcripts using the final codebook, and discrepancies were resolved through a consensus coding process conducted by two student coders in consultation with the study team. Although quotations were initially stratified by participant cancer history (participant numbers in the 200s indicate a personal cancer history; numbers in the 100s indicate no cancer history), that stratification yielded few differences and we collapsed the two strata in analysis. We examined descriptive statistics for closed-ended questions using SPSS 19.0. Because of the small sample size, we did not examine whether descriptive statistics significantly varied across subgroups. Open-ended follow-up interview responses were quantitatively coded using closed-ended categories for analysis.

Results

As shown in Table 1, most participants had a high school education or higher (72 %), and the mean age was 55.0 years. Although a large majority of participants (94 %) thought that knowing FHH information was "very" important, only 56 % reported collecting such information (either systematically or informally) before the baseline interview. More participants without a cancer history had collected FHH previously than participants with a personal cancer history (75 % vs. 38 %).

Behavioral steps to complete FHH

A major theme that emerged from the qualitative data was that, for most participants, people in their family do not track FHH information in any systematic, written way. Many participants stated that no one in their families keeps track of FHH information, although some qualified this statement by saying family members do keep track in their heads; the word "tracking" was used differently by different people, with some participants counting only written tracking and others counting mental tracking. Many participants reported family members kept track of FHH information in their heads and shared it verbally through family discussions. Table 2 includes quotations selected because they are either typical responses or important discrepancies. In some cases, these FHH discussions were seen as a way to bring family members closer together and promote a shared

Table 1 Participant characteristics and baseline family health history (FHH) beliefs and practices among 32 African American women

Participant characteristics	Personal history of cancer (n=16) M (SD) or % (n)	No personal history of cancer (n=16) M (SD) or % (n)	Total (N=32) M (SD) or % (n)
Mean age	57.6 (6.8)	52.4 (10.5)	55.0 (9.1)
High school or higher	68.8 (11)	75.0 (12)	71.9 (23)
Confident filling out medical forms all/most of the time	93.8 (15)	93.8 (15)	93.8 (30)
Married/partnered	31.3 (5)	43.8 (7)	37.5 (12)
Pap smear[a]	100.0 (16)	100.0 (16)	100 (32)
Mammogram (if 40+)[b]	87.5 (14)	86.7 (13)	87.1 (27)
Colon cancer screening (if 50+)[c]	73.3 (11)	81.8 (9)	76.9 (20)
Beliefs and practices about FHH			
Believes FHH very important	93.8 (15)	93.8 (15)	93.8 (30)
Believes FHH of cancer very important	100.0 (16)	93.8 (15)	96.9 (31)
Very sure about collecting FHH	81.3 (13)	68.8 (11)	76.9 (24)
Has collected FHH information	37.5 (6)	75.0 (12)	56.3 (18)
Collected and wrote down FHH information	12.5 (2)	31.3 (5)	21.9 (7)

[a]For cancer screenings, responses indicate percentage of participants who had received each screening on schedule

[b]n=16 women with cancer history and 15 women without cancer history were 40+

[c]n=15 women with cancer history and 11 women without cancer history were 50+

understanding of the family's history. As Participant 213 said about discussions with her family, "the more I talk about [FHH information], the more I explain to them and show them, the more they understand." A few participants stated that mental tracking could be problematic in the case of older relatives who developed memory problems or passed away. Although some participants saw benefits to writing FHH information down, including increased reliability, accuracy, and ease of sharing, few had actually done so. While some participants thought that online or computer tracking could be useful, a few raised concerns about privacy or computer literacy among certain family members.

Reactions to biomedical FHH tool at baseline

Asking participants to use the MFHP tool during the interview yielded several themes related to the potential usefulness of this FHH tool for this audience. Participants had mixed but generally positive reactions to the tool. Table 3 includes quotations selected because they are either typical or represent important discrepancies. One major theme was that the FHH tool output enabled participants to see patterns in their family history. Many participants believed that a visual depiction of those patterns was useful, with Participant 116, for example, saying that seeing the FHH information on paper "opens up your eyes," and Participant 209 saying "[I]f you don't see it in black and white like this, it doesn't seem like there's any pattern." A few people, however, thought the tool only showed them information they knew already.

Another major theme was that most participants felt the FHH tool was inclusive and fit their family well. Some participants, however, did not like the fact that family members such as cousins were not easily added to the tool. Although some were bothered by this omission, others thought that adding extended family members would significantly increase the time needed to complete the tool. A few participants expressed concern about the time necessary to complete the tool.

A third major theme was that using the FHH tool made participants realize they were missing information about their family. According to Participant 105, "I really don't know much about my family, and it worries me. So I definitely have to find out more." A few participants named people they could ask for more information, but others accepted of their lack of FHH information, in some cases because they knew they would be unable to obtain it (due, for example, to family division or deceased relatives).

These qualitative themes were supported by participants' responses to closed-ended questions about the MFHP tool. On average, participants found the tool to be easy to use (6.2 [out of 7], SD=0.8), understandable (6.6, SD=0.7), a good fit for their family (6.1, SD=1.4), and a good support for talking to their family about family history of cancer (6.4, SD=1.5). Participants were interested in using the tool to learn more about FHH (6.3, SD=1.4).

Choice of FHH tool

When participants were asked to choose one paper FHH tool to take home, they were given a chance to examine both MFHP and *Does It Run in the Family*?. The paper version of MFHP was chosen by 38 % (n=12) of the participants, and 63 % (n=20) chose *Does It Run in the Family*? Although a few participants said they felt the two tools were very similar, many mentioned liking *Does It Run in the Family*? because it was detailed and informative, and they liked that it included stories and strategies for collecting FHH

Table 2 Qualitative themes about discussion and recording of FHH information among African American women (N=32)

Theme	Representative Quotes	Discrepant Quotes
Mental and verbal collection. Many people reported that they or their relatives kept track of FHH information in their heads and shared it verbally with others but did not record it in writing.	Participant 116: "I just think communication [is the best way to share FHH information]. Because the more I talk about it, the more I explain to them and show them, the more they understand… So a lot of times, you don't have to keep everything on paper. If you keep informing people and keeping them up to date, they remember. And they love you."	Participant 104: "Me, I need to write stuff down."
Written collection. Some participants believed that writing down FHH information could be useful, but few reported that they or relatives had done so.	Participant 102: "When you write things down you got it there and you can always go back and look at it and reference and when you go by just your memory…sometimes your memory fails you and you forget stuff. Like I had forgotten when I was talking about cancer that anybody in my family had had cancer. Well, as we talked, I remembered my sister had ovarian…I mean colon cancer so if you write down you will have it. I think writing is better. Definitely." Participant 215: "I don't necessarily think computer but probably a log of, you know, we have now where you can go in and do a family tree on the computer I guess, but you can also start it in a book and just start your family tree and, I don't know, you can list what this person has. I mean it's a lot of work but that's one thing, that's one way you could do it."	None.
Electronic collection. Some participants thought a computer or the internet would be a helpful way of recording FHH information, but only a few people had done so. Electronic resources raised concerns about privacy and accessibility, especially for older family members.	Participant 212: "Well, I guess you could [collect FHH information] by computer but I just never thought about doing it." Participant 201: "I've got pieces of paper and records and stuff like that, but I need to get it together. As a matter of fact, when I leave here I'm going to call [my brother] - telephone call - and ask him how can we put this on the web you know, because we're trying to tie the family up more because the basic 10 [children there] is 7 of us left. We need to prepare them to take over. Cause we're tired, and we've lost 3."	Participant 210: "The phone, you know, in person… But, you know, this e-mail stuff, the e-mail is OK. The Facebook is not. And, and I've noticed that, you know, people will put out a little more information out there than they should."
No collection. Some participants reported that no one collects or records information about diseases that run in their family.	Participant 213: "I don't know any families that [keep track]."	None.

information and information about lifestyles in general. Participant 110 said, "I like this one better because it's easy to read, then it has suggestions on how to obtain a portrait and ways to help you share while [your family is] sharing with you." Participant 112 said, "It seems like it gives me more questions to talk about, more thoughts that come across my mind. … Talking about how you eat, smoke and exercise." A few participants saw the benefit of using both tools together; according to Participant 214, "I will probably use [*Does It Run In the Family*?] along with the Family Health Portrait. It'll help me modify [MFHP]… because it doesn't just give a health history, it also gives the lifestyle history. And that's also important."

Use of FHH tools based on different paradigms

After 3 weeks, we examined use of the selected tool and self-reported barriers to use (see Table 4). The primary "use" of both tools seemed to be to promote discussion among family members. Of the 20 people who reported using the selected tool, 75 % said that they had shared it with someone else, and a large majority (93 %) discussed FHH

Table 3 Qualitative themes related to reactions to the biomedical FHH tool after initial use (N=32)

Theme	Representative Quotes	Discrepant Quotes
Showing patterns and connections. Many people thought that the FHH generated by the tool enabled them to see patterns in their family history, and many believed a visual depiction of those patterns was useful.	Participant 116: "I think just seeing it on paper, it just kind of opens up your eyes. You know, 'cause you can talk about things, but until people actually see it written down, it kind of changes everything…. 'Cause like my kids know, well, your uncle so-and-so has this, and your aunt has this. … I think that would help them more if they saw it more on paper." Participant 209: "[I]f you don't see it in black and white like this, it doesn't seem like there's any pattern. It doesn't seem like it ….You don't really think about it until after you see, oh that connects."	Participant 212: "There was nothing I didn't already know…. It's not like all of a sudden someone jumps out and you say, I didn't know that…. It would be helpful for someone else if they were looking at it you know and see what's going on, but as far as I'm concerned I, you know, I pretty much know."
Seeing missing information. Many participants said the tool made them realize they were missing information about their family.	Participant 105: "I see…an empty page and …I've pretty much filled out everything I can actually confirm…. And it makes me feel like I really need to do some research.…I really don't know much about my family, and it worries me. So I definitely have to find out more." Participant 114: "I don't know all of the information, I'm sure there is other information I don't know. But, basically this is, this is, the information I have so far."	None.
Inclusiveness of tool. Most participants felt the tool fit their family well, but many participants also noted that some extended family members such as cousins were difficult to include.	Participant 116: "I think it summarizes my family very well. I think it's a very useful tool."	Participant 110: "[I feel] like that's not a complete history. Incomplete…. my cousins were like my brothers and sisters, that's just the way my family raised us." Participant 106: "My spouse and in-laws [were left out]…. I was surprised, but it's about me and they're not blood-related to me so…they're blood related to my children not me so I understand."
Time and effort to use the tool. Some participants thought the FHH tool was time-consuming.	Participant 201: "[A barrier to collecting FHH is] just taking the time to talk to individuals and write and record their information, because it's time-consuming." Participant 212: "In my family…people [would] just be too busy to [use the tool] or would not take the time to do it."	Participant 213: "I don't think it takes much [time]."

Table 4 Use of FHH tool at 3-week follow-up by selected tool (N=30)

	Chose *My Family Health Portrait* (n=11)	Chose *Does It Run in the Family*? (n=19)	Total (N=30)[a]
Discussed FHH	90.9 % (10)	94.7 % (18)	93.3 % (28)
Used tool	54.5 % (6)	73.7 % (14)	66.7 % (20)
Used tool and wrote down information[b]	10.0 % (1)	44.4 % (8)	32.1 % (9)
Intends to use tool in future	90.9 % (10)	94.7 % (18)	93.3 % (28)
Time spent using tool, scale 1–7 (SD)	4.3 (1.2)	5.3 (.8)	5.0 (1.0)
Satisfaction using tool, scale 1–7 (SD)	5.8 (1.0)	6.1 (1.2)	6.0 (1.1)
Good experience using tool, scale 1–7 (SD)	6.0 (0.9)	6.5 (0.7)	6.3 (0.8)

[a]Two participants lost to follow-up are excluded from these analyses

[b]Due to missing data for this item, n=10 for *My Family Health Portrait* and n=18 for *Does It Run in the Family*?

information since the baseline interview. Of the people who used the selected tool, level of satisfaction was high (6.0, SD=1.1). Larger numbers of people who chose *Does It Run in the Family*? used the tool (74 % vs. 44 %) and wrote down information (44 % vs. 10 %) compared with MFHP.

Few types self-reported barriers to using either FHH tool were consistently mentioned. Of those who had used their tool, 40 % mentioned specific barriers, the most common of which were lack of time (30 %) and lack of information about FHH (10 %). All 10 participants who did not use their tool cited at least one barrier, the most common of which were lack of time (40 %), distance from family (20 %), and forgetting to use the tool (20 %). There was no clear difference in self-reported barriers by tool type.

Discussion

This study examined different behavioral steps needed to collect FHH information and compared different paradigms for FHH tools among an underserved racial/ethnic group in the United States. Participants clearly separated discussing FHH and writing the information down. At baseline, participants reported believing that it is important to know and collect FHH information, which is consistent with prior research (Yoon et al. 2004). However, although many agreed that writing down such information could be useful, few had previously done so. Many people reported that their families track FHH information verbally, and the FHH tools also prompted more discussion than recording of FHH information. At the three-week follow-up, many participants discussed FHH information with their families using the tools, but few had recorded the information on paper. Overall reaction to the biomedical MFHP online tool was positive, with some participants stating that it helped them see FHH patterns and gaps in FHH awareness. However, more participants selected the *Does It Run in the Family*? tool, and many reported liking the fact that it gave detailed suggestions for talking with family members about FHH. Overall, more people who chose *Does It Run in the Family*? recorded FHH information in writing than those who chose the MFHP tool.

Behavioral steps to collect FHH

Many people reported keeping track of FHH information informally, either in their heads or through discussions with family members. Our findings extend the literature by suggesting that, while these discussions could be a way to promote family closeness, people may also be receptive to creating a written FHH record if prompted by an intervention; many people thought that writing down FHH information was an effective way to keep track of it, and seeing some family history information in a chart prompted many to want to collect more information.

Our sample was purposefully comprised in equal numbers of cancer survivors and people without a personal history of cancer. It was surprising that, at least in this small sample, people with a personal history of cancer were *less* likely to have collected FHH information at baseline than people without a personal history of cancer. Although these findings need to be explored in larger samples, the results suggest that a cancer diagnosis by itself may not make the discussion or recording of FHH information more salient, despite the fact that biological relatives may need to know the information for their own care. We did not collect information about when our participants had been diagnosed with cancer; it is therefore possible that, for some of our participants, their cancer diagnosis and treatment predated recent public campaigns to collect FHH information. Our results suggest, however, that patients who are diagnosed with cancer or other chronic diseases may need explicit encouragement to record that information and share it with other biological family members.

Reactions to biomedical FHH tool at baseline

Participants generally reacted positively to the online biomedical tool used during the baseline interview. Although a few participants found the MFHP tool time-consuming, many believed it helped them to understand family health patterns, helped them see FHH information they were missing, and was a good fit for their family. These results suggest dissatisfaction with biomedical FHH tools may not be a major barrier to FHH collection.

Use of FHH tools based on different paradigms

The majority of participants reported using their FHH tool during the three week follow-up period; however, few wrote down this information. People who used either FHH tool during the follow-up period generally reported having a positive experience and feeling satisfied. Our follow-up interview findings highlight the importance of precision in assessing use of FHH tools by separately investigating component steps. Many participants, for example, reported "using" the tool, but most of those did not write down FHH information. These results are especially concerning because the characteristics of our study participants (e.g., high adherence to screening, high levels of self-efficacy to collect FHH information) suggest that they might be somewhat *more* likely than the general population to collect written FHH. It is important to note that more participants used the non-biomedical FHH tool than the biomedical one and recorded more information, which may be due to the difference in underlying paradigm or to the cultural tailoring of

the *Does It Run in the Family*? tool. Participants liked the fact that the tool provided suggestions for talking to family members about FHH, as well as information about collecting health information other that disease history. This difference between use of the tools certainly warrants exploration in future quantitative studies powered to detect statistically significant differences between FHH tools.

Participants reported few types of barriers to using either FHH tool. The fact that all participants who did not use their tool mentioned at least one barrier could mean those participants actually faced more barriers, they were motivated to explain their lack of tool use to the interviewer, or both. Participants did not mention several barriers to FHH collection commonly cited in the literature, such as lack of interest, difficulty understanding FHH materials, poor or distant relationships with family members, or lack of health information (Wallace et al. 2009; Petruccio et al. 2008; Murray et al. 2007). However, both people who used the tools and people who did not use the tools cited lack of time as the main barrier, consistent with prior research (Petruccio et al. 2008; Wallace et al. 2009; Murray et al. 2007). This finding suggests that, although people consider collecting FHH information to be important, other tasks may take short-term priority. People may need additional interventions that can motivate them to prioritize creating a written FHH record that can be shared with health care providers. Having primary care providers explain the importance of FHH, for example, may be one way to encourage participants to collect FHH information (Murray et al. 2007).

It is also important to note that all 32 participants were willing to create the beginning of a written FHH during the baseline interview. This finding is consistent with a demonstration project in which 100 % of the participants created a FHH while participating in an educational session (Wallace et al. 2009), and it suggests that having a designated time and place, as well as in-person encouragement, may be helpful in promoting the creation of written FHHs. Strategies such as asking patients to complete a FHH form prior to coming in for an appointment, giving patients time to record the information they do have before seeing a provider (e.g. while in the waiting room), and supplying support from a patient educator or nurse may be effective in encouraging people to create written FHH records.

Strengths and limitations

Most research on family history has studied highly selected populations, often those who are white and of high socioeconomic status (O'Neill et al. 2009; Acheson et al. 2010; Wideroff et al. 2010; Cohn et al. 2010). The present study extends current research by focusing on members of one minority population in the United States. In addition, we addressed important research gaps in the literature by examining separately different behavioral steps needed to collect and record FHH and by investigating different paradigms for FHH tools. The use of qualitative methods allowed us to explore these questions in much greater depth than we could have in a quantitative study.

Because the sample size was based on our primarily qualitative approach to the interviews, we did not have adequate statistical power to compare results between subgroups, but future research should investigate these questions in larger, quantitative studies. We pre-selected the FHH tools used in the study and it is possible that different FHH tools would better motivate the collection and recording of FHH information. In addition, our convenience sample was drawn from a single metro area, and women who were motivated to collect and discuss FHH may have been overrepresented.

These data suggest that future intervention research should develop strategies to encourage the creation of written FHHs in different subgroups as well as exploring how different FHH tool paradigms affect this outcome. Future studies of FHH interventions should explore which paradigm for FHH tools might best bridge the gap between verbal/mental FHH tracking and the creation of a written FHH that could be shared with family members and health care providers, as well as whether using tools based on different paradigms in conjunction with one another may improve collection of FHH information. Future research should also analyze the effects of diagnoses of different types of cancer, as well as other chronic diseases, on use of different kinds of FHH tools. In addition, our findings suggest that researchers assessing FHH collection should employ carefully constructed survey items that differentiate between different behavioral steps required to complete a written FHH record. Taken together, these steps can expand the current knowledge base about FHH collection and strengthen the use of FHH information in clinical practice.

Conclusion

Simply making FHH tools available for patients to use on their own may be insufficient to promote creation of a written FHH record, a step critical to sharing this information with health care providers. Although most participants endorsed the importance of collecting FHH information and felt confident in their ability to do so, few took the additional step of writing down FHH information, even when given a FHH tool. Providers and public health practitioners should consider additional ways to encourage patients to create written FHHs in order to maximize the potential of FHH information to inform and tailor prevention and screening recommendations.

Acknowledgments Erin Thimmesch and Maria Torres Galvan contributed to data collection and coding. Funding provided through a developmental research grant from P50-CA095815. Thanks to the Recruitment Enhancement Core in the Regulatory Support Center of the Institute of Clinical and Translational Sciences at Washington University (funded by NIH grants UL1 TR000448, KL2 TR000450, and TL1 TR000449) for assistance with recruitment.

References

Acheson L (2003) Fostering applications of genetics in primary care: what will it take? Genet Med 5(2):63–65

Acheson LS, Wang C, Zyzanski SJ, Lynn A, Ruffin MT, Gramling R, Rubenstein WS, O'Neill SM, Nease DE (2010) Family history and perceptions about risk and prevention for chronic diseases in primary care: a report from the Family Healthware Impact Trial. Genet Med 12(4):212–218

Acton R, Burst N, Casebeer L et al (2000) Knowledge, attitudes, and behaviors of Alabama's primary care physicians regarding cancer genetics. Acad Med 75(8):850–852

American Cancer Society (2011) Facing Disparities. http://www.cancer.org/MyACS/Eastern/AreaHighlights/cancernynj-news-mlk-facing-disparities

American Cancer Society (2012) American Cancer Society Guidelines for the Early Detection of Cancer. http://www.cancer.org/Healthy/FindCancerEarly/CancerScreeningGuidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer

Audrain-McGovern J, Hughes C, Patterson F (2003) Effecting behavior change: awareness of family history. Am J Prev Med 24(2):183–189

Beatty P, Willis G (2007) Research synthesis: the practice of cognitive interviewing. Public Opin Q 71:287–311

Berg AO, Baird MA, Botkin JR, Driscoll DA, Fishman PA, Guarino PD, Hiatt RA, Jarvik GP, Millon-Underwood S, Morgan TM, Mulvihill JJ, Pollin TI, Schimmel SR, Stefanek ME, Vollmer WM, Williams JK (2009) National Institutes of Health State-of-the-Science conference statement: family history and improving health. Ann Intern Med 151(12):872–877

Buchanan AH, Skinner CS, Rawl SM, Moser BK, Champion VL, Scott LL, Strigo TS, Bastian L (2005) Patients' interest in discussing cancer risk and risk management with primary care physicians. Patient Educ Couns 57:77–87

Butty J, Richardson F, Mouton C, Royal C, Green R, Munroe K (2012) Evaluation findings from genetics and family health history community-based workshops for African Americans. J Community Genet 3:1–12

Carmona RH, Wattendorf DJ (2005) Personalizing prevention: the U.S. Surgeon General's family history initiative. Am Fam Physician 71(1):36–39

Chew LD, Griffin JM, Partin MR, Noorbaloochi S, Grill JP, Snyder A, Bradley KA, Nugent SM, Baines AD, VanRyn M (2008) Validation of screening questions for limited health literacy in a large VA outpatient population. J Gen Intern Med 23(5):561–566

Clarke AJ (2009) Musings on genome medicine: the value of family history. Genome Medicine 1:75

Coffey A, Atkinson P (1996) Making sense of qualitative data: Complementary research strategies. Sage Publications, Thousand Oaks, CA

Cohn W, Ropka M, Pelletier S, Barrett J, Kinzie M, Harrison M, Liu Z, Miesfeldt S, Tucker A, Worrall B, Gibson J, Mullins I, Elward K, Franko J, Guterbock T, Knaus (2010) Health Heritage, a web-based tool for the collection and assessment of family health history: initial user experience and analytic validity. Public Health Genomics 13(7–8):477–491

Cree RA, Lynch J, Au MG, Myers MF (2009) Decisions to seek healthcare based on family health history among urban Appalachian women. J Genet Couns 18:534–550

Dunlop K, Barlow-Stewart K (2009) Start the conversation: the New South Wales (Australia) Family Health History Campaign. Public Health Genomics 13(5):301–309

Feero WG, Bigley MB, Brinner KM (2008) New standards and enhanced utility for family health history information in the electronic health record: an update from the American Health Information Community's Family Health History Multi-Stakeholder Workgroup. J Am Med Inform Assoc 15(6):723–728

Fuller M, Myers M, Webb T, Tabangin M, Prows C (2010) Primary care providers' responses to patient-generated family history. J Genet Couns 19(1):84–96

Genetic Alliance (2009) Programs. http://www.geneticalliance.org/programs. Accessed January 29, 2009

Grover S, Stoffel EM, Bussone L, Tschoegl E, Syngal S (2004) Physician assessment of family cancer history and referral for genetic evaluation in colorectal cancer patients. Clin Gastroenterol Hepatol 2:813–819

Guttmacher AE, Collins FS, Carmona RH (2004) The family history - More important than ever. N Engl J Med 351(22):2333–2336

Hampel H, Sweet K, Westman JA, Offit K, Eng C (2004) Referral for cancer genetics consultation: a review and compilation of risk assessment criteria. J Med Genet 41:81–91

Kaphingst K, Goodman M, Pandya C, Garg P, Stafford J, Lachance C (2012) Factors affecting frequency of communication about family health history with family members and doctors in a medically underserved population. Patient Educ Couns 88(2):291–297

Kelly K, Sweet K (2007) In search of a familial cancer risk assessment tool. Clin Genet 71:76–83

Miles M (1983) Qualitative data as an attractive nuisance: The problem of analysis. In: Maanen J (ed) Qualitative Methodology. Sage Publications, New Dehli

Miles M, Huberman A (1994) Qualitative data analysis: An expanded sourcebook. Sage Publications, Thousand Oaks, CA

Murray MF, Holbrook KJ, Giovanni MA (2007) Brigham and Women's Hospital Family History Project. Final Report on Phase 1: A Hospital Employee-Focused Family History Project. Brigham and Women's Hospital and Harvard Medical School. http://www.genome.gov/Pages/About/OD/ECIB/FHDemonstrationProjectReports/BWHFinalReport.pdf. Accessed September 28, 2012

National Human Genome Research Institute (2011) Family History Demonstration Projects. http://www.genome.gov/27026369 Accessed September 27, 2012

O'Leary J, Edelson VT, Gardner NR, Gepp AJ, Kyler P, Moore PJ, O'Quinn K, Petruccio CL, Terry SF, Bowen D (2009) Community empowerment for public health: the role of family health history. Paper presented at the American Public Health Association annual meeting. Philadelphia, PA, November 9, 2009

O'Neill SM, Rubenstein WS, Wang C, Yoon PW, Acheson LS, Rothrock N, Starzyk EJ, Beaumont JL, Galliher JM, Ruffin MT (2009) Familial risk for common diseases in primary care: the family healthware impact trial. Am J Prev Med 36(6):506–514

Orom H, Coté ML, González HM, Underwood W, Schwartz AG (2007) Family history of cancer: Is it an accurate indicator of cancer risk in the immigrant population? Am Cancer Soc 112(2):399–406

Petruccio C, Mills Shaw KR, Boughman J, Fernandez C, Harlow I, Kruesi M, Kyler P, Lloyd-Puryear MA, O'Leary J, Skillman A, Terry S, McKain F (2008) Health choices through family history: a community approach to family history awareness. Community Genet 11:343–351

Qureshi N, Bethea J, Modell B, Brennan P, Papageorgiou A, Raeburn S, Hapgood R, Modell M (2005) Collecting genetic information

in primary care: evaluating a new family history tool. Fam Pract Adv Access 22(6):663–669

Qureshi N, Carroll JC, Wilson B, Santaguida P, Allanson J, Brouwers M, Raina P (2009) The current state of cancer family history collection tools in primary care: a systematic review. Genet Med 11(7):495–506

Reid G, Walter F, Brisbane J, Emery J (2009) Family history questionnaires designed for clinical use: a systematic review. Public Health Genomics 12:73–83

Rich EC, Burke W, Heaton CJ, Haga S, Pinsky L, Short P, Acheson L (2004) Reconsidering the family history in primary care. J Gen Intern Med 19(3):273–280

Sandelowski M (1995) Qualitative analysis: what it is and how to begin. Res Nurs Health 18:371–375

Scheuner MT, Wang S-J, Raffel LJ, Larabell SK, Rotter JI (1997) Family history: a comprehensive genetic risk assessment method for the chronic conditions of adulthood. Am J Med Genet 71(3):315–324

Schroy I, Paul S, Barrison AF, Ling BS, Wilson S, Geller AC (2002) Family history and colorectal cancer screening: a survey of physician knowledge and practice patterns. Am J Gastroenterol 97(4):1031–1036

U.S. Surgeon General's Office (2011) My Family Health Portrait. https://familyhistory.hhs.gov/. Accessed September 20, 2012

Sweet K, Bradley T, Westman JA (2002) Identification and referral of families at high risk for cancer susceptibility. J Clin Oncol 20(2):528–537

Tyler CV, Snyder CW (2006) Cancer risk assessment: examining the family physician's role. J Am Board Fam Med 19:468–477

Valdez R, Yoon PW, Qureshi N, Green RF, Khoury MJ (2010) Family history in public health practice: a genomic tool for disease prevention and health promotion. Annu Rev Public Health 31:69–87

Vernon SW, Meissner H, Klabunde C, Rimer BK, Ahnen DJ, Bastani R, Mandelson MT, Nadel MR, Sheinfeld-Gorin S, Zapka J (2004) Measures for ascertaining use of colorectal cancer screening in behavioral, health services, and epidemiologic research. Cancer Epidemiol Biomark Prev 13:898–905

Wallace JP, Baugh C, Cornett S, Hood B, Prows CA, Ryan N, Warren NS, Au MG, Brown MK, Glandorf K, Jarrell JJ, Nolan TL, Sorrell J, Walters J, Myers MF (2009) A family history demonstration project among women in an urban Appalachian community. Prog Community Health Partnerships 3(2):155–163

Wang C, Gallo RE, Fleisher L, Miller SM (2011) Literacy assessment of family health history tools for public health prevention. Public Health Genomics 14(4–5):222–237

Wideroff L, Garceau AO, Greene MH, Dunn M, McNeel T, Mai P, Willis G, Gonsalves L, Martin M, Graubard BI (2010) Coherence and completeness of population-based family cancer reports. Cancer Epidemiol Biomarkers Prev 19(3):799–810

Willis G (2005) Cognitive interviewing: A tool for improving questionnaire design. Sage Publications, Thousand Oaks, CA

Yoon PW, Scheuner MT, Peterson-Oehlke KL, Gwinn M, Faucett A, Khoury MJ (2002) Can family history be used as a tool for public health and preventive medicine? Genet Med 4(4):304–310

Yoon PW, Scheuner MT, Gwinn M, Khoury MJ, Jorgensen C, Hariri S, Lyn S (2004) Awareness of family history as a risk factor for disease – United States, 2004. Morb Mortal Wkly Rep 53(44):1044–1047

Yoon PW, Scheuner MT, Jorgensen C, Khoury MJ (2009) Developing Family Healthware, a family history screening tool to prevent common chronic diseases. Prev Chronic Dis 6(1):1–11