Family health history and genetic services—the East Baltimore community stakeholder interview project

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Abstract

Discussion of family health history (FH) has the potential to be a communication tool within families and with health providers to stimulate health promotion related to many chronic conditions, including those with genetic implications for prevention, screening, diagnosis, treatment. Diverse communities with disparities in health outcomes may require different approaches to engage individuals and families in the evolving areas of genetic risk communication, assessment, and services. This work was a partnership of a local urban agency and academic genetics professionals to increase understanding of community concerns and preferences related to FH and genetic awareness. Thirty community stakeholders in the East Baltimore area participated in structured interviews conducted by community members. We identified key themes on family health history FH, risk assessment, and genetic services. Forty-three percent (18/27) of community stakeholders thought families in East Baltimore did not discuss family health history FH with doctors. Stakeholders recognized the benefits and challenges of potential actions based on genetic risk assessment and the multiple competing priorities of families. FH awareness with community engagement and genetics education were the major needs identified by the participants. Research undertaken in active collaboration with community partners can provide enhanced consumer perspectives on the importance of family health history and its potential connections to health promotion and prevention activities.

Keywords Family health history · Health disparities · Community engagement · Genetic services · Communication

Introduction

Family health history assessment may be considered the first genetic screen (Beery and Shooner 2004) and a potential public health tool to discern highly familial conditions, such as hypercholesterolemia and certain cancers (Ramsey et al. 2006; Khoury and Evans 2015). Reviewing a family history is an important step in the analysis of both health and disease across the lifespan among relatives. Family history provides information about genetic susceptibilities based on both shared genes and environmental factors such as diet and behaviors that may interact to cause most common diseases such as cancer, diabetes, and heart disease. Over 90% of U.S. respondents of all races recognize the importance of family history, and 32.9% of non-Hispanic blacks and 30.2% of non-Hispanic whites reported collecting family history information (Yoon et al. 2004). While collection of three-generational family history is still considered a gold standard in primary care practice (Tarini and McInerney 2013), existing literature suggests that even binary (presence, absence) knowledge of family history of certain cardiovascular conditions may be useful for primary care

“We now know that gathering and maintaining family medical information, which should reach as far back as three to four generations is vital. It reminds us of the monetary banking system, (squirreling information away and withdrawing it when needed).”
Community partner comment

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risk assessment (Qureshi et al. 2012; Weng et al. 2015). Awareness of higher risk due to family history may be first step in the path from discussion among relatives to patient with doctor communication and subsequent uptake of preventive behaviors and screening.

Although African-American and Hispanic women are at a higher risk of some hereditary cancers such as triple negative breast cancer, this population is underrepresented in current genetic referral and testing practices, including a lower likelihood of participation in provider discussions. This is a potential contributing factor to existing disparities in cancer prevention and early detection (Cragun et al. 2017; Underhill et al. 2016; Allford et al. 2014; Butrick et al. 2014). Racial disparities have been described in trust, access, patient awareness, and uptake of genetic services (Sheppard et al. 2013; Mai et al. 2014; Armstrong et al. 2005; Pagán et al. 2009; Lucas-Wright et al. 2014). The influence of family history may be especially important in recruiting African-Americans to early detection programs (Avis-Williams et al. 2009) and clinical research studies (Rivers et al. 2013; Hughes et al. 2017). While only 2% of health-related news in Black newspapers has been found to be genetics-related, the importance of family health history is more likely to be emphasized in these newspapers than in general audience newspapers (Caburnay et al. 2014). Limited available research suggests low awareness and understanding of familial risk among minority ethnic communities, along with possible stigmatization, although the overall importance of family relationships may stand in contrast (Allford et al. 2014; Sussner et al. 2011).

The majority of U.S. genetic health professionals are Caucasian (Mittman and Downs 2008). Some recent research raises concern about the implicit racial attitudes some genetic counselors may bring to their practice (Schaa et al. 2015). Researchers have recommended introduction of culturally sensitive provider and counseling initiatives, and enabling patient self-referral as potential strategies to help meet the needs of diverse communities (Allford et al. 2014). Programs to enhance family history communication have included national initiatives such as the U.S. Surgeon General's Family History web-based tool (Guttmacher et al. 2004), community-based workshops (Manswell Butty et al. 2012), and other culturally adept family history approaches (O'Leary et al. 2011; Pettey et al. 2015).

In general, families and communities have not been asked how, when, and where they want the flow of family history and genetic information to occur. Some have begun to address these concerns (Gallo and Knafl 2009; Kuo et al. 2012). Community engagement can provide enhanced consumer perspectives on the availability of and access to varied genetic and family health history services (Morgan and Lifshay 2006). Studies on community-based participatory research have demonstrated that the productivity of collaborations between community leaders and academic researchers may be maximized when partners understand and value each other's contribution to the

partnership, often considered as a time-consuming and complex process (Rosenthal et al. 2014; Wallerstein and Duran 2010). This study was designed and conducted within the framework of community-based participatory research—early and consistent engagement with the community partners, mutual learning, equitable involvement, shared decision-making, effective communication, transparency, and commitment to follow-up. The goal of the project was to develop a community-based qualitative assessment of family history concerns, genetic awareness, and service needs to inform future health and well-being initiatives related to genetic risk assessment and health promotion in East Baltimore. We sought to increase understanding of the attitudes and concerns of the neighborhoods surrounding our academic health center in order to have a more comprehensive appreciation of the various points of access and interaction at family, community and genetic service levels. Our long-term goal is to address growing health disparities in genetic services.

Methods

Project development The study idea stemmed from ongoing discussions with community and academic health center members about the importance of family health history as a tool for approaching genetic issues that was not focused on technical scientific understanding and historical community issues of distrust in research. Funded by the Urban Health Institute at the Johns Hopkins Bloomberg School of Public Health, this study was a collaborative partnership with the Jesus' Stop Restoration Center—a community organization addressing public health prevention in Baltimore; the Community Advisory Group (CAG) of the Johns Hopkins Cancer Disparities Program at the Sidney Kimmel Comprehensive Cancer Center; and the Community Research Advisory Council (C-RAC) of the Institute for Clinical and Translational Research (ICTR) at the Johns Hopkins School of Medicine. The study documents for the semi-structured interviews were finalized after multiple discussions with the collaborators. Two leaders of the Jesus' Stop Restoration Center, referred to as community partners, completed Institutional Review Board (IRB) training and two mock interview sessions with the study coordinator to implement the IRB-approved study protocol. The community partners established initial contact with community stakeholders (the research participants), screened for eligibility, obtained informed consent, interviewed participants, transcribed the interviews, and contributed to data analysis and manuscript preparation. Participants, a convenience sample who were known to the collaborative partners, needed to be over 18 years of age and English-speaking, willing to spend 30–60 min for the interview, and willing to avoid talking about their personal, friends', and/or family's health history.

Recruitment The community partners and the CAG and C-RAC members identified a broad range of community stakeholders who worked or lived in East Baltimore. The community partners sent the introductory letter, which included an opt-out option, to establish initial contact and eligibility screening with the community stakeholders. Any East Baltimore resident who met the eligibility criteria was identified as a community stakeholder. Fifty-eight individuals 18 years of age and older were screened for their interest in the study. Three declined, 25 did not follow-up, and 30 agreed to participate. The community partners scheduled the interviews with the community stakeholders and obtained informed consent.

Interviews The community partners used a semi-structured interview guide they had developed and finalized with the principal investigator and study coordinator. The guide included both specific and open-ended questions that helped the interviewers interact with participants and elicit detailed responses to the study questions. The participants were asked not to share personal or family health information and to share their views of the community. The following topic areas were included in the interview guide: understanding how families learn and talk about their family health history; possible connections of family history with improved well-being, health education, health care, and genetic services; risk perceptions; family history documentation; and community resources and dissemination mechanisms relevant to family history. Some examples of the questions included in the interview guide were: What is your opinion about the importance of family health history? What are your thoughts on families talking about Family Health History with their doctors? What does the word “genetics” mean to you? Do you think people want to know if they are at a higher risk for a genetic condition? How should the family health history (FHH) be kept? How can we help people in the community be more aware about the importance of knowing and discussing their family histories? Please tell us about any problems or challenges you see in increasing awareness about genetics and available resources.

Participants chose either in-person or phone interview and were told it would take up to an hour to complete the interview. The community partners digitally recorded the interviews, transcribed them verbatim, and deidentified the data. A \$25 gift card was given to the participants after the interview.

Analysis Each of the study team members individually used thematic analysis without specific software to summarize the findings of the 30 key informant interviews. In the first step of the analytic process, each person identified key points from the responses to each question. In the second

step, each study team member looked for specific themes related to personal, sociocultural, and preventive aspects of family health history and genetics, health communication, and community engagement strategies. The study team reviewed and discussed the transcripts and various themes several times to identify, compare and code the themes within and between interviews.

Results

Participant characteristics (Table 1) Thirty English-speaking participants (23 females and 7 males) completed interviews. Seventeen interviews were conducted in-person and 13 interviews were conducted through phone. Twenty-nine were African-American and one was Latino. Three individuals were 18–30 years old; seven were 31–40 years old; 11 were 41–50 years old; five were 51–60 years old; and four were 61 years or older. Fourteen worked in health care with an East Baltimore community focus; three identified themselves as educators; three as advocacy group leaders; and ten as community/business leaders. The study cohort is representative of the community of East Baltimore where the majority of the population is African-American.

Findings: Table 2 provides an overview of the overarching categories, themes and subthemes, stakeholders endorsing each theme and supporting quotations illustrating each theme.

Family health history relevance

Knowing family history is important Stakeholders overall considered family history very important for residents of East Baltimore to know, as well as important in general. However, family history may not be viewed as part of preventive health or other priorities, and therefore family history may not be known or collected. While family cohesiveness and the impact of poverty were noted as issues for some families, the general emphasis was on further education and increased attention to family history.

Family health history communication and documentation

Family history communication and documentation preferences vary Stakeholders were generally willing to share their family history ahead of their healthcare visit and participate in meaningful discussion about the implications of their family history with their provider(s).

Stakeholders' family history communication preferences varied between using mail, phone, internet, and in-person discussion. Most stakeholders preferred to send family health

Table 1 Demographics of the participants

<i>N</i> = 30	Females (<i>N</i> = 23)	Males (<i>N</i> = 7)
Age group (years)		
• 18–30	2	1
• 31–40	3	4
• 41–50	10	1
• 51–60	5	0
• 61–70	3	1
Total	23	7
Work area		
• Health care	12	2
• Community/business leaders	6	4
• Educators	3	0
• Advocacy group leaders	2	1
Total	23	7

history information via mail ahead of their medical visit. Those who mentioned any security concerns were matter of fact, and noted, for example, similarity to banking online. Stakeholders noted an overall lack of initiative from their providers about integrating family history in their care. They allowed the doctor to direct them through the visit.

Risk assessment

Knowing about genetic risk can be beneficial Most stakeholders favored knowing about genetic risks similar to the responses related to importance of family history. The magnitude of risk paralleled interest in learning more about the implications of risk or seeking preventive measures. Better preparation for dealing with genetic conditions and taking preventive measures were noted as reasons to learn about risk.

Preferences for how risk information is conveyed may vary

Stakeholders preferred percentages as the best means to convey genetic risks. Equal number of stakeholders preferred natural frequencies and scores to know their genetic risks. Approximately three-fifths of stakeholders favored communicating with doctors about genetic risks. The term “doctors” was used to represent the medical care community considering that some stakeholders may be seeing allied health professionals such as physician assistants or registered nurse practitioners. Stakeholders also acknowledged the influence of other life priorities such as job or livelihood and child care and the utility of the risk information.

Risk information can raise concerns Stakeholders expressed concerns that risk information can be associated with worry, especially if adding to uncertainty. Participants framed it as potential bad news.

Genetic services

Preferences for genetic testing and services vary Stakeholders considered doctors as the best source to learn more about genetic testing and services and highlighted concerns related to cost, the context of providing genetic services, and psychosocial issues such as family dynamics, perceptions, and support.

Family health history public health strategies

Genetic education is needed through a variety of mechanisms

Participants highlighted the importance of churches, lay educators, and community centers as sources to learn more about genetics and family history. They preferred the Center for Disease Control and Prevention’s motto on family history “Talk it up. Write it down. Pass it on” among several alternatives that the community partners offered (“Knowing your family,” 2014).

Discussion

Family health history has many implications in health communication and prevention. Our African-American community stakeholders generally acknowledged that family history is an important component of optimizing preventive health when conditions run in families. Only a few studies have focused on communication about family health history among African-Americans (Thompson et al. 2015). Recent work in older adults suggests that older African-American adults favor open family history communication with a desire to change patterns of non-communication in previous generations (Hovick et al. 2015). The overarching family health history themes discussed by East Baltimore community members were: acknowledgment of the relevance of family health history, lack of communication with family or documentation standards, understanding of risk, risk communication, and implications, knowledge of and access to genetic services as well as strategies to address barriers and further education.

Community stakeholders shared a variety of preferences and concerns in discussing family history within their families, documenting it, and incorporating it in medical visits and preventive health care. A minority thought that community individuals discussed their family health histories with their doctors. One respondent commented, “Some families don’t want to face it; people, especially, African-Americans tend to keep that information to themselves, unless it becomes a situation people have to know.” These findings are consistent with previous studies that highlight the contrast in understanding of family health history importance and uptake of family health history discussion in families and with doctors (Yoon et al. 2004; Vogel et al. 2007;

Table 2 An overview of the overarching categories, themes and subthemes, stakeholders endorsing each theme, and supporting quotations illustrating each theme

Category	Themes and subthemes	Stakeholders who endorse themes No. (%) (N = 30)	Supporting quotations
Family health history (FH) relevance	Knowing FH is important	25 (83)	“...Gives information on how to proceed with your (health)care” and “...gives insight to preventive measures for healthcare.” “It’s very important, because of the genes that are passed down from generation to generation”
	Knowing FH can lead to prediction and prevention	26 (90)	“Predicts what an individual might encounter later in their life to do something about it.” “Unless there are special circumstances, where you have something like cancer, then you ask your family.”
FH communication and documentation	FH communication habits	12 (40)	“I do not find that it is a habit within families, but it should be.” “Some families do not want to face it; people, esp. African-Americans tend to keep that information to themselves, unless it becomes a situation people have to know.”
	Barriers to FH discussion	17 (57)	“Lack of communication between the generations is a problem. if it’s not shared information, you will not be able to pass it down.” “Shame, fear, denial, omission (about diseases)”
	FH documentation preferences vary ^a	10 (33) keep in family 10 (33) doctor keeps 10 (33) Secure location ^b 4 (13) Faith Based Book	In the family: I think it should be kept with the family. Only for the purpose of a person maintaining their healthcare.” “I think that it should be kept with the doctor or the family. Uh, because just in case something should happen uh you know the doctor would have information right there on hand” “If it is kept in secure website I can have access to that (FH) is not a problem. Family and doctor having access to secure website” “I would say, we keep ours in the Bible”
	FH dissemination preferences vary ^a	13 (43) mail ahead of doctor visit 5 (17) phone ahead 4 (13) internet ahead 4 (13) wait until visit	“FH has a lot to do with the way people think about sharing personal information.”
	FH discussion with providers varies ^a	8 (27) talked with MDs 6 (20) unsure 13 (43) did not think families discussed FH with doctors	“Very important for doctor to know details, how can they help you if they do not know.” “People intimidated by doctor, doctor should initiate, put in layman’s terms, lower income people do not understand.”
	Risk assessment	27 (90) Yes 1 (3) No	“So they know what to look for and know what genetic diseases they may be up against”
Genetic services	Preferences for risk information format ^a	17 (57) percentages 4 (13) fractions 4 (13) scores	“Would depend on who information was being given to and how used”
	Risk communication preferences vary ^a	18 (60) talk with doctor 4 (13) talk with lay educator 4 (13) learn from church 3 (10) use privately 1 (3) learn from community center	“It depends on the generation, race, there are so many factors regarding disease” “Science and technology improving- might be available down the road.”
	Risk information can prompt preventive action	22 (73) more likely to take a helpful health action	“Some people are more attentive, thoughtful about their lifestyle.”
	Some concerns about risk	9 (30)	“Could cause some anxiety at first but then actually lead to mitigating risks of certain conditions” “We have a good population that gets a lot of bad news, even though it could possibly help them.”“Hardest part...like telling somebody this is going to prevent something but they do not know whether or not it’s going to work.” “Health issues put stress on the mind, creating a lot of mental health issues among a lot of people.”
	Genetic services	26 (87) yes	

Table 2 (continued)

Category	Themes and subthemes	Stakeholders who endorse themes No. (%) (N = 30)	Supporting quotations
	Knowledge of genetic testing ^a	1 (3) no	“People should be offered genetic testing, because these are issues that come up in reproduction.”
	Benefits of genetic testing	23 (77)	“If they were at a higher risk and they knew about it, I think people would do something about it, or you know, get help or things like that” “It could help them in making decisions about their lifestyle”
	Know someone who used genetic services/information ^a	20 (67) yes 3 (10) no	“If somebody knows they have diabetes, they usually know someone in their immediate family that has diabetes. So usually if they are going to their doctor, they would say, hey I do know whether my father or mother had this or that.”
	Genetic testing should be offered ^a	23 (67) yes 1 (3) no	“Only if it known that they may be at higher risk” “Have more testing and make it available to the uninsured.” “If people not equipped to handle, it should not be offered to every human being”
	Locations to offer genetic testing ^a	18 (60) doctors 8 (27) community groups 2 (7) direct to consumer 1 (3) pharmacies 1 (3) do not offer	“..with African American’s it would be church, for Native Americans, in their centers”
	Access to/availability of genetic services	6 (20)	“I think it could help the nation if used properly, and used effectively and not just for the purpose of receiving data.” “Use them if you can afford them.” “If people are not equipped to handle and should not be offered to every human being.”
	FH public health strategies	Multiple strategies for FH education ^a	“Each one teach one.” “Some may not have resources or know how to go about receiving history information.”
		6 (20) churches 5 (17) schools 5 (17) health fairs 5 (17) newsletter (with stories) 4 (13) community seminars 4 (13) internet 4 (13) leaflets 3 (10) family history day/-month	
	Motto ^a	12 (40) Talk it up, write it down, pass it on 6 (20) It’s time to talk with your family 5 (17) here’s my family tree 3 (10) it can help your family 1 (3) your lips can save lives	“Once you start doing a family tree, it makes you curious, because it’s gonna be some leaves missing and you are gonna want to know about those leaves, because you come from somewhere.”
	Addressing community barriers	27 (90)	“Talk to them and not necessarily over them.” “It would have to be somebody that’s knowledgeable in the genetics and the demographics...they would have to be able to understand literally their language.” “There may have to be just more public education, where communication is readily available”

^a Themes/Subthemes identified from responses to specific answer choices. These choices are included in column 3

^b Secure location included password-protected web resource and flash drive, and safety deposit box

Kaphingst et al. 2012). Barriers that had been noted more than 10 years ago were still mentioned, such as lack of knowledge of one’s own risk, lack of knowledge of genetic services as well as lack of trust in health care and insurance coverage for genetic testing (Beene-Harris et al. 2007).

Respondents raised the issue of privacy and discussed a range of ideas about who should have access to the information to ensure its safety. Community members acknowledged the utility of sharing their family members’ health details so that doctors should have access to the information “in case

something should happen”. A respondent commented on family health history documentation, “I think that it should be kept with the doctor or the family. Uh, because just in case something should happen uh you know the doctor would have information right there on hand”. Some members suggested that their family health history be kept on a secure website that providers can access and where patient can update information as conversations occur. These concerns suggest how sensitive family health history is and how important it is for health care providers to address concerns about privacy.

Communication with the physician was a central concern of the stakeholders. However, some respondents noted that doctors could be perceived as intimidating and suggested that healthcare providers initiate conversations about family health history in plain language. Health care providers can also emphasize the importance of conversations with family members about health while also empowering patients to be active in their own care (Baer et al. 2013).

The need for genetics education for providers and community groups, perhaps the first step towards reducing health disparities related to genetic services, was consistently highlighted in participants’ responses. Studies continue to document the challenges medical providers face in utilizing family history information effectively with limitations in electronic health records, meaningful use standards, varied risk algorithms, incorporation of molecular information from genetic tests, and multiple competing priorities in the current healthcare system (Rahimzadeh and Bartlett 2014; Williams 2014).

Genetic testing and services were generally reviewed favorably without mention of potential disparities, except for access impacted by insurance (Banks et al. 2014). Respondents understood that the knowledge of genetic testing results might lead to action but acknowledged that knowing risk status had positive and negative implications. According to one respondent, “Hardest part...like telling somebody this is going to prevent something but they don’t know whether or not it’s going to work.”

Stress, anxiety, fear, and uncertainties were noted as possible consequences of addressing genetic risks, which most participants preferred to receive in the percentages format. These possible consequences may or may not be unique to the study population. Some participants considered other life priorities to take precedence over family history and genetic issues. This suggests that further education efforts with community members may be important if understanding and use of family history information, genetic testing and services are to expand in healthcare without increasing disparities by race and resources. Health equity issues range from health literacy to primary care referral and access to genetic services that address community, personal and family concerns such as trust, stress, fears, anxiety, and uncertainty. Multiple approaches have been suggested including enhanced community health

worker and primary care provider education in genetics, broader inclusion in research, and more diversity in the workforce (Chen et al. 2018; Blazer et al. 2012; Warren 2011).

The project had several limitations. The participants were not representative of all communities in the East Baltimore area and thus findings may not be generalizable. Additionally, participants were asked to comment on what they thought were generalized community perspectives and not give personal family health information, but this occasionally occurred. Because of the depth of discussion, most relevant issues relating to both personal experience as well as to perceptions of community concerns were likely mentioned. Themes and subthemes were repeated and reached saturation.

This study has several strengths such as the implementation of the study protocol by community partners. Networking with the community partners helped in recruitment and likely the sharing of opinions in this study. The community partners knew the stakeholders through some natural connection and addressed the range of needs for genetics education, enhanced communications and systems to increase family health history communication and uptake of genetic services.

Conclusion

Our study provides insight into some of the attitudes and needs related to family health history communication and genetic services in a largely African-American urban community sample in which a large academic health center is based. Genetics education is needed to address health disparities related to genetic services. Further research on the impact of meaningful community engagement might inform new strategies to increase the use of and access to family health history and genetic services.

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Compliance with ethical standards

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

Conflict of interest The authors declare that they have no conflict of interest.

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