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Structural and Contextual Patterns in Family Health History Knowledge among African American Adults: A Mixed-Methods Social Network Analysis Study*

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Abstract

Background: Family health history is a strong risk factor for many chronic diseases. Ethnic minorities have been found to have a low awareness of their family health history (FHH), which may pose a contributing factor to health disparities. *Purpose:* The purpose of this mixed-methods social network analysis study was to identify structural and contextual patterns in African American adults' FHH knowledge based on interpersonal communication exchanges with their family members. *Methods:* African American adults completed individually administered family network interviews. Participants' 3-generation family pedigree served as a visual aid to guide their interview. Our primary outcome of interest for this analysis was whether a family member was reported as someone who talks to the participant about their own (i.e., the family member's) health, which we refer to as a "personal health informant." To contextualize quantitative findings, participants were asked to describe *how* they learned about the health history of the relatives they identified during their interview. *Results:* Participants (n=37) reported an average family network size of 29.4 relatives (SD = 15.5; Range = 10-67). Each participant, on average, named 17% of their familial network as personal health informants. Multivariate regression results showed that participants

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were more likely to name an alter as a personal health informant if the alter was female (OR = 2.14, p = 0.0519), from the maternal side of the participant's family (OR = 1.12, p = 0.0006), had one or more chronic health conditions (OR = 2.41, p = 0.0041), was someone who has discussions with the participant about the participant's health (OR = 16.28, p < 0.0001), was a source of family health information (OR = 3.46, p = 0.0072), and was someone whose health the participant helps to monitor or track (OR = 5.93, p = 0.0002). Complementary qualitative findings indicate that FHH knowledge is facilitated by open, direct communication among relatives. Personal health informants were described as disclosing information for the purposes of informing others for preventive purposes and for gaining social support. Participants also learned about FHH via other methods, including direct observation, during caretaking, and following a relative's death. *Conclusions:* Communication and disclosure practices is an important determinant of African Americans' FHH knowledge. More culturally and contextually meaningful public health efforts are needed to promote family health history sharing, especially regarding paternal family health history, siblings, and extended relatives.

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Introduction

Family Structure and Function

The family is a *functional* unit, serving as a complex relational system that allows the exchange of resources, such as information (Koehly et al., 2003). The extent of these exchanges is highly dependent upon the family capital (i.e. availability of resources). Within families, "key" individuals may serve in specific functions that influence the actions and outcomes of their relatives. For example, findings from several studies of familial networks have suggested that *mothers* are key influential figures in family networks (Koehly et al., 2003). Additionally, past studies have identified *parents* and *older adults* as key figures, often serving in the role as gatekeepers for communication and decision-making (Ashida, Kaphingst, Goodman, & Schafer, 2013; Koehly et al., 2009). The close involvement of extended family members (i.e. non-first degree) is a uniquely important aspect of the African American family structure and function (Hecht, Jackson, & Ribeau, 2003). In particular, African American family members have a high degree of interaction across multiple generations.

Family Networks and Health

The family/kinship system offers a unique intergenerational network, where preventive and hereditary health information can be shared intergenerationally among all members of a family - men, women, and children. To date, most research on hereditary risk has been limited to first- or second-degree relatives. However, relevant to the African American family network structure, recent research suggests that there is utility in assessing hereditary risk in the context of the extended family (Solomon, Whitman, & Wood, 2016).

Limited research has been done regarding the assessment of individual disease risk based on multi-generational family health history (FHH). In clinical practice, providers typically only obtain the health history of patients' first-degree relatives – a process that primarily occurs during patients' initial visit with providers and is rarely updated during follow-up appointments (Daelemans et al., 2013; Rich et al., 2004). However, scholars have increasingly emphasized the importance of conducting "comprehensive" FHH, which extends beyond first-degree relatives and includes as many family members as possible (Maradiegue and Edwards, 2006). Within genetic counseling and medical genetics, the recommended FHH is a 5-generation pedigree (Solomon et al., 2016). Information obtained is important for developing a more accurate appraisal of FHH risk, in order to determine individuals' risk for developing conditions based on their FHH. A recent study on the contribution of extended family history assessment in cancer risk by Solomon, Whitman, and Ward (2016) found that limited FHH information can have a detrimental impact on determining patients' eligibility for screenings. In particular, their results indicated that over 70% of patients eligible for breast cancer screening is missed if extended family history is not utilized.

FHH and Disease Risk

FHH is an important, but often underestimated, aspect of disease risk. FHH includes any health conditions or illnesses that a person's biological relatives have been diagnosed with or that run in a person's family. Individuals are more likely to develop certain chronic diseases if they have a

family history of those conditions, especially among close relatives (Annis, Caulder, Cook, & Duquette, 2005). For example, having one first-degree female relative (sister, mother, daughter) diagnosed with breast cancer doubles an individuals' risk of developing breast cancer, and this risk is increased by five times if an individual has/had two first degree relatives with diagnoses (Breastcancer.org, 2018).

Importance and Utility of FHH Knowledge

A variety of benefits have been associated with having increased knowledge about one's FHH. When FHH information is shared, family members are informed about health problems and possibly even risk behaviors related to those health problems, that may have occurred generation after generation in their family. By connecting this information with adverse health outcomes they have observed in their family (i.e. lingering illness and premature death), individuals may be more motivated to engage in preventive behaviors. In particular, awareness of one's FHH has been associated with increased practice of preventive behaviors, such as physical activity, healthy diet, and participation in chronic disease health screenings (Baptiste-Roberts et al., 2007). Individuals' knowledge and awareness of their FHH also has important clinical implications. For example, increased awareness of FHH information can improve accuracy of information shared with clinicians (Kaphingst et al., 2012). Consequently, healthcare providers have more information available to guide clinical decisions, such as targeted disease screenings, genetic counseling recommendations, and preventive health behavior recommendations. Several studies have also emphasized that the sharing of health history information in familial networks is especially useful for younger generations of family members (Ashida & Schafer, 2014; Forrest et al., 2003; Newcomb, Raudonis, Snow, & Cauble, 2012), who often still have time to engage in health behaviors and decision-making that can prevent or delay the onset of conditions that run in their families.

In contrast, lack of FHH information can have a detrimental impact on individuals. Among some racial and ethnic minority groups (Black, Hispanic, Asian), low FHH knowledge has been associated with a decrease in perceived risk of disease (Orom, Kiviniemi, Underwood, Ross, & Shavers, 2010). Previous intervention research has demonstrated a strong positive association between individuals' knowledge of their FHH risk and their perceived risk and worry over developing common diseases (coronary heart disease, stroke, diabetes, and breast, ovarian, and colon cancers) (Acheson et al., 2010). Risk perception, as an important determinant of individual health decision-making, plays a vital role in preventive health decisions. Consequently, individuals who have a low perception of FHH risk may also have a decreased practice of preventive and/or screening and early detection behaviors (Sivell et al., 2008; Ward et al., 2008; Yoon et al., (2003). Scholars also note that individuals' non-disclosure about their health conditions limits the decision-making autonomy of at-risk relatives who would greatly benefit from the information (Forrest et al., 2003; Wilson et al., 2004).

FHH Knowledge and Collection

Despite its importance, individuals among the public have been found to have a low awareness of their FHH (Catz et al., 2005). Results from a former national study found that though most respondents (96.3%) acknowledged that FHH is important, only 29.8% of respondents indicated

that they had ever actively attempted to collect their FHH (Yoon, Scheuner, Gwinn, Khoury, & Jorgensen, 2004). Some studies have found that ethnic minority groups, including Latinas and Latinos, have a lower likelihood of having collected their FHH than other populations (Chen, Li, Talwar, Xu, & Zhao, 2016; Yoon et al., 2004). In a recent qualitative study on African American women's perspectives and experiences regarding FHH collection and communication, few participants reported that anyone in their family kept formal FHH records (Thompson et al., 2015). However, several characteristics have been associated with increased likelihood of FHH collection, including being female (Halbert et al., 2016), being an older adult, and individuals having a higher income (Case, 2008). Among these groups, FHH information was primarily gathered by designated family historians, and was obtained from documents, such as death certificates, and obituaries (Case, 2008). Qualitative studies have also found that FHH information is learned via other, less formal approaches including "word of mouth" (Newcomb et al., 2012; Pettey et al., 2015; Yamasaki & Hovick, 2015). Degree of relation has also been identified as an important factor in FHH knowledge. In particular, studies have found that individuals' knowledge is more accurate about the health history of their most proximal relatives (i.e. first-degree) rather than other relatives (Mai et al., 2011; Theis, Boyd, Lockwood, & Tritchler, 1994; Wideroff et al., 2010). Overall, individuals' access to, and knowledge of, their FHH is influenced by a variety of factors, including family structure and norms, as well as cultural characteristics, particularly as it relates to health communication.

Purpose

The purpose of this mixed-methods social network analysis study was to identify structural and contextual patterns in African American adults' FHH knowledge, based on their interpersonal communication with their relatives. In particular, the first aim of this study was to identify patterns regarding the characteristics of family members who have directly shared their personal health history information with our participants. A second aim of this study was to gather contextual information to understand *how* the participants learned about the health history of their relatives.

Methods

Participants and Recruitment

Individuals were eligible to participate in the *African American Family Networks and Health* study if they self-identified as African American and were at least 18 years of age. An additional criterion for participation was residence in the [Name Removed for Blind Review] metropolitan area, so that individuals could complete the study interview in person. Participants were recruited from a variety of community venues, including local churches, health fairs, universities, African American community events, and African American family reunions. At these venues, an announcement was made by a research team member about the opportunity to participate in the study and/or an information table was available for participants to speak with research team members and sign up to be contacted for an interview appointment in the near future. Additionally, participants were recruited via electronic flyers and word of mouth. Prior to being enrolled, all prospective participants were screened for eligibility by the study project manager (L.R.). Data collection for the study began in September 2016 and was completed in December 2016. The

study received Institutional Review Board approval from the Indiana University Human Subjects Office (protocol # 1502818898).

Study Design

The *African American Family Networks & Health* study employed a convergent parallel mixed methods study design (Creswell and Clark, 2017) to gather information about participants' familial networks. Convergent parallel mixed-methods study designs afford researchers the opportunity to simultaneously collect quantitative and qualitative data from each participant during his or her interview, thus allowing for more comprehensive information to be gathered. In the *African American Family Networks and Health* study, quantitative data was collected about participants' familial networks and corresponding qualitative data was collected to contextualize the quantitative findings.

Procedures

Each participant was asked to complete a "family tree interview" in order to gather information about his or her familial network. Specifically, the interview was conducted to elicit information regarding participants' knowledge of their FHH, as well as to elicit information about their interpersonal exchanges with their family members, including health communication and social support. Interviews were scheduled to accommodate each participant's convenience and availability. The family tree interviews were conducted in a private conference room at the Indiana University Fairbanks School of Public Health, and were administered by trained research assistants (K.B., H.S.), who were racially matched with the study sample (i.e., African American). Upon each participant's arrival to his or her interview, the research assistant reviewed the informed consent form with the participant and answered any questions he or she had.

Next, the research assistant gathered the participant's demographic information and constructed a family tree for the participant, using Progeny Genetic Pedigree Software (Progeny Genetics LLC, 2018), a secure web-based program. The pedigree was constructed to function as a visual aid during each participant's interview. Information provided by the participant to construct the pedigree was gathered prior to the interview via a structured workbook provided by the research team. Specifically, the workbook gathered information about the participant and all relatives in his or her generation (i.e., siblings and cousins). The workbook also gathered information about the participants' parents' generation (i.e., parents, aunts, and uncles), as well as gathered information about the participants' grandparents. In this family pedigree, information about younger generations (i.e., children, nieces and nephews, and grandchildren) was also collected, but we excluded these younger generations from our analyses to focus on individuals' knowledge of health history, based on the sharing of personal health information (health history) from relatives in previous generations and within the ego's current generation. For each participants' family network members (alters), the following information was gathered: 1) familial status (full, half, step, or adopted); 2) vital status (living or deceased); 3) age (current or at death); and 4) current city and state of residence (if living).

Following the construction of the participants' family pedigree, his or her family tree interview was administered. The qualitative component of the interview was audio recorded. Interviews

lasted approximately 1.5 hours on average, and participants were compensated with a $65 gift card and a copy of their family tree for completion of the pedigree construction and network interview process.

Data Collection

Participant Demographic Characteristics

Demographic characteristics for each participant were collected and recorded using Research Electronic Data Capture (REDCap), a secure web-based electronic data management software. General demographic variables collected include age, gender, household size, marital status, and education level. Health-related demographic variables were also collected for each participant, including personal health history and self-rated health status.

Colored Eco-Genetic Relationship Map (CEGRM)

The Colored Eco-Genetic Relationship Map (CEGRM) (Kenen & Peters, 2001) was used to collect information about each participant's family network. The CEGRM approach is highly interactive and engages participants throughout the entire data collection process. First, the participant generates a family pedigree (prior to the interview). Next, during an in-person interview, the participant's family tree is used as a visual aid to guide his or her discussion of health information exchanges with his or her family members on the pedigree. Throughout the interview, participants are asked to apply color-coded symbols to represent characteristics of specific "key" family network members, such as relatives who function in specific health communication and social support roles (See figure 1). In the *African American Family Networks and Health* study, participants were asked to identify biological relatives (alters) who: 1) talk to the participant about the participant's health; 2) who talk to the participant about their own health; 3) who avoid having discussions about health; 4) are sources for general family health information; 5) whose health the participant helps to monitor and track; 6) for whom the participant helps with managing their personal health; and 7) who share helpful health facts or information with the participant. Our primary outcome of interest for this analysis was whether a family member was named as someone who talks to the participant about their own (i.e., the family member's) personal health information. Throughout this paper, we refer to family members named in this role as "personal health informants."

In addition to providing quantitative characteristics about participants' familial networks, the CEGRM approach also allows the participant to provide qualitative contextual information about the key family members who, to the participants' knowledge, were diagnosed with specific conditions. For the *African American Family Networks and Health* study, participants were asked to discuss *how* he or she learned about the health diagnosis the identified family members, including those who were identified as "personal health informants." Specifically, participants were asked, "How do you know that your family member has or had "X" condition? For example, what were the circumstances of you learning this information?"

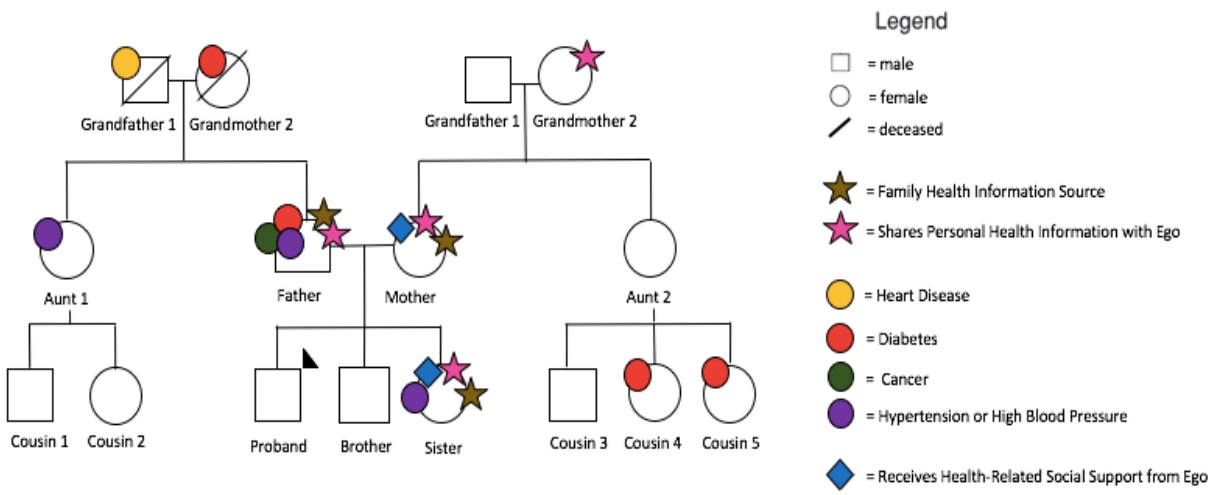

Figure 1. Example Family Health History CEGRM for 41-year-old Male Study Participant

Data Analysis

The analytic sample for this study included family members in the same generation as the participant (i.e., siblings and cousins), a generation older than the participant (i.e., parents, aunts and uncles), and two generations older than the participant (i.e., grandparents).

Quantitative Data Analysis

Quantitative analysis of participants' familial network data from their CEGRMs functioned to identify structural network patterns regarding African Americans' interpersonal communication exchanges regarding their relatives' personal health history. In particular, the network analysis sought to identify patterns in FHH information sharing based on characteristics of the family members who were named by the participant as personal health informants, such as their gender, geographic location, or their degree of relation to the participant. All quantitative data were analyzed using SPSS 24.0 and SAS 9.4 statistical software.

Standard descriptive statistics (percentage, mean, standard deviation, and range) were generated for the participant sample (egos) and the resulting sample of family network members (alters). Descriptive variables reported for the participant sample (egos) include age, gender, marital status, household size, educational level, health status, personal history of specific health conditions, and history of work in the health care field (see Table 1). Descriptive variables reported for the sample of family network members (alters) are presented in Table 2, and include alter gender, age, health conditions, and geographic homophily (operationalized as whether the network member lives in the same state as the participant). Table 2 also presents relational (tie) characteristics, including alter relationship to the participant (e.g., parent, sibling), the familial generation of the alter (i.e. whether the familial alter was in the same generation, a generation above, or two generations above the participant), as well as health communication and support roles of the familial alters. Finally, network-level descriptive statistics were generated based on the aggregate sample of family network members provided by participants (see table 3). Network-level statistics calculated include network size, gender proportions, homophily characteristics (gender, generation, and state

of residence), and proportions of networks by relationship (e.g., the proportion of cousins in an average network), health communication roles (e.g., the proportion of network members named as a health discussant of the ego's health information or a personal health informant of the alters' health information), and generation (i.e., same generation, parents' generation, or grandparents' generation).

For our primary quantitative analysis, a generalized estimating equation (GEE) model was used to identify significant predictors associated with the likelihood of an alter (family network member) being identified as a personal health informant (i.e. a family member who talks to the participant about the family member's personal health) during the family tree interview (see Table 4). Predictors of interest included alter gender, gender homophily (whether the alter identified as the same gender as the participant), geographic homophily (whether the alter identified lives in the same state as the participant), alter generation (whether the alter was in the same generation as the participant, a generation above, or two generations above), alter family side (maternal or paternal), and whether the alter was reported to have one or more chronic health conditions. The model also took into account whether the alter was identified as participating in any of the following specific health communication and support roles in relation to the participant: familial alter talks to the participant (ego) about the participant's health; familial alter avoids having discussions about health; familial alter is a source for general family health information; the participant (ego) helps to monitor and track the alter's health; the participant helps the alter in managing the alter's health; and the alter shares helpful health facts or information with the participant. In our analysis, standard errors were clustered at the participant level to account for correlation within family units.

Qualitative Data Analysis

Analysis of qualitative data collected during each participant's family network interview functioned to gain in-depth contextual information regarding *how* African Americans learn about their relatives' health history. Audio-recorded data collected during each participant's family tree interview was professionally transcribed, and later analyzed using Dedoose qualitative and mixed-methods software. Emergent themes were identified in the transcripts using inductive content analysis (Dedoose version 8.0.35, 2018). Specifically, open codes were applied to participants' narrative statements, where statements with similar content were grouped together in categories to reveal primary themes (Saldaña, 2015). Qualitative analysis and coding was conducted by two research members who were trained in qualitative methods. Each research team member independently coded the data and they later convened to discuss and agree upon final emergent themes occurring in participants' narrative data.

Results

Participant (Ego) Characteristics

A total of 37 African American adult participants (egos) were included in the analytic sample, with a mean age of 43.8 years (SD = 16.8 years; range = 19-68 years) (see Table 1). About half of the participant sample was comprised of males (n = 19; 51.4%). Over half of the participants were non-married (i.e., single, divorced, or widowed; 48.6%), while 45.9% were married or in a

Table 1. Participant demographics and self-reported health status (n = 37)

	Percent	Mean	Standard Deviation	Range
Gender				
Female	48.6			
Male	51.4			
Age (Years)		43.8	16.8	19-68
Marital status				
Single	47.2			
Married or in long-term partnership	47.2			
Divorced	2.8			
Household size		1.6	1.3	0-5
Educational level				
High school or less	11.1			
Some college	19.4			
College graduate	38.9			
Master's degree or higher	27.8			
History of health issues				
Hypertension	35.1			
High cholesterol	27.0			
Asthma	13.5			
Diabetes or high blood sugar	10.8			
Cancer	8.1			
Stroke	5.4			
Heart attack	0.0			
Other	18.9			
Health status				
Excellent	13.9			
Good	61.1			
Fair	19.4			
Poor or very poor	5.4			
Experience working in health care field	40.5			

long-term partnership. The sample was highly educated, with a majority of participants having completed at least some college or more (94.6%). Nearly two-fifths of the sample (40.5%) reported previous experience working in the health care field. A majority of participants rated their health status as "excellent" (13.9%) or "good" (61.1%). Specific health conditions indicated among participants included hypertension (35.1%), high cholesterol (27.0%), asthma (13.5%), and diabetes or high blood sugar (10.8%). No significant demographic differences were observed by ego gender, with the exception of marital status, where male participants were significantly more likely to be married than female participants were.

Familial Alter and Tie Characteristics

A total of 1,078 familial alters were generated from the participants' family tree interviews (see Table 2).

Table 2. Alter and tie descriptive statistics (n = 1,078)

	Percent	Mean	Standard Deviation	Range
Gender				
Female	51.8			
Male	48.2			
Age (Years)		49.6	23.5	1-97
Relationship to ego				
Grandparent	12.1			
Parent	6.5			
Aunt or uncle	24.8			
Sibling	13.0			
Cousin	43.7			
Lives in same state as ego	34.3			
≥1 health conditions reported	25.5			
Health conditions*				
Hypertension	10.8			
Cancer	6.9			
Diabetes	6.0			
Heart disease	5.4			
Mental illness	5.3			
Kidney disease	2.1			
Health communication exchanges				
Alter talks to ego about ego's health	11.0			
Alter talks to ego about alter's health	14.5			
Reciprocal health discussions	8.5			
Alter avoids discussions about health	9.2			
Alter is a source of family health information		13.2		
Ego monitors and tracks alter's health	12.3			
Ego helps alter with managing health	5.6			
Alter shares helpful health facts	7.4			

The network sample contained an even proportion of male and female alters (48.2% male alters and 51.8% female alters). On average, familial alters were 49.6 years of age (SD = 23.5). One-quarter of alters (25.5%) were reported to have at least one of the six chronic conditions that were inquired about during family tree interview, with hypertension (10.8%) and cancer (6.9%) the most common conditions reported. Approximately one-third of alters (34.3%) were reported to live in the same state as the participant. Regarding familial alters' ties to participants, the majority of alters in the network data sample were cousins (43.7%) and aunts or uncles (24.8%). Concerning health communication roles, nearly 15% of alters were identified as personal health informants who talk to the ego about his or her (the alter's) health, while 11% were identified as discussants of the ego's health. Only 8.5% of alters were acknowledged as functioning in both roles (i.e., as a reciprocal communicator about health). Almost one-tenth (9.2%) of the alter sample was identified as someone who tends to avoid discussions about health. Approximately 13.2% of alters were acknowledged as sources of FHH information, while 7.4% were reported to share helpful health facts or information with the participant. Finally, 12.3% of alters were identified as someone whose

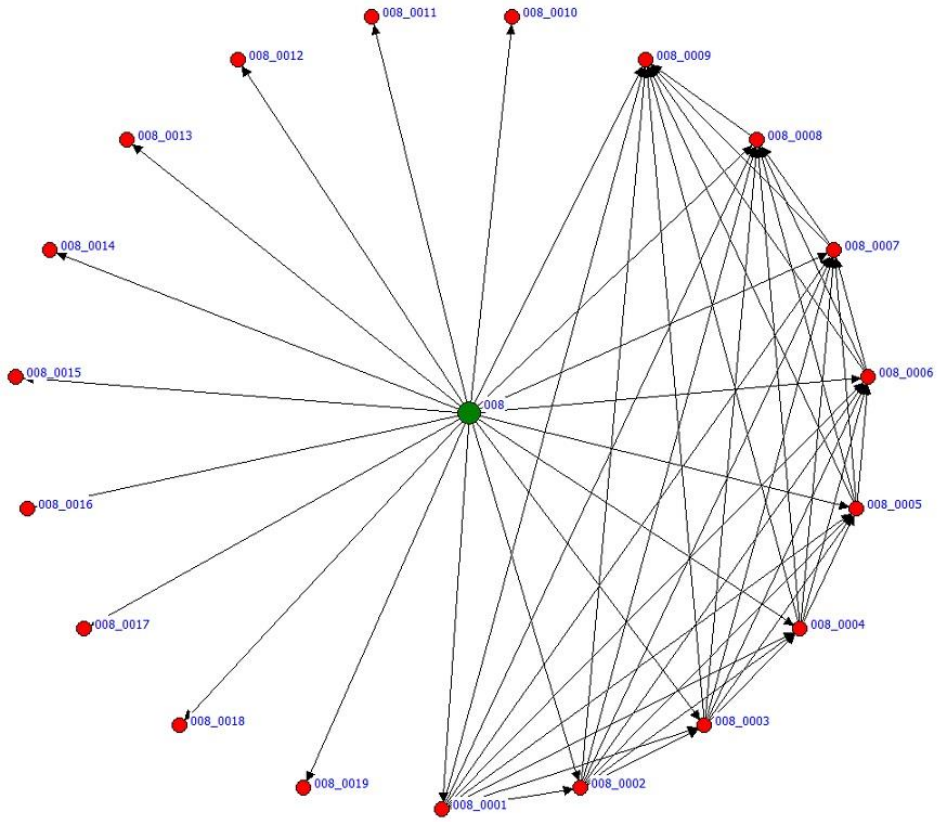

Figure 2. Example Familial Network, 33-year old Male Participant

health the participant monitors or tracks and 5.6% of alters were identified as someone whose health the participant helps to manage.

Figure 2 (pictured above) illustrates an example familial network of a 33-year old African American male participant from the *African American Family Networks and Health* study.

Familial Network Characteristics

Characteristics of participants' familial networks are presented below in Table 3. The average size of a participant's family network was approximately 29 relatives (SD = 15.5), with network sizes ranging from 10 to 67 alters among the participant sample. On average, half of a participant's familial network was homophilous to the participant with respect to gender (mean = 0.50) and generation (mean = 0.52), respectively, and about one-third of the average family network lived in the same state as the participant (mean = 0.34). Networks, on average, were proportionately comprised of 36% cousins, 25% aunts or uncles, 15% siblings, 15% grandparents, and 8% parents. On average, about one-half of networks were comprised of family members in the same generation as the participant and another one-third from the participant's parents' generation. Participants, on average, reported FHH information for about one-quarter (mean=0.26) of their familial network. In terms of health communication roles, the largest proportion of family network members was comprised of personal health informants, or alters who talk to the ego about their (the alter's) health (mean = 0.17), followed by alters whose health the participant monitors and tracks (mean = 0.15), alters who talk to the ego about the ego's health (mean = 0.13), and alters

Table 3. Network descriptive statistics (n = 37 networks)

	Mean	Standard Deviation	Range
Network size	29.14	15.54	10.00-67.00
Proportion male	0.48	0.07	0.39-0.67
Homophily			
Gender	0.50	0.07	0.40-0.67
Generation	0.52	0.15	0.07-0.72
Same state	0.34	0.29	0.00-1.00
Proportion of network by family relationship			
Grandparent	0.15	0.08	0.04-0.40
Parent	0.08	0.04	0.03-0.20
Aunt or uncle	0.25	0.10	0.10-0.71
Sibling	0.15	0.10	0.00-0.39
Cousin	0.36	0.19	0.00-0.63
Proportion of network reporting ≥1 health conditions	0.26	0.13	0.00-0.58
Proportion of network by health communication role			
Alter talks to ego about alter's health	0.17	0.11	0.00-0.50
Alter talks to ego about ego's health	0.13	0.12	0.00-0.56
Reciprocal health discussions	0.10	0.09	0.00-0.40
Alter avoids discussions about health	0.09	0.10	0.00-0.50
Alter is a source of family health information	0.13	0.09	0.00-0.42
Ego monitors and tracks alter's health	0.15	0.10	0.00-0.40
Ego helps alter with managing health	0.05	0.07	0.00-0.30
Alter shares helpful health facts	0.08	0.07	0.00-0.27
Proportion of network by generation			
Same generation as ego	0.52	0.15	0.07-0.72
1 generation above ego	0.33	0.11	0.22-0.78
2 generations above ego	0.15	0.08	0.04-0.40

who know FHH information (mean = 0.13). Only one-tenth of networks, on average, were comprised of alters who avoid or "block" health discussions. Average network proportions of other health communication and support are listed in Table 3.

Table 4. Alter characteristics associated with alter being named as a personal health informant by ego

	Odds Ratio	95% Confidence Interval	*p*-value
Alter gender			
Male	[Reference]		
Female	2.14	1.65, 2.77	0.0519
Geographic homophily			
Alter and ego lives in different states	[Reference]		
Alter and ego live in same state	1.55	1.45, 3.46	0.2873
Gender homophily			
Alter and ego are different genders	[Reference]		
Alter and ego are the same gender	1.15	0.58, 2.27	0.6918
Alter generation			
Alter and ego are in the same generation	[Reference]		
Alter is 1 generation above ego	1.26	0.93, 3.19	0.6305
Alter is 2 generations above ego	0.82	0.31, 2.16	0.6804
Alter family side			
Paternal	[Reference]		
Maternal	1.12	0.48, 2.56	0.0006
Alter has ≥1 chronic health condition	2.41	1.32, 4.62	0.0041
Alter talks about ego's health	16.28	6.42, 40.85	<0.0001
Alter avoids health discussions	5.00	2.51, 16.61	0.0969
Alter is a source of family health information	3.46	1.40, 8.50	0.0072
Ego monitors and tracks alter's health	5.93	2.36, 14.88	0.0002
Ego helps alter with managing health	2.77	2.18, 16.78	0.2663
Alter shares helpful health facts	1.20	2.69, 3.86	0.7672

Note: The results presented were analyzed using generalized estimating equation logistic regression at the alter level with the binary outcome "0=Alter was not named as a personal health informant" and "1=Alter was named as a personal health informant". N = 936 due to missing data for model covariates. Standard errors were clustered at the ego-level to account for clustering within families.

Multivariate Analyses

In our multivariate analysis (Table 4), we found that participants were more likely to name an alter as a personal health informant if the alter was female (OR = 2.14, $p = 0.0519$), from the

Table 5. Emergent themes and exemplary quotes for family health history knowledge prompts

Theme	Quote
Open Communication	"Well growing up, my mother often talked about kidney disease as well as diabetes running in our family. So, we made an effort – on physicals and so forth – that they also check those organs out."
Observation	"So that was known my entire life because…he [my grandfather] always had the syringe and the needle...It was something I saw and it was always a big deal. It was a really big deal… Him having to take insulin."
Caregiving	"I took care of him [my father] for a while, so, I learned a lot of his health issues and concerns because I was the caretaker. I had to know his pill schedule and different little things… then [I] was able to talk to the doctors, because I was the one giving him his care, I learned a lot and did research about what they were telling me that his conditions were."
Post-Death Knowledge	"I actually didn't know while he [my father] was living that he had diabetes. I didn't find out until after… when I had to clean out his things and then being the one who he left in charge of everything, I had to speak with the doctors. So, I was finding out a lot more about his health after he had passed."
Speculation*	"I don't know if she [my cousin] would even take meds, but she definitely is either manic depressant or bipolar or something. Even her mother thinks so…Observing her behavior."

*Reports of a relative's history of mental illness was more speculative than confirmed.

maternal side of the participant's family (OR = 1.12, $p = 0.0006$), had one or more chronic health conditions (OR = 2.41, $p = 0.0041$), is someone who had discussions with the participant about the participant's health (OR = 16.28, $p < 0.0001$), was a source of family health information (OR = 3.46, $p = 0.0072$), and was someone whose health the participant helped to monitor or track (OR = 5.93, $p = 0.0002$).

Qualitative Contextual Results

Qualitative data collected during the Family Tree Interviews gathered important contextual information regarding *how* participants learned about the health history of relatives in their family network (via direct interpersonal communication and other mechanisms). The data yielded several emergent themes, including *open family communication*, *observation of illness*, *caregiving*, *post-death knowledge* (see Table 5).

During the integrated analysis of our quantitative network data and our qualitative contextual data, it was observed that participants who reported more "personal health informant" alters during the network interview portion typically learned about their family's health history from *open*

discussions, where participants described having direct conversations with specific family members about the family members' health. In these instances, information was described as being shared for the purposes on informing the ego about his or her potential risk, or for gaining social support from the ego. For example, one female participant discussed how her cousin disclosed her hypertension diagnosis to inform her that she may also be at risk. Another female participant described receiving open communication from her sister about her sister's breast cancer diagnosis, emphasizing that "we communicate, there is no secrets and all that." Similar to our quantitative finding that "personal health informant" alters were more likely to be female, most participants' description of open-discussions via direct communication with relatives were focused on their open communication exchanges with female family members.

In contrast, our participants who reported less FHH knowledge (based on fewer reported personal health informants) typically described their family as having closed communication patterns. In such instances, these participants described how they learned about the health history of their relatives via indirect methods, such as personal observations of their relatives' illness, hearsay, gaining information during caretaking activities, as well as learning about a relative's health issues following the relatives' death. Similar to the quantitative network analysis findings, many of the relatives who did not disclose their own health history tended to be males. Limited disclosure about personal health information, including among first-degree relatives, as well as relatives that are in close geographic proximity to participants, was often perceived as being the result of relatives wanting to maintain their privacy due to being embarrassed by their diagnosis or not wanting to appear as being "weak" or "needy." Additionally, participants indicated that they perceived that their more proximal relatives might not want to be burdensome and cause them to worry. The exhibition of closed communication behavior was especially discussed in the context of male family members, including fathers and brothers, and was oftentimes linked to masculinity and males' continuous efforts to be viewed as "strong."

Among discussions about closed communication, diabetes, in particular, was a condition that participants frequently discussed that they learned about by observing their relatives' self-management behaviors, especially administering insulin. While participants directly described how they learned of relative's diagnosis of some conditions, such as diabetes, hypertension, and cancer, their reports of a relative's diagnosis of mental illness were discussed in a *speculative* context, rather than as a confirmed diagnosis. This was primarily directed toward female family members. In very few instances did participants discuss learning about their FHH through their own intentional efforts to collect the information. Table 5 presents a list of emergent themes observed in the qualitative contextual data, which are accompanied by exemplary quotes from study participants.

Discussion

A dearth of literature exists about FHH communication and awareness within African American families. To date, most intergenerational research on FHH sharing has been conducted with White study participants. Our study builds upon a growing literature-base of diverse studies on health communication in family networks. In addition to providing structural network data regarding patterns of FHH knowledge occurring among African Americans, our study also provided insightful qualitative contextual data. This mixed-methods approach yielded *comprehensive* data

on FHH communication and awareness among African Americans, a population that is tremendously burdened by health disparities.

A unique study finding that has been underrepresented in the family networks and health literature is the fact that individuals were much more knowledgeable about the health history of their maternal relatives than their paternal relatives. This important finding highlights health related implications of family dynamics that warrant further exploration. While most of our participants were able to develop their paternal pedigree, some participants had difficulty doing so. In particular, some participants had "absent" or estranged fathers, whose identity they were aware of, but in a few instances, participants' fathers were unknown. In such cases, several of these participants shared that the experience of participating in the *African American Family Networks and Health* study motivated them to learn more about the fathers who they knew little about. As demonstrated by our study findings, when an individual has limited interaction with his or her father, this inevitably places a limit on what the individual knows about his or her father, including his family's health history. Though this was a prominent finding among participants who had estranged paternal relationships, our data also indicated that participants' limited awareness of their paternal FHH was a trend in most of our study sample. Our findings regarding participants' limited paternal health history information is consistent with previous research by Rubenstein et al. (2011), whose data suggest that participants demonstrated a limited understanding and awareness of their paternal health history, as well as a diminished perceived relevance of this information. While efforts are needed to enhance family health communication and awareness in general, these findings highlight the need to emphasize the importance of sharing and collecting paternal health history information for prevention and early detection purposes. The absence of FHH information in some individuals may also support the need for more in-depth individual risk assessments, as part of prevention and treatment planning.

Overall, our results highlight the important role that healthcare professionals can play with regards to encouraging their patients to actively collect their FHH information from their relatives, as well as share their own health information. As indicated in our qualitative results, the sharing of FHH information within familial networks serves to prompt preventive behaviors among undiagnosed relatives and facilitates the provision of health-related social support for diagnosed relatives.

Our network analysis results show variability in FHH knowledge based upon characteristics, such as degree of relation. Closely related, previous studies of FHH knowledge have found that individuals are more accurate about the information that they report for first degree relatives than the information that they report for second degree relatives (Mai et al., 2011). Informed by our findings and the extant literature, we encourage the promotion of FHH communication among African Americans in general, and especially among African American extended family networks. While some recent studies of familial networks have begun to employ more rigorous designs, such as multiple-informant data collection, future studies of African American family networks would benefit from a sociometric "whole" network study approach, where a large extended family units are engaged and studied in-depth (Hood, 2018; Lin, Marcum, Myers, & Koehly, 2018).

As with many other cultures, older adults in the African American culture (i.e. elders) play a special role and are a tremendous source of information. Our results also highlight the importance of involving "key" influential figures to enhance family history knowledge. Younger generation

family members have been observed to have a limited knowledge of their FHH (Goergen et al., 2016; Newcomb et al., 2012). Several studies have recognized the importance of engaging older adults as key figures to enhance FHH knowledge among younger generations. (Ashida et al., 2013; Ashida & Schafer, 2014; Moore et al., 2015).

Previous study findings have suggested that communication and disclosure about health conditions often varies based upon the disease context. For example, African American focus group participants in a study by Hovick et al. (2015) suggested that individuals only discuss common, non-stigmatized illnesses, such as heart disease, with their family (Hovick, Yamasaki, Burton-Chase, & Peterson, 2015). Our quantitative network findings are reflective of this trend, as hypertension was the most commonly reported condition that participants' relatives discussed with them. Closely related, similar to our network analysis results, African American participants in a recent study by Pettey et. al. (2015) also demonstrated a strong awareness of their family's history of hypertension. Collectively, these results emphasize the importance of making strategic efforts to work with African American families to reduce stigma surrounding the topic of "health" in general, as well as the destigmatization regarding discussing specific health topics, such as mental illness, which is often considered embarrassing or taboo. Efforts to enhance FHH communication and awareness among African Americans must be sensitive to cultural factors that influence interpersonal communication about health (Hood, 2018), as public health education approaches are not "one size fits all."

Several factors may explain the relatively low awareness of FHH knowledge demonstrated by African American study participants. Closed and/or limited communication has been identified as a primary barrier to FHH knowledge among African Americans. Our study participants were more knowledgeable about the health history of relatives that were identified as individuals to talk to the participants about his or her (the relative's) health. A recent dyad study by Lin et al. (2018) found that racial disparities in knowledge of FHH between African American and White participants was largely due to the fact that their African American participants had fewer reciprocation ties – highlighting the detrimental impact of limited communication within families. However, this knowledge is likely to increase with the practice of enhanced two-way (reciprocal) communication among relatives.

Closely related, Communication Privacy Management (CPM) theory posits that individuals apply a set of social rules in their decision-making regarding the sharing of personal information, including health information (Petronio, 2010). African American study participants have reported that health is not regularly discussed among family members, and have identified *privacy* as an important FHH communication barrier (Hovick, 2014). We observed a similar trend in our study, as participants' qualitative contextual discussion often indicated "secrecy," "embarrassment," and "pride" as reasons for why their relatives delayed disclosure of their diagnoses. This finding was especially discussed in the context of male family members, and among individuals who had diagnoses of stigmatized conditions such as obesity and diabetes.
In many instances, participants reported that their knowledge of a relatives' health history was prompted by a catastrophic event, such as a hospitalization or death. More efforts are needed to help families understand that lack of discussion consequently limits other family members' knowledge about health conditions for which they may be at risk of developing.

An additional barrier to FHH knowledge among African Americans might pertain to *genetic literacy*, as ethnic minority families have been found to have a limited understanding of genetics (Catz et al., 2005). As healthcare professionals seek to enhance the genetic literacy and FHH collection practices of African Americans, it is imperative that future efforts are sensitive to the needs and preferences of this population. In a mixed methods study on FHH practices of African American women, participants demonstrated a preference for gathering FHH information informally, instead of writing it down (Thompson et al., 2013). Despite national efforts over the past decade, there has been little change in FHH collection among the general public (Welch, O'connell, & Schiffman, 2015). While many free FHH collection tools exist, many members of the public may not be aware of their existence or may not be able to access them. Moreover, research has shown that a majority of publicly available FHH collection tools are beyond an 8th grade reading level, which increases difficulty of use and potential effectiveness/accuracy (Wang, Gallo, Fleisher, & Miller, 2011).

Strengths and Limitations

The *African American Family Networks and Health* study possesses several strengths. While the Colored Eco-Genetic Relationship Map (CEGRM) approach has been used to study a variety of conditions, including ovarian-breast cancer (Peters, Hoskins, Prindiville, Kenen, & Greene, 2006; Peters et al., 2004) and testicular cancer (Peters et al., 2012), this familial network data collection method has only been used with White participant samples. To our knowledge, the *African American Family Networks and Health* study is the first study to utilize the CEGRM approach with an African American participant sample, thus diversifying the application of its use. Additionally, the use of a mixed-methods research design is a significant strength of our study, as the qualitative data collected complemented and contextualized our quantitative network findings. Mixed-methods studies are considered to be particularly rigorous, because they afford the opportunity to gather *comprehensive* information about the topic of study, and thereby tell a more complete story when answering research questions. Regarding our study, the collection of quantitative network data facilitated our understanding of "what" FHH information sharing patterns look like within African American families. The rich, complementary qualitative data that was collected as part of our participant interviews enhanced our understanding of "when," "where," "how," and even "why" FHH information is shared and/or obtained within African American families. While many studies have sought to assess the extent of individuals' health history knowledge, and identify patterns of FHH knowledge consistency among relatives, very few have gathered information about how individuals learn about their family's health history, and which contexts facilitate this knowledge. This contextual information provides valuable insight for future efforts to enhance the transmission of health history information in this population.

While our study consists of various strengths, there are several limitations worth noting. First, we recognize the limitation of our single-informant design, as it limited the ability to confirm our participants' reports of their FHH. Closely related, our use of health communication exchanges with relatives identified as "personal health informants" as a proxy for FHH participants' is a limiting factor in the depth of our results, as it pertains to understanding FHH knowledge among African Americans. Additionally, our study sample size may limit the generalizability of our findings. Finally, our decision not to include younger generations in our analytic sample may be

a limiting factor in our reported study results. However, it is important to note that the number of family members from younger generations named as personal health informants (the outcome of interest) was extremely small in our total sample of familial alters (less than 3%).

Conclusion

Low awareness of FHH knowledge among racial and ethnic minority groups, such as African Americans, may pose a contributing factor to health disparities in this population (Corona et al., 2013). Thus, it is imperative to enhance genetic literacy, FHH collection, and FHH knowledge among African Americans. Our study results, in particular, highlight the importance promoting interpersonal health communication within *extended* family networks, a context that is understudied in health promotion and social networks research. Moreover, our findings offer new insights regarding paternal family networks. In particular, there is a need to strategically increase paternal FHH knowledge among African Americans–an effort that will require interdisciplinary efforts and collaborative involvement of disciplines, such as family studies, public health, and genetics. Future efforts in the population should continue to promote the practice of open communication and reciprocal communication within African American families, as these approaches have been demonstrated to facilitate FHH knowledge in this population. Finally, we underscore the importance of engaging female and older adult family members as facilitators of FHH knowledge intergenerationally, and especially for the benefit of younger family members.

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