Social determinants of family health history collection

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Abstract Family health history (FHH) is the most basic form of genomic information. Although public health efforts have been made to promote FHH collection, empirical data on the extent to which community residents in rural areas actively collect FHH is limited. Therefore, we examined rates of FHH collection in a community-based sample of South Carolina residents. We conducted a structured telephone survey in a random sample of black and white South Carolina residents. Respondents were asked if they had ever actively collected FHH from relatives using an item developed by the Centers for Disease Control and Prevention. Overall, 42 % of respondents reported that they had actively collected their FHH. Blacks were significantly more likely than whites to have collected their FHH in bivariate analysis, but race did not have a significant association with FHH collection in the multivariate model (OR=1.36, 95 % CI=0.79, 2.35, $p=0.26$). The

likelihood of collecting FHH was increased among respondents whose last medical visit occurred in the past year compared to those whose last medical visit was more than 1 year ago (OR=2.00, 95 % CI=1.12, 3.56, $p=0.02$). In addition, older respondents had a reduced likelihood of collecting their FHH (OR=0.69, 95 % CI=0.53, 0.90, $p=.01$). Lastly, women were about twice as likely as men to have collected their FHH (OR=1.83, 95 % CI=1.12, 2.99, $p=0.02$). Greater efforts are needed to increase the collection of FHH information; these efforts may need to target men, the elderly, and individuals who have not had a recent medical visit.

Keywords Family health history · Social determinants · Racial disparities

Introduction

It has now been more than a decade since the Human Genome Project was completed (Green and Guyer 2011); during this time, several genomic tools and services have been developed and implemented in clinical care and public health practice. We have moved into a new era of genomic medicine; genetic testing has evolved from being delivered in specialized high risk programs to greater integration into primary care practice (Kaphingst et al. 2010; Reid et al. 2012). Many more personalized strategies for disease prevention and treatment are anticipated; it is now possible for individuals to obtain genetic risk information and targeted therapies for multiple chronic conditions simultaneously. Family health history (FHH) is the basis for this type of genomic medicine and is critical for the accurate interpretation of genetic information (Khouri et al. 2010; Orlando et al. 2011; Valdez et al. 2010). National efforts encourage individuals to obtain their FHH and share it with their relatives and health care providers (US Department

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of Health and Human Services); however, data from national samples have shown that individuals are not likely to have obtained their FHH even though most believe that it is important to their health (Yoon et al. 2004).

The value of existing and emerging approaches for genomic medicine will ultimately be judged based on whether they can be translated into clinical and public health practices that improve health care and outcomes. However, the racial disparities observed for health care, morbidity, and mortality overall are observed in genomic medicine (Armstrong et al. 2005; Armstrong et al. 2003). Previous studies have shown that African Americans have limited knowledge about basic genomic concepts and specific applications of FHH to disease (Ashida et al. 2012; Kessler et al. 2007). Further, recent research has shown that African Americans may not record their FHH in writing, even though many believe that FHH tools are effective for tracking this information (Thompson et al. 2013). For this reason, ensuring equitable access to and promotion of all types of tools for retrieving genetic information among racial minorities is a high priority. Prior studies have compared racial groups in genetic test result acceptance, evaluated how race/ethnicity is used in genomic research, and examined the implications of genetics on conceptualizations of race/ethnicity (Sankar 2003; Sankar et al. 2007; Shields and Crown 2012). At this point, the more critical issue is how to offer genomic tools and services to racial minorities so that access and benefits are maximized and exposure to potential risks and harms are minimized. The first step to effectively implementing genomic medicine and tools into clinical care and public health practice is to identify factors that facilitate and hinder use of strategies that are fundamental to identifying patients who need more intensive primary and specialty care because of their FHH.

Social factors are increasingly recognized as being important to health behaviors; according to models that focus on social determinants of health, variables related to the health care system, social isolation, health beliefs, and socioeconomic factors are critical determinants of health behaviors and outcomes (Commission on Social Determinants of Health 2008). Prior studies have examined racial differences in FHH collection and evaluated beliefs about the value of FHH in specific racial groups, but other social variables may be important to FHH collection (Yoon et al. 2004; Thompson et al. 2013). Social isolation, for instance, reflects an individual's interpretation of the quality of their social relationships and whether or not these relationships meet their needs (Hughes et al. 2004). Social isolation has been associated with an increased risk for morbidity and mortality (Cacioppo et al. 2011). Social isolation may be important to FHH collection because individuals who feel lonely may be less inclined to communicate with relatives about health issues. On the other hand, individuals who are concerned about their risk of developing chronic diseases may take active efforts to obtain family

health history information from relatives to be more informed. Previously, we found that the most important reason for communicating BRCA1 and BRCA2 genetic test results to family members was to provide them with risk information (Hughes et al. 2002). In this study, we examined rates of FHH collection in a random sample of South Carolina (SC) residents. SC is a predominantly rural state that has a large proportion of black residents; according to the 2010 census, 29 % of SC residents were black (US Census Bureau). Since previous reports have identified racial differences in utilization of genomic services (Armstrong et al. 2005; Armstrong et al. 2003), we were particularly interested in examining FHH collection between black and white respondents. We hypothesized that blacks would be less likely to have collected their FHH compared to whites. We also evaluated the relationship between FHH collection and other social determinants such as social isolation, concern about developing cancer and cardiovascular disease, and health care variables to identify those that had a significant independent association with actively obtaining FHH information from relatives.

Materials and methods

Study population

We conducted a telephone survey in a random sample of black and white SC residents. To be eligible for the survey, individuals had to be between the ages of 18–75, self-identify as being black or white, and be a current resident of SC. We only included blacks and whites in this study because these are the two largest racial groups in the state. This study was approved by the Institutional Review Board at the Medical University of South Carolina.

Procedures

Respondents for the survey were identified by the University of South Carolina's Institute for Public Service and Policy Research (IPSPR) using a dual sampling frame approach that was based on landline telephone exchanges and cell phone telephone numbers. For the landline component, respondents were selected from a random sample of households with telephones in SC. Respondents in the cell phone sample were randomly selected from a list of cell phone exchanges in the state. Each of these numbers was called by the survey interviewers. Numbers that were found to be businesses, institutions, not-in-service, or otherwise not assigned were ineligible for the survey. The remaining numbers, when called, resulted in contacts to residences in the landline or cell phone component. When contact was made with a residence in the landline component, a respondent between the ages of 18–75 was randomly chosen from the household's occupants using a

standardized process. As in the landline component, when contact was made with an individual in the cell phone component, they were asked a series of questions to determine eligibility, including confirming that the number reached was for a cell phone, that the individual who answered was between the ages of 18–75, that they were a SC resident, and they self-identified as being black or white. If an individual reached on a cell phone also had a landline telephone in his/her household, and received less than 90 % of calls on his/her cell phone, he/she was not interviewed for this study. All respondents were given a US\$20 gift card after completing the interview. Surveys were completed from October to November 2013; 178 (57 %) were completed in the landline component and 134 (43 %) were completed in the cell phone component. The response rate was 27.1 % for the landline component and was 14.4 % for the cell phone component. The overall response rate was 27.1 %. Respondents who were missing data on FHH or social determinants ($n=4$) were excluded from the analysis; therefore, the final sample included 309 respondents.

Measures

Sociodemographic characteristics

We obtained gender, age, marital status, education, employment, and household income by self-report using items from our previous research (Halbert et al. 2005). Some respondents ($n=35$) refused to provide their household income; we used the respondent's zip code to determine the median household income for the census tract in which they resided and used this value in the analysis.

Medical history

Respondents were asked if they had a personal history of any of the following diseases: hypertension, diabetes, heart problems, stroke, cancer, arthritis, or asthma. Those who reported a personal history of at least one of these conditions was categorized as having a chronic disease. Respondents who did not have a personal history of any of these diseases were categorized as not having a chronic disease. We also obtained height and weight and used the established formula to determine body mass index (BMI) (Centers for Disease Control and Prevention (d)).

Health care variables

Health care variables included insurance status (yes or no), the amount of time since their last medical visit, and the type of facility for usual medical care. Specifically, respondents were asked how long had it been since they had their last routine health care checkup unrelated to a specific problem (within

the past year, within the past 2 years, within the past 5 years, more than 5 years, never, do not know) using an item from the Behavioral Risk Factor Surveillance Survey (BRFSS) (Centers for Disease Control and Prevention (c)). We re-coded responses to this item as ≤ 1 versus >1 year. Responses of never or do not know were categorized as >1 year. Respondents were also asked where do they usually go when they are sick or need advice about their health to determine the type of facility for usual medical care (doctor's office, public health clinic/community health center, hospital outpatient department, hospital emergency room, urgent care center, some other place, no usual place, do not know). Responses to this item were categorized as doctor's office versus some other type of facility.

Social isolation

We used the three-item loneliness scale developed by Hughes et al. to evaluate social isolation. This measure asks respondents to indicate how often they lack companionship, feel left out, and feel isolated from others (1=hardly ever, 2=some of the time, 3=often) (Hughes et al. 2004). Responses to this item are scored so that higher scores reflect greater social isolation. This instrument had good internal consistency in our sample (Cronbach's $\alpha=0.71$).

Concern about cancer

We adapted a Likert style item from our previous research (Halbert et al. 2006) to measure how concerned respondents were about diseases for which FHH is a risk factor. In this study, we focused on concern about cancer and heart disease because these conditions are leading causes of morbidity and mortality nationally and among SC residents (South Carolina Department of Health and Environmental Control). Further, the presence of these conditions confers risks to unaffected family members (American Cancer Society 2014; US Department of Health and Human Services, National Health, Lung, and Blood Institute). Specifically, respondents were asked how concerned they were about heart disease and cancer (1=not at all concerned, 2=a little concerned, 3=somewhat concerned, 4=very concerned). We re-coded responses to these variables into dichotomous variable based on the distribution of responses and conceptual relevance (e.g., concerned versus not concerned).

FHH collection

Respondents were asked if they had ever actively collected FHH from relatives using an item from the CDC (yes or no) (Yoon et al. 2004).

Data analysis

First, we generated descriptive statistics to characterize respondents in terms of sociodemographics, medical history, health care experiences, social isolation, concern about cancer, and collection of FHH. Next, we used Chi Square Tests of Association to evaluate the bivariate relationship between FHH collection and social determinants. Last, we used logistic regression analysis to identify factors having significant independent associations with FHH collection. Variables that had a bivariate association of $p < 0.10$ with FHH were included in the logistic regression model. We also included the method of survey administration (landline or cell phone) in the logistic regression model.

Results

Table 1 shows the characteristics of the study sample. Thirty-one percent of respondents were black and 69 % were white. In addition, 40 % of respondents were male, 53 % were married, 67 % had some college education or were college graduates, and 53 % were employed. Thirty-five percent of respondents had an annual household income that was greater than

US\$50,000. In terms of health care variables and medical history, 83 % of respondents had health insurance, 75 % reported having a routine medical checkup during the past year, 72 % usually received medical care at a doctor's office, and 63 % had a chronic health condition.

Overall, 42 % of respondents reported that they had actively collected FHH from their relatives. The results of the bivariate analysis of FHH collection are provided in Table 1. There were significant racial differences in the rates of FHH collection. Blacks (53 %) were significantly more likely than whites (37 %) to have collected their FHH (chi square=7.24, $p=0.01$). In addition, women and respondents who had a medical visit during the past year were significantly more likely to have collected their FHH compared to men and those whose last medical visit was more than 1 year ago. Age also had a significant bivariate association with FHH collection; respondents who had collected their FHH were younger in age (mean=46.5, SD=14.8) compared to those who had not collected their FHH (mean=51.2, SD=16.4) ($t=2.53$, $p=0.01$). FHH collectors (mean=29.7, SD=7.8) also had a higher body mass index compared to non-collectors (mean=27.8, SD=6.8) ($t=-2.21$, $p=0.03$). Social isolation did not have a significant bivariate association with FHH collection.

Table 1 Sample characteristics and analysis of FHH collection by social determinants ($n=309$)

Variable	Level	<i>n</i> (%)			<i>p</i> value
			Collected FHH (%)	Chi square	
Race	African American	96 (31)	53	7.24	0.01
	White	212 (69)	37		
Gender	Male	123 (40)	32	7.37	0.01
	Female	185 (60)	48		
Marital status	Married	163 (53)	40	0.21	0.65
	Not married	144 (47)	43		
Education level	≥Some college	207 (67)	43	0.25	0.62
	≤High school	100 (33)	40		
Employment status	Employed	160 (53)	46	1.85	0.17
	Not employed	140 (47)	38		
Income level	>US\$50,000	109 (35)	38	1.26	0.26
	<US\$50,000	199 (65)	44		
Health insurance	Yes	254 (83)	43	0.35	0.55
	No	52 (17)	38		
Chronic condition	Yes	195 (63)	43	0.31	0.58
	No	113 (37)	40		
Last medical visit	≤1 year	232 (75)	45	4.40	0.04
	>1 year	76 (25)	32		
Type medical care facility	Doctor's office	223 (72)	44	0.86	0.35
	Other	85 (28)	38		
Concerned about heart disease	Concerned	162 (53)	49	6.41	0.01
	Not concerned	145 (47)	34		
Concerned about cancer	Concerned	176 (57)	47	4.07	0.04
	Not concerned	131 (43)	35		

To further explore racial differences in FHH collection, we conducted a stratified analysis to determine if different factors were associated significantly with FHH collection among blacks and whites. Among black respondents, those who had some college education or were college graduates (62 %) were more likely to have collected their FHH compared to those with less education (43 %) (chi square=3.54, $p=0.06$). Among whites, women (44 %) were more likely than men (28 %) to have collected their FHH (chi square=6.06, $p=0.01$). In addition, whites who had collected their FHH were younger in age (mean=48.9, SD=14.7) compared to non-collectors (mean=52.9, SD=16.7) ($t=1.75$, $p=0.01$). Since there were few differences in factors that were associated with FHH among blacks and whites, we did not stratify the multivariate regression analysis based on race.

Table 2 shows the results of the multivariate logistic regression analysis of FHH collection. Gender, the amount of time since the last medical visit, and age had significant independent associations with FHH collection. Specifically, women were about twice as likely as men to have collected their FHH (OR=1.83, 95 % CI=1.12, 2.99, $p=0.02$). Respondents who had their last medical visit during the past year also had a greater likelihood of collecting their FHH compared to those who last medical visit was more than 1 year ago (OR=2.00, 95 % CI=1.12, 3.56, $p=0.02$). Lastly, older respondents had a reduced likelihood of collecting their FHH (OR=0.69, 95 % CI=0.53, 0.90, $p=.01$).

Discussion

FHH is the most basic form of genomic information; personalized approaches for primary and specialty medical care depend on the identification of individuals who have a family

history that is suggestive of an increased risk of disease. In this study, we examined rates of FHH collection in a random sample of SC residents. While a substantial minority of respondents reported that they had collected their FHH (42 %), many respondents had not ever asked relatives about their history of disease. Previously, only 29.8 % of adults in a national survey reported that they had obtained actively collected their FHH (Yoon et al. 2004). While our rates of FHH collection are higher than those previously reported, the rates we found are disappointing in light of the extensive public health efforts that have been made to promote FHH collection. The Surgeon General's Initiative on Family Health History was a national campaign that encouraged individuals to discuss and document their FHH (US Department of Health and Human Services). The CDC also launched a family history public health initiative to increase awareness about the importance of family history for chronic disease risk and to promote the use of FHH in health promotion and disease prevention programs (Centers for Disease Control and Prevention (b)). Clinical decision support tools are now being developed to identify individuals at increased risk for disease based on their FHH in primary care (Orlando et al. 2011), and FHH is now an element in national standards for meaningful use of electronic health records (Centers for Disease Control and Prevention (a)). Importantly, FHH is now a consideration in at least 17 US Preventive Services Task Force (USPSTF) recommendations for health care services (Centers for Disease Control and Prevention (a)). The USPSTF is a panel of national experts that makes evidence-based recommendations about clinical services for disease prevention. However, 58 % of respondents in our study had not ever actively collected their FHH. Thus, even though clinical decision support tools have been developed and efforts are being made to implement these programs into primary care, a substantial proportion of patients may not be able to provide information about the

Table 2 Multivariate logistic regression model of FHH collection

Variable	Level	Odds ratio	95 % C.I.	<i>p</i> value
Age	^a	0.66	0.50, 0.87	0.01
Race	African American White	1.36	0.79, 2.35	0.26
Gender	Female Male	1.80	1.08, 2.98	0.02
BMI	^a	1.19	0.94, 1.51	0.14
Last medical visit	≤1 year >1 year	2.06	1.13, 3.73	0.02
Concerned about heart disease	Concerned Not concerned	1.71	0.94, 3.12	0.08
Concerned about cancer	Concerned Not concerned	1.16	0.63, 2.12	0.64
Study	Landline Cell phone	0.84	0.50, 1.44	0.53

n=306

^aOR for continuous variable reflects 1 SD unit change

presence of disease in their families, or the information they provide may be inaccurate.

Interestingly, blacks were more likely than whites to have collected their FHH in the bivariate analyses, but race did not have a significant association with FHH collection in the multivariate logistic regression analysis. Further, there were few differences in factors that were associated with FHH in stratified analyses that were conducted among blacks and whites, and neither concerns about cancer and cardiovascular disease nor social isolation had significant independent associations with FHH collection. Of the social determinants that we measured, only gender and age were associated significantly with FHH in the multivariate logistic regression analysis in the total sample. The gender differences we found are consistent with the results of prior studies, but other work has shown that older adults are more familiar with their FHH compared to younger individuals (Ashida et al. 2012; Yoon et al. 2004). For instance, women feel responsible as “gatherers” or “kin keepers” of family health data including genomic medical information (Green et al. 1997; Richards 1996; Koehly et al. 2009). Other research has shown that women collect and share family health and genetic testing information regarding themselves and their spouse, whether they are at risk of disease or not, within their family (Richards 1996). Although men feel a sense of responsibility for informing family members of genetic testing results and risks (Hallowell et al. 2005), they are more reluctant to share health information about cancer and genetics (Koehly et al. 2009). When they do share genetic test results, it is shared with an immediate family member such as a spouse (D’Agincourt-Canning 2001). Further, the sharing of genomic data for men is more appealing when it is shared with a spouse compared to another family member (Akpınar and Ersoy 2014). FHH is highly relevant for men, especially men from racial and ethnic minority groups, who are likely to have a history of chronic diseases (e.g., diabetes, hypertension) that confer risks to relatives (Yoon et al. 2012). Our findings underscore the importance of developing programs to increase knowledge about the importance of FHH and improve the capacity of men to obtain their FHH. Additional research is needed to evaluate the impact of FHH education programs on the collection of this information and to identify the most effective setting for delivering these types of programs to men. Recently, we found that African American men were as likely as women to complete a community-based risk education program about cancer and cardiovascular disease (Halbert et al. 2014; Wu et al. 2013). Community-based programs may be an effective setting for delivering education about the importance of FHH collection and strategies for obtaining this information to men.

We also found that respondents whose last medical visit was completed during the past year were about twice as likely to have collected their FHH compared to those whose last medical visit was completed more than 1 year ago. A possible explanation for this finding is that respondents were prompted

to ask relatives about their health history after providers asked them questions about relatives who have been diagnosed with chronic diseases as part of primary or specialty care. However, there are several barriers (e.g., time constraints, limited standardization of collection tools) to providers obtaining FHH from patients (Berg et al. 2009). We did not ask respondents who had collected their FHH to indicate if this information was obtained as part of a primary or specialty care or if they used a self-collection FHH tool. Previous research has examined experiences and satisfaction with FHH tools in clinical settings (Owens et al. 2011); however, to our knowledge, national data are not available on the characteristics of individuals who use publicly available FHH websites and collection tools. Future studies are needed to establish these rates, characterize individuals who use publicly available FHH collection tools, and evaluate the impact of FHH information on health care and outcomes.

In considering the results of this study, some limitations should be considered. First, our analysis was based on a random sample of black and white respondents from one state. Also, more than 60 % of our sample had some college education or were college graduates. Although education level was not associated significantly with collecting FHH in our analyses, education level has implications for general literacy as well as health literacy. Our response rate was modest; additional research is needed to characterize FHH collection rates in larger samples that are drawn from states across the USA. Declining response rates is an issue across all types of survey research; the Pew Research Center has shown that their response rate for telephone surveys has declined from 36 % in 1997 to 9 % in 2012 (Pew Research Institute). Despite this decline in response rates, the samples enrolled in telephone surveys are likely to be similar to the US population in terms of demographics and other variables (Pew Research Institute). This increases confidence that the estimates we obtained on FHH collection are not likely to be biased because of non-response. Nevertheless, we had a greater proportion of women respondents in our sample. According to the US Census, 51 % of South Carolina residents are women and 27.9 % are black (US Census Bureau). Thus, the representation of blacks and women in our sample appears to be consistent with the representation of these groups in the state. While an additional limitation may be that we evaluated FHH collection using a single item, the item we used had acceptable face validity and it was used in a national survey to examine rates of FHH collection among adults in the USA (Yoon et al. 2004).

Despite these potential limitations, our findings suggest improvement in FHH collection rates relative to previous reports (Yoon et al. 2004). But, within the context of the substantial public health efforts that have been made to promote FHH collection (Centers for Disease Control and Prevention (b); US Department of Health and Human Services), the rates we observed were modest overall. Our findings indicate a need

for greater efforts to improve access to and utilization of FHH collection tools, especially among men. FHH is now an element in national standards for meaningful use of electronic health records ([Centers for Disease Control and Prevention \(a\)](#)); systems are being developed to obtain this information from patients as part of primary care (Orlando et al. 2011) in order to identify those who need specialty care or preventive services that are recommended for individuals at increased risk for disease. Respondents who had a recent medical visit had an increased likelihood of collecting their FHH; thus, it may be important to provide self-reported FHH to patients and encourage communication of this information with relatives after medical visits. To assist with collecting FHH from relatives, providers could give patients instructions on how to complete FHH at home during medical visits. Health care providers and public health practitioners can promote FHH collection through clinic- and community-based efforts that are designed to increase recognition of the importance of FHH to one's personal health and encouraging patients to complete FHH tools prior to clinic visits, identify barriers to obtaining and sharing this information from family members, and encouraging individuals to complete FHH tools.

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