

Donation Intentions for Cancer Genetics Research Among African Americans

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Aims: Scientific agencies rely on individuals to donate their DNA to support research on chronic conditions that disproportionately affect African Americans; however, donation is variable in this population. The purpose of this study was to identify sociodemographic characteristics, health care variables, and cultural values having significant independent associations with intentions to donate blood or saliva samples for cancer genetics research among African American adults. **Method:** Cross-sectional survey of donation intentions. **Results:** The majority of respondents (73%) were willing to donate a biological sample for cancer genetics research. The results of the multivariate regression model found that respondents who received care at a facility other than a doctor's office (e.g., community center) were about five times more likely to be willing to donate a sample for cancer genetics research (odds ratio [OR]=5.28, 95% confidence interval [CI]=1.16–24.12, $p=0.03$); whereas, greater levels of religiosity (OR=0.09, 95% CI=0.01–0.75, $p=0.02$) and present temporal orientation (OR=0.23, 95% CI=0.06–0.79, $p=0.02$) were associated with a lower likelihood of donating a sample. **Conclusion:** Efforts to enhance donation of biological samples for cancer genetics research may need to target diverse clinical sites for recruitment. Additionally, recruitment materials may need to address cultural values related to religiosity and present temporal orientation.

Introduction

TO CONTINUE THE SCIENTIFIC and clinical advances that have been made through the human genome project, a number of agencies are invested in developing and maintaining large biobanks to support research that investigates the genetic basis of disease, environmental exposures, and the interaction between genetic and environmental factors (Anton-Culver *et al.*, 2003; Austin *et al.*, 2003; Kaiser, 2003; Mailman *et al.*, 2007). For example, the National Cancer Institute has invested in the development of the Cancer Human Biobank to supply quality human tissue to further understand cancer dysregulation (Massett *et al.*, 2011; Shaw and Patterson, 2011; Vaught *et al.*, 2011). Biobanks house large collections of biological samples along with information on an individual's personal health, lifestyle, and environmental exposures to support research on complex diseases (Ollier

et al., 2005; Godard *et al.*, 2007; Kaiser Permanente News Center, 2007; Mailman *et al.*, 2007). For genetic research and biobanks to flourish, investigators rely on individuals to donate their DNA or provide consent for researchers to access their health information. Contributing to biobanks is considered minimally invasive with little risk of physical harm (National Bioethics Advisory Commission, 1999). An individual's privacy is protected by stripping identifying information such as name, address, birth date, or identifying numbers before the genomic data is made available to the researchers (National Bioethics Advisory Commission, 1999; U.S. Department of Health and Human Services, 2003). Despite these protective measures, there are many ethical, legal, and social concerns surrounding participation in genetic research and biobanks (International Society for Biological and Environmental Repositories, 2008). For example, confidentiality and privacy concerns range from the degree of control

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that participants have over their personal information, the type of studies that will be supported, and who has access to the information (Kaufman *et al.*, 2009; Murphy *et al.*, 2009; Lemke *et al.*, 2010).

Although it is anticipated that the results from genetics research will contribute to the amelioration or reduction of racial disparities in health outcomes, this type of research is challenged by difficulties in recruiting racial minorities. Only about 15% of African Americans agreed to participate in a national cancer genetics research study compared with 36% of whites (Moorman *et al.*, 2004). Further, even though the majority of African Americans provided consent for their DNA to be stored and used in future genetic studies as part of their participation in the National Health and Nutrition Examination Survey (NHANES), these rates were lower than those reported for whites (McQuillan *et al.*, 2006). On the other hand, recent research has shown that African Americans who have enrolled in research designed to explore genetic factors involved in disease have favorable attitudes about genetics research (Henderson *et al.*, 2008) and are willing to donate samples for future studies (Bussey-Jones *et al.*, 2010). But, evaluating attitudes and expectations in individuals who have already agreed to participate in genetics research may have limited generalizability because these individuals may express opinions that support their original enrollment decisions. This may also explain why consent rates for sample donation were relatively high among African Americans who were participating in the NHANES (McQuillan *et al.*, 2006). An additional limitation of prior studies is that their primary focus has been on examining racial differences in attitudes, beliefs, and expectations even though African Americans are a heterogeneous group of individuals with differing sociodemographic backgrounds, health care experiences, and beliefs and values. Previous studies have shown that variation in these factors is important to participation decisions related to genetics research. For instance, cultural values related to religion and spirituality and temporal orientation are associated with decisions to participate in genetic counseling and testing offered through a research protocol among African Americans (Hughes *et al.*, 2003). In other research, African American women who had a stronger family history of breast and/or ovarian cancer were most likely to enroll in a genetic counseling research protocol (Halbert *et al.*, 2005). However, limited empirical data are available on factors that may enhance or diminish sample donation specifically in African Americans.

The purpose of this study was to identify sociodemographic characteristics, clinical factors, and health care variables having significant independent associations with intentions to donate blood or saliva samples for cancer genetics research in a sample of African Americans who were not currently participating in research. We focused on intentions to donate samples for cancer genetics research because cancer is the second leading cause of death in the United States that disproportionately affects African Americans in terms of morbidity and mortality (American Cancer Society, 2009). Also, recent research has shown that African Americans are concerned about this disease (Weathers *et al.*, 2011) and national efforts are being made to establish biobanks that will support research on the genetic basis of cancer (Shaw and Patterson, 2011; Vaught *et al.*, 2011). Since prior studies have recommended that greater efforts be made to increase awareness about genetics research among African Americans in order to enhance recruitment, we also

evaluated the association between exposures to information about genetic factors involved in chronic disease to determine if exposure was important to willingness to participate in a genetics study. We also evaluated the relationship between cultural factors and donation intentions because these variables are important to acceptance of genetic risk information that is offered in research settings among African Americans (Hughes *et al.*, 2003; Kessler *et al.*, 2005; Gurmankin Levy *et al.*, 2006; Edwards *et al.*, 2008). Based on previous research (Hughes *et al.*, 2003; Kessler *et al.*, 2005), we predicted that individuals with greater religiosity would be least willing to donate samples for genetics research while those with greater levels of future temporal orientation, or more concerned about future outcomes and consequences, would be more willing to donate samples for studies.

Materials and Methods

Sample characteristics

This study was a cross-sectional survey of individuals who were past or current patients at the University of Pennsylvania Hospital System. The study was approved by the Institutional Review Board at the University of Pennsylvania. Respondents were African American men and women who had seen a primary care provider between April 15, 2003 and November 30, 2009. We identified a random sample of these patients from a billing database managed by the University of Pennsylvania Office of Research. To be included in the study, individuals had to be at least age 18 and be able to speak English. We excluded individuals who were currently participating in a research study. A total of 2062 patients were invited to participate and were contacted to complete a screening interview. Of these, 126 (6%) were not eligible, 575 (28%) could not be reached because their telephone number was disconnected or no longer in service, and 428 (21%) had not yet completed the screening interview. Of the remaining 933 patients, 298 (32%) completed the screening interview. Seventy-four percent of individuals who completed the screening interview were eligible and 206 (93%) of these individuals completed the survey. The sample included 202 respondents.

Procedures

Following identification from the patient billing records, individuals were mailed an invitation letter that described the purpose of the study and the procedures involved in participation. A self-addressed reply card was included in the invitation letter for individuals to return if they did not want to be contacted. Those who did not opt out of the study were contacted, and following provision of a verbal consent, completed a 5-min screening interview. Those who remained eligible after the screening interview then completed a 40-min structured, telephone interview to obtain sociodemographics and to evaluate exposure to information about genetics, cultural beliefs and values, and donation intentions. Those who completed the telephone interview were mailed a \$20 American Express gift check.

Measures

Sociodemographics characteristics. We obtained information on race, gender, marital status, education level, employment status, and income level by self-report.

Clinical experiences. We obtained personal history of cancer and family history of disease by self-report using items from our previous research (Halbert *et al.*, 2006b). Specifically, respondents were asked whether they had ever been diagnosed with cancer or had a family history of disease (yes or no). We used an item from the Behavioral Risk Factor Surveillance Survey to determine where respondents usually obtained medical care (CDC, 2002). We created a dichotomous variable for usual source of health care based on the distribution of responses (doctor's office vs. other types of facilities).

Exposure to information about genetics. We adapted items from our previous research (Hughes *et al.*, 1997) to evaluate exposure to information about genetic factors involved in chronic disease; respondents were asked how much they had heard or read about genes involved in cancer, heart disease, hypertension, and diabetes before the survey. We summed these items to create an exposure to genetics scale; this scale had good internal consistency (Cronbach's $\alpha=0.82$). Higher scores reflected greater exposure to information about genetic factors involved in disease.

Cultural factors. We used the temporal orientation and religiosity scales developed by Lukwago *et al.* (2001) to evaluate present and future temporal orientation and religious and spiritual beliefs and practices. These instruments had acceptable internal consistency in our sample (Cronbach's alphas = 0.69 and 0.72 for present and future temporal orientation, respectively, and 0.88 for religiosity). Higher scores reflected greater endorsement of cultural values.

Donation intentions. We adapted an item from previous research to evaluate donation intentions (Halbert *et al.*, 2006a). Specifically, respondents were asked how much they agree or disagreed (1 = strongly disagree, 2 = disagree, 3 = neutral, 4 = agree, 5 = strongly agree) with the following item: I would be willing to donate a blood or saliva sample within the next 12 months for research to find genes that affect cancer development.

Data analysis

First, we generated descriptive statistics to characterize respondents in terms of sociodemographic factors and intentions to donate blood or saliva samples for cancer genetics research. We created a dichotomous variable for donation intentions by categorizing those who reported "strongly agree" and "agree" as being willing to donate a sample and those who reported "strongly disagree, disagree, or neutral" as being unwilling to donate a sample. We used Chi Square tests of association and *t*-tests to evaluate the bivariate relationship between donation intentions and sociodemographic factors, clinical experiences, exposure to information about genetics, and cultural factors. We then used multivariate logistic regression analysis to identify factors having significant independent associations with donation intentions. Variables that had a $p < 0.10$ association with intentions in the bivariate analyses were included in the regression model.

Results

Table 1 shows the characteristics of the study sample. Most respondents were female (59%) and were not married (65%).

TABLE 1. SAMPLE CHARACTERISTICS (N=202)

Variable	Level	n (%)
Gender	Female	112 (59%)
	Male	83 (41%)
Marital status	Not married	132 (65%)
	Married	70 (35%)
Education level	≥ Some college	116 (57%)
	≤ High school	86 (43%)
Employment status	Employed	99 (49%)
	Not employed	103 (51%)
Income level ^a	> \$35,000	92 (51%)
	≤ \$35,000	90 (49%)
Personal cancer history	Yes	19 (9%)
	No	183 (91%)
Family history of cancer ^a	Yes	82 (42%)
	No	115 (58%)
Health insurance	Yes	185 (92%)
	No	17 (8%)
Usual source of health care	Doctor's office	179 (89%)
	Other type of facility	23 (11%)
Previous research participation	Yes	75 (37%)
	No/don't know	127 (63%)

^aTwenty respondents were missing data for income and five were missing data for family history of cancer.

Fifty-seven percent of respondents had some college education or were college graduates, 51% had an annual household income that was less than \$35,000, and 51% were not employed. The majority of respondents (91%) did not have a personal or family (58%) history of cancer. The usual source of health care was a doctor's office for 89% of participants. Thirty-seven percent of respondents had previously participated in a research study.

Overall, 73% of respondents were willing to donate a blood or saliva sample for cancer genetics research and 27% were unwilling to donate a sample. Table 2 shows the results of the bivariate analysis of donation intentions. Education level had a significant association with donation intentions; respondents with some college education and those who were college graduates were significantly more likely to be willing to donate a blood or saliva sample compared with those with less education ($\chi^2 = 3.73, p = 0.05$). Usual source of medical care also had a significant association with donation intentions. Respondents who received medical care at a facility other than a doctor's office were significantly more likely to be willing to donate a sample compared with those who usually received care at a doctor's office ($\chi^2 = 4.31, p = 0.04$).

Of the cultural factors, religiosity and present temporal orientation had significant associations with donation intentions (Table 3). Respondents who were willing to donate a blood or saliva sample had significantly lower levels of religiosity compared with those who were not willing to donate a sample ($t = 2.16, p = 0.03$). In addition, respondents who were willing to donate a sample had significantly lower levels of present temporal orientation ($t = 2.23, p = 0.03$). Exposure to information about genetics ($t = -1.03, p = 0.30$) and future temporal orientation ($t = -0.94, p = 0.34$) were not significantly associated with donation intentions.

The results of the multivariate regression model are provided in Table 4. Usual source of health care had a significant

TABLE 2. ASSOCIATION BETWEEN DONATION INTENTIONS AND SOCIODEMOGRAPHIC FACTORS AND CLINICAL CHARACTERISTICS

Variable	Level	% Donate sample	Chi square
Gender	Female	73%	0.004
	Male	73%	
Marital status	Not married	74%	0.18
	Married	71%	
Education level	≥Some college	78%	3.73 ^a
	≥High school	66%	
Employment status	Employed	74%	0.02
	Not employed	73%	
Income level	>\$35,000	78%	0.89
	≤\$35,000	72%	
Personal cancer history	Yes	84%	1.28
	No	72%	
Family history of cancer	Yes	77%	0.75
	No	71%	
Health insurance	Yes	72%	0.78
	No	82%	
Usual source of health care	Doctor's office	71%	4.31 ^a
	Other type of facility	91%	
Previous research participation	Yes	68%	1.69
	No/don't know	76%	

^a*p* < 0.05.

independent association with donation intentions. Respondents who received care at a facility other than a doctor's office (e.g., public health clinic, community health center) were significantly more likely to be willing to donate a sample compared with those who received care at a doctor's office (odds ratio [OR]=5.28, 95% confidence interval [CI]=1.16, 24.12, *p*=0.03). Greater levels of religiosity (OR=0.09, CI: 0.01–0.75, *p*=0.02) and present temporal orientation (OR=0.23, CI: 0.06–0.79, *p*=0.02) were associated with a significantly lower likelihood of being willing to donate blood or saliva samples for cancer genetics research.

Discussion

As national efforts are implemented to understand the genetic basis of cancer, access to banked human tissues that represent a cross section of the population will continue to be emphasized (Shaw and Patterson, 2011). But, previous re-

TABLE 3. CULTURAL AND EXPOSURE VARIABLES

Variable	Mean (SD)		t-Value	p-Value
	Willing	Not Willing		
Religiosity	27.26 (4.6)	28.85 (4.6)	2.16	0.03
Future temporal orientation	15.38 (2.5)	15.01 (2.3)	-0.94	0.34
Present temporal orientation	8.92 (2.5)	9.83 (2.8)	2.23	0.03
Exposure to information about genes	14.18 (4.1)	13.50 (4.1)	-1.03	0.30

SD, standard deviation.

TABLE 4. MULTIVARIATE REGRESSION MODEL OF DONATION INTENTIONS

Variable	Level	OR	95% CI	p-Value
Education level	≥Some college	1.60	0.81, 3.14	0.18
	≤High school			
Usual source of health care	Doctor's office	5.28	1.16, 24.12	0.03
	Other type of facility			
	[Continuous]	0.09	0.01, 0.75	
Religiosity	[Continuous]	0.23	0.06, 0.79	0.02
Present temporal orientation	[Continuous]	0.23	0.06, 0.79	0.02

OR, odds ratio; CI, confidence interval.

search has shown that African Americans may be unwilling to participate in resources that are established to support this type of research (Moorman *et al.*, 2004). The present study adds several new findings to the growing body of literature on African American participation in cancer genetics research that may involve biobanks. First, we found that cultural factors had significant independent associations with intentions to donate a blood or saliva sample. Specifically, respondents who had greater levels of religiosity and present temporal orientation had a lower likelihood of being willing to donate samples for cancer genetics research. Previous research has shown that religious frameworks are used to understand health and disease (Harris *et al.*, 2009) and these frameworks also shape beliefs about genetics (Harris *et al.*, 2004). For instance, in qualitative research with African Americans and whites, Harris *et al.* (2004) found that both African Americans and whites believe that God created genes and plays an active role in how genes are expressed. Some participants in this research also questioned the value of genetics research and whether these types of studies reflected efforts to "play God." It could be that individuals with greater religious values are less likely to be willing to donate samples because of these types of beliefs.

Temporal orientation, or beliefs about specific domains of time (e.g., past, present, and future), is one of the primary contexts through which individuals understand and give meaning to their experiences (Strathman and Joireman, 2005). Present temporal orientation reflects a focus on immediate or short-term consequences (McGrath, 1988); previous research has shown that greater present temporal orientation is negatively associated with knowledge about breast cancer and utilization of mammography among African American women (Lukwago *et al.*, 2003). A possible explanation for the negative association between present temporal orientation and donation intentions in our study is that respondents who focus more on short-term or immediate consequences may see less value in studies that have distal health implications. Biobanks, in particular, are established to support research over long periods of time and may not yield scientifically meaningful results for several years. Respondents with higher levels of present temporal orientation may give greater priority to things that are happening in their lives right now.

Overall, donation intentions were high among respondents in the present study. Importantly, donation intentions in our

sample were consistent with those that have been reported in other research (Henderson *et al.*, 2008). This could be because of continued racial disparities that exist in cancer morbidity and mortality among African Americans (American Cancer Society, 2009) and concerns about this disease. In a recent study with random digit survey study with a community-based sample of African Americans (Weathers *et al.*, 2011), cancer was identified as a top health priority. High levels of donation intentions could have positive implications for recruiting African Americans into genetics research and efforts to establish biobanks (Haga and Beskow, 2008). But, previous research has shown that this is not the case (Lerman *et al.*, 1999; Moorman *et al.*, 2004). Future studies should determine whether the intentions reported in our study translate into similar levels of donation to biobanks and participation in other types of cancer genetics research.

We found that respondents who usually receive health care at places such as a community health clinic or public facility were about five times more likely to be willing to donate a sample. In a review of minority recruitment for hereditary breast cancer research, Hughes *et al.* (2004) found that hospital-based resources such as billing records and tumor registries are often used to recruit participants for studies. To our knowledge, empirical data are not available on the number of times that individuals are approached about participating in studies as part of their clinical care, but patient registries are frequently used to recruit subjects into many different types of research (Anton-Culver *et al.*, 2003; Heger, 2011; Lainka *et al.*, 2010). It could be that being solicited for study participation multiple times reinforces distrust in researchers that has been found among African Americans in primary care settings (Corbie-Smith *et al.*, 1999), especially if patients are not aware that their information is being provided to investigators for study recruitment. Only 38% of cancer patients enrolled in a state registry remembered receiving an educational brochure that described the process through which their personal information may be shared with researchers for study recruitment (Beskow *et al.*, 2005). Although recruitment for cancer genetics research in settings in which patients are receiving emergency or acute medical care is neither advisable nor feasible, future studies should evaluate the effects of recruitment efforts for cancer genetics research in public health clinics or community health centers. Our experiences in the present study suggest that resources at an academic health center may have several important limitations. Close to one-third of all patients who were identified from our billing records could not be reached because their telephone was disconnected or no longer in service. Additional research is needed to determine if participation differs according to whether or not potential subjects are recruited at academic health centers or public health clinics and community health centers.

When considering the results of the present study, some limitations should be noted. First, we were not able to reach a sizeable number of individuals who were invited to participate in the study and we recruited our sample from a single health care system. These aspects of our study may limit the generalizability of our results, especially since African Americans who are not patients at an academic health care system may have a different level of donation intentions. But, according to the 2000 Census, our sample was similar to Philadelphia residents in terms of most sociodemographic characteristics. Nevertheless, future studies should evaluate donation inten-

tions in national samples of African Americans who have more diverse usual sources of health care. Another possible limitation is that our outcome variable was hypothetical in nature. Yet, our previous research suggests that these measures may be reliable proxies for actual behavior among African Americans (Kessler *et al.*, 2005; Halbert *et al.*, 2006b; Bussey-Jones *et al.*, 2010). Additional research is needed to determine whether donation intentions translate into similar levels of actual participation. The cross-sectional nature of our study is an additional limitation that should be considered.

Despite these potential limitations, our results have several important implications for African American recruitment in cancer genetics research and biobanks. First, it may be important to include places other than doctors' offices as recruitment sites for these efforts. This may be easier said than done because these facilities may have limited resources to support recruitment activities. It may also be important to address cultural factors as part of recruitment materials and strategies, regardless of the type of facility in which they are implemented. In doing so, we can learn from previous studies that have evaluated these types of approaches. For instance, recruitment materials that were designed to facilitate trust by increasing an individual's identification with study investigators and emphasized the importance of participation were not more effective in improving recruitment outcomes compared with standard materials among African Americans (Ashing-Giwa, 1999; Satia *et al.*, 2005). Resnicow *et al.* (1999) make an important distinction between surface cultural and deep cultural characteristics; while the former may increase the attractiveness and visual appeal of health materials, those that address deeper cultural factors, or beliefs and values may be more effective at promoting health behavior because they target issues that are fundamental to one's worldview. Recruitment materials and messages targeted to African Americans may need to address deep cultural factors related to religious and spiritual values and temporal orientation (Ashing-Giwa, 1999; Lukwago *et al.*, 2001; Kreuter and Wray, 2003; Satia *et al.*, 2005).

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