Factors associated with willingness to provide biospecimens for genetics research among African American cancer survivors

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Abstract

This study evaluated factors associated with willingness to provide biospecimens for cancer genetic research among African American cancer survivors. A total of 200 African American adults diagnosed with breast, colon, and/or prostate cancers completed a self-administered survey. Family history information, beliefs about cancer research, cancer genetics and disparities knowledge, willingness to provide a biospecimen, and demographics were obtained. Chi-square, independent samples *t* tests, and logistic regression analyses were performed. Overall, 79% of this sample was willing to provide a biospecimen for cancer genetics research. Independent associations of willingness to provide a biospecimen existed among demographics (males ($p = 0.041$)), those who believed in the importance of genetic causes of cancer ($p < 0.001$), individuals who believe it is important to participate in genetics research ($p < 0.001$), and those who indicated they would participate in genetics research to help future generations ($p = 0.026$). Overall, 12.5–56% of participants demonstrated some level of genetics and cancer disparities. This study identified factors that may be incorporated into future research interventions to engage the African American cancer population in cancer genetics biobanking research.

Keywords Biospecimens · Willingness to participate · Cancer genetics research · African American cancer survivors · Cancer health disparities

Introduction

Completion of the Human Genome Project (HGP) ushered in the ability to uncover the genetic underpinnings of numerous diseases including cancer (Kohonen-Corish et al. 2011; Liu and Seidel-Dugan 2006; Naidoo et al. 2011; Zoon 2004). Additional advancements in genetics and genomics since the

HGP have increased our understanding of the interplay between genetics, environment, and disease which led to subsequent national efforts such as the Precision Medicine Initiative (PMI). Initiated by President Barack Obama in January 2015 (Collins and Varmus 2015), the PMI seeks to prevent disease and improve health outcomes through the development of therapies that treat disease that are specific to an individual's

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genetic and genomic makeup (Ashley 2015). Emphasis on individualized medical efforts is important in addition to remaining attentive to the demographic profiles of persons and populations with varying degrees of interest in and access to genomic resources such as PMI.

With the emergence of genetic and genomics research, racial and ethnic minorities are underrepresented, posing challenges towards the generalizability of findings (Haga 2010; Landry et al. 2018). As a result, the utility of genetic testing results is less informative in guiding clinical management for racially ethnic and diverse populations, such as African Americans (Caswell-Jin et al. 2018). Since African Americans are disproportionately impacted by cancer disparities, and cancer is a disease that originates from an inherited and/or acquired genetic mutation, it is critically important that diverse populations engage in cancer genetic research opportunities in order to better understand the genetic and genomic contributions of cancer on a population health level.

More recent cancer genetic studies have become increasingly reliant on biobanking for research purposes (Davis and Khoury 2007; Kinkorová 2015; Braun et al. 2014; Patil et al. 2018). Biobanking is the storage of biological samples (e.g., blood, saliva, tissue, urine) for the purposes of accessing the specimens in the future for research and testing purposes. It is expected that large-scale research on biological samples, also referred to as biospecimens, stored in biobanking facilities will ultimately lead to improvements in disease detection rates and reductions in disease morbidity and mortality among all populations represented (Collins and Varmus 2015). Recent studies have identified factors, such as the option of a narrow consent model and protocol transparency, which were found to favorably influence willingness to engage in biobanking research among African American (Ewing et al. 2015; Hagiwara et al. 2014). If the scientific community improves efforts for inclusion of underrepresented populations in research, then biospecimen research may be a potential avenue through which we better understand the genetic variation of disease in diverse populations and ultimately ameliorate health disparities observed in minority populations disproportionately impacted by cancer and other diseases. The potential of biospecimens to help eliminate and address cancer disparities on a population level is contingent upon a number of factors, possibly including African American cancer survivors' (1) participation in research studies, (2) trust of the research community, (3) level of comfort with the biobanking process, and (4) clear understanding of the benefits of biospecimens in biobanking.

While researchers have made some progress in understanding reasons why African Americans are underrepresented in genetics research, some gaps in knowledge still remain. Several seminal cancer genetics studies inclusive of African Americans have evaluated the impact of participant's beliefs about cancer and knowledge of genetics on utilization of cancer genetics resources and services (Donovan and Tucker 2000;

Hall et al. 2010; Hughes et al. 1996, 1997; Singer et al. 2004). Other studies revealed that cancer genetics materials and previous research experience correlate with favorable opinions about genetics research among African Americans (Halbert et al. 2006a, b; Manswell Butty et al. 2012). Barriers include misperceptions, limited awareness of cancer genetics, and mistrust of the health system and researchers involved in clinical trials (Achter et al. 2004; Corbie-Smith et al. 1999; Halbert et al. 2009; McDonald et al. 2012a). However, these barriers do not always deter African Americans from recognizing the value in biobanking research efforts (Ewing et al. 2015; Halbert et al. 2006a, b; McDonald et al. 2012b), and/or donating biospecimens specifically for biobanking research (Adams-Campbell et al. 2016). It is possible that beliefs about genetics research, genetic contributions to disease, and knowledge of cancer health disparities may facilitate increased interest and willingness of African American cancer survivors to participate in biospecimen research aimed at reducing cancer disparities.

The purpose of this study was to evaluate the contributions of factors associated with willingness to provide biospecimens for cancer genetic research among African American cancer survivors. The hypotheses for this study proposed that African American cancer survivors' willingness to provide biospecimens for cancer genetics research would be associated with their beliefs about genetic research, knowledge of cancer genetics and disparities, and personal experience with cancer. If African American cancer survivors are (1) aware of the disproportionate impact of cancer on their population, (2) conscious of the genetic contributions to cancer, and (3) have favorable beliefs about cancer genetics research, then they may be more inclined to view biobanking as a viable means to reduce existing disparities and more willing to provide a biospecimen/participate. Furthermore, it is possible that African American cancer survivors may not be well informed that knowledge gleaned from their participation in cancer genetics biobanking research will immediately benefit their personal health and that of their communities. This concept of therapeutic misconception is a phenomenon that may ensue throughout various phases of federal initiatives—such as the PMI and *All of Us* research program—that seek to improve our understanding of genetics and disease, yet strive to engage and representative and diverse population (US Department of Health and Human 2018). Therefore, this study is paramount in clarifying variables that sway interest in participation in cancer genetics biobanking.

Methods

Study population and recruitment African American adults, 18 years of age and older, with a medical history of breast, colon, or prostate cancers were recruited for the study. Respondents completed a self-administered cancer genetics

survey in various cancer clinics at Howard University Hospital (HUH)-Cancer Center or via Survey Monkey. The survey elicited (1) personal and familial cancer history, (2) beliefs about genetic research, (3) knowledge about genetics and cancer disparities, (4) willingness to provide a biospecimen for cancer genetics research, and (5) sociodemographic information. Participants were prompted to read an informational preamble about the study prior to starting the survey. All responses were anonymized.

A convenience sample was recruited through distribution of study information and announcements to HUH community members including support groups, such as the Sisters Network, Inc., Howard University Cancer Center S.E.E.D.S. Cancer Support Group,

Men Take Ten Cancer Support Group, and numerous health care professionals. Other local and national cancer support groups disseminated information to their respective memberships. Additional participants were recruited from HUH cancer clinic waiting areas. Snowball sampling was also used as a recruitment technique. This sampling approach was used because the HUH provides medical attention to a predominantly minority, especially and African American, population. The Howard University (HU) Institutional Review Board (IRB) approved the study.

Study variables

Sociodemographics and cancer characteristics Demographic information used in this study included a continuous measure of age at survey completion and categorical measures of income, marital status, education, and health insurance. We created a single dichotomous family history variable based on a comprehensive checklist of family members with histories with breast, colon, and/or prostate cancer.

The outcome variable was captured in a single question: “If provided the opportunity, would you be willing to provide a sample of blood, saliva or tissue biopsy for cancer genetic analysis purposes?” The primary outcome variable responses used for the purpose of this study was the simple “yes” or “no” response, without regard to the type(s) of specimens.

Beliefs about genetic research Initially, seven items were taken from previously validated instruments that assessed beliefs, interests, and perceptions about genetics research and were modified for use in the survey (Hadley et al. 2003). First, all responses were assessed using a 5-point Likert scale (i.e., 1 = strongly disagree, 2 = disagree, 3 = uncertain, 4 = agree, 5 = strongly agree). Responses were collapsed and recoded into three categories (i.e., 1 = disagree, 2 = uncertain, and 3 = agree). Responses were then analyzed in a series of steps. For the purposes of this study, exploratory factor analysis with promax rotation generated a two-factor solution that explained

67.69% of the variance with three of the seven items either cross-loaded or minimally loaded onto one of the two factors selected. These three items were excluded from final analyses. The remaining four questions converged on one of two factors—importance of genetics and no benefits of genetics research. Next, summative scores based on the two factors were calculated and used in bivariate and logistic analyses.

Cancer disparities and genetics knowledge The knowledge domain initially included 14 items related to cancer genetics and disparities. Genetics items were obtained from a previously validated instrument, and the majority of the cancer disparity questions were constructed based on content and statistics provided in the 2011–2012 Cancer Facts & Figures for African Americans and Green et al. (Green and Kelly 2004; Murphy et al. 2009; National Cancer Institute 2012; Thurman et al. 2009). This information was obtained in “true,” “false,” or “do not know” response format. Correct responses resulted in a score of 1 for each item and incorrect or do not know responses received a score of 0. For the purposes of this study, an exploratory factor analysis with promax rotation model generated a three-factor solution that explained 63.48% of the variance and consisted of eight items. Six items were removed from analysis after exploratory factor analysis revealed cross-loading or minimal loading. In final analyses, the eight remaining items were assigned to one of three factors: (1) cancer risk disparities, (2) genetics and breast cancer, and (3) cancer mortality disparities. The cancer risk disparities domain contained four questions about comparative cancer risks between European Americans and African Americans. The genetics and breast cancer domain included two questions about breast cancer genetics and breast cancer (BRCA) genes, and the cancer mortality disparity factor consisted of two items on prostate and colon cancers in African Americans. Responses were summed to form a composite score/index variable for each sub-scale with values ranging from 0 to 4 for cancer risk disparities, 0–2 for the genetics and breast cancer factor, and 0–2 for the cancer mortality disparity constructs.

Statistical analyses All statistical analyses were performed with Statistical Package for Social Sciences (SPSS) version 22.0 (2012). Chi-square tests were used to identify sociodemographic and individual cancer-related factors associated with willingness to provide biospecimens for cancer genetics research. Independent samples *t* tests were used to calculate differences in cancer genetics and disparity knowledge between individuals who expressed a willingness to provide biospecimens for cancer genetics research relative to those who were unwilling. Logistic regression models were used to detect the simultaneous contribution of those variables with significant associations in bivariate models to willingness to provide biospecimens. An alpha level of $p < 0.25$ was used

as the threshold value of variable to include in the multivariate logistic model. Variables were considered statistically significantly at $p < 0.05$.

Results

Sociodemographics and willingness to provide biospecimens

A total of 200 respondents provided information for this study. The cohort was mostly female (72%), with an average age of 59.9 ± 12.1 years. Nearly 27% of the sample earned between \$20,000 and \$49,999 annually, and close to half (49.5%) of the sample was married. Additionally, slightly more than half, 51%, obtained a graduate school education. Table 1 describes sociodemographics and personal and familial cancer characteristics of the study sample by willingness to provide a biospecimen for cancer genetics research. Overall, 79% of this sample indicated a willingness to provide a biospecimen for cancer genetics research. Participants significantly differed in their willingness to provide a biospecimen by gender, income, and insurance type. Those willing to provide a biospecimen were more likely to be male ($p = 0.041$), have higher income ($p = 0.014$), and not have government insurance ($p < 0.001$).

Predictors of willingness to provide a biospecimen Table 2 illustrates participants' responses to questions of *perceived benefits of genetic research* and statements on the *importance of genetics*, and whether these questions influenced *willingness to provide a biospecimen*. The *agree* response (a combination of *strongly agree* and *agree* categories) was used as the reference group in comparison to *disagree* (combined *strongly disagree* and *disagree* categories) and *uncertain* responses. With reference to the *No Benefits of Genetic Research* domain items, those who did not perceive genetic research as a benefit to their own race/ethnicity (i.e., *agree*) were equally as willing to provide a biospecimen as those perceiving a benefit (i.e., *disagree*) and those uncertain of genetic research as a benefit. Thus, there was no significant difference between a negative regard for participating in genetic research and willingness to provide a biospecimen. However, significant associations existed between the other *No Benefits of Genetic Research* item and willingness to provide a biospecimen, as well as both *Importance of Genetics* domain items and willingness to provide a biospecimen. In the *No Benefits of Genetic Research* domain item, those who would not participate in genetic research to help future generations (those who *agreed*) were less willing to provide a biospecimen compared to those uncertain of their participation in genetic research ($OR = 0.251$, $p = 0.026$). This significance persisted after adjusting for sociodemographic factors ($OR = 0.081$, $p = 0.035$). In terms of the *Importance of Genetics* domain items, those uncertain of the importance of knowing the genetic causes of cancer were less likely to provide a biospecimen than those who

agreed about the importance in knowing about genetic causes of cancer ($OR = 0.154$, $OR = 0.081$, $p < 0.001$). Additionally, those who either disagreed ($OR = 0.129$, $p = 0.005$) or were uncertain ($OR = 0.107$, $p < 0.001$) about the importance of participating in genetic research, when given the opportunity, were less willing to provide a biospecimen compared to those who agreed with the statement. After adjusting for sociodemographics, those uncertain of the statement remained significantly less willing to provide a biospecimen.

Genetics and cancer disparity knowledge and willingness to provide biospecimen

As shown in Table 3, knowledge of (1) cancer risk disparity, (2) cancer mortality disparities, and (3) genetics and breast cancer was illustrated by the rates of correct responses to each of the items in these three knowledge areas. Rates of correct responses to items on cancer risk disparity ranged from 37.5 to 56%. These scores were the highest of all three knowledge areas indicating that this was the area with which most participants were familiar. The genetics and breast cancer items were not as well known. Rates for genetics and breast cancer knowledge ranged from 19 to 26%. The cancer mortality disparity knowledge rates were even lower—12.5 to 21%. These lower ratings suggest that participants did not know as much about the leading causes of cancer death as they did about the racial disparities in cancer or BRCA genes. However, it is important to note that the rates of correct responses did not differ by willingness to provide biospecimen or indicate a difference in knowledge between those that would willingly provide biospecimen and those that would not. Hence, knowledge of genetics and cancer disparities did not influence willingness to provide biospecimen.

Discussion

This study is one of the few, to the authors' knowledge, to examine simultaneously the influence of knowledge about cancer genetics and cancer health disparities as well as beliefs about genetics research on African American cancer survivors' willingness to provide biospecimens for cancer genetics research. Despite previous reports of limited involvement of African Americans in genetics research (Ford et al. 2006; Moorman et al. 2004), more than three-quarters of the sample in this study expressed a willingness to provide biospecimens. This finding is consistent with previous studies that reported that an overwhelming percentage of African Americans are willing to engage in biospecimen and cancer genetics research, and that a lack of participation is not due to a lack of interest (Buseh et al. 2013; Hagiwara et al. 2014; McDonald et al. 2012b, 2014). Given this finding, subsequent studies should be conducted in a more representative sample of African Americans and may suggest the need for educational interventions that will

Table 1 Sociodemographics

	Overall	Willingness to provide a biospecimen for cancer genetic analysis		<i>p</i>
		Yes	No	
Sociodemographics				
Gender (<i>n</i> , %)				0.041*
Male	54 (27%)	48 (89%)	6 (11%)	
Female	144 (73%)	109 (76%)	35 (24%)	
Age	(mean ± SD)	59.74 ± 11.39	60.63 ± 14.62	0.717
Income (<i>n</i> , %)				0.014*
< \$20,000	43 (26%)	30 (70%)	13 (30%)	
\$20,000–\$49,999	53 (32%)	41 (77%)	12 (23%)	
> \$50,000	68 (42%)	62 (91%)	6 (9%)	
Marital status (<i>n</i> , %)				0.756
Single/never married	100 (50%)	78 (78%)	22 (22%)	
Married	99 (50%)	79 (80%)	20 (20%)	
Education (<i>n</i> , %)				0.241
High school	77 (39%)	56 (73%)	21 (27%)	
Post high school	20 (10%)	17 (85%)	3 (15%)	
Graduate school	101 (51%)	83 (82%)	18 (18%)	
Insurance (<i>n</i> , %)				< 0.001**
No government	83 (42%)	53 (64%)	30 (36%)	
Government	114 (58%)	102 (90%)	12 (11%)	
Personal/familial experience				
Cancer type (<i>n</i> , %)				0.403
Breast	130 (65.0%)	99 (76%)	31 (24%)	
Colon	26 (13.0%)	22 (85%)	4 (15%)	
Prostate	44 (22.0%)	37 (84%)	7 (16%)	
Family history of cancer (<i>n</i> , %)				0.53
Yes	115 (59%)	93 (81%)	22 (19%)	
No	81 (41%)	61 (75%)	20 (25%)	
Family history of cancer in first-degree relative (<i>n</i> , %)				0.345
Yes	84 (72%)	70 (83%)	14 (17%)	
No	33 (28%)	25 (76%)	8 (24%)	
Cancer screening history (<i>n</i> , %)				0.272
Yes	133 (66)	108 (81%)	25 (19%)	
No	66 (33%)	49 (74%)	17 (26%)	
Age of onset (<i>n</i> , %)				0.484
< 50 years	61 (30%)	46 (75%)	15 (25%)	
50+ years	134 (67%)	107 (80%)	27 (20%)	
Year diagnosed (<i>n</i> , %)				0.874
2007–2011	89 (45%)	71 (80%)	18 (20%)	
1981–2006	104 (52%)	82 (79%)	22 (21%)	
Currently receiving treatment (<i>n</i> , %)				0.197
No	111(56%)	84 (76%)	27 (24%)	
Yes	89 (45%)	74 (83%)	15 (17%)	

* = $p < 0.05$, ** = $p < 0.001$

capitalize on converting high intention levels, in African American cancer survivors, into actual donation of

biospecimens and understanding the importance of access to more representative samples for cancer genetics research.

Table 2 Beliefs and importance of genetics

Beliefs			Unadjusted			Adjusted		
			OR	95% CI	<i>p</i>	OR	95% CI	<i>p</i>
No benefits of genetic research								
Genetic research will NOT benefit people of my racial and ethnic background	Disagree		1.763	(0.57, 5.41)	0.322	1.690	(0.38, 7.49)	0.490
	Uncertain		1.006	(0.29, 138)	0.992	1.134	(0.22, 5.87)	0.881
I would NOT participate in genetic research to help future generations	Disagree		1.762	(0.52, 5.95)	0.362	1.694	(0.38, 7.56)	0.490
	Uncertain		0.251	(0.07, 0.85)	0.026*	0.183	(0.04, 0.88)	0.035*
Importance of genetics								
It is important for people to know about genetic causes of cancers	Disagree		0.360	(0.08, 1.53)	0.167	0.200	(0.02, 1.84)	0.155
	Uncertain		0.154	(0.06, 0.37)	< 0.001**	0.081	(0.02, 0.30)	< 0.001**
It is important to participate in genetic research when given the opportunity to do so	Disagree		0.129	(0.03, 0.54)	0.005*	0.163	(0.03, 1.00)	0.050
	Uncertain		0.107	(0.04, 0.23)	< 0.001**	0.066	(0.02, 0.20)	< 0.001**

p* < 0.05, *p* < 0.001

This study adds to the growing body of knowledge about biospecimen and cancer genetics research inclusive of African American cancer survivors by providing evidence of gender differences in willingness to participate. Results from this study indicate that African American male cancer survivors were more likely to express a willingness to provide biospecimens for cancer genetics research than African American female cancer survivors. This is a similar comparison to a finding in a previous study that revealed females were less likely to consent to biospecimen storage for future research use (McQuillan et al. 2003; Murthy et al. 2004). Although there has been recent success in recruiting African American women into various biobanking research efforts through the AMBER Consortium (Palmer et al. 2014), a similar approach for men may yield an increase in the representation of African American men in cancer genetics research involving biospecimens.

Research has suggested that the environment in which recruitment and the study is conducted may have an impact on males' willingness to participate in biospecimen research (Drake et al. 2017). Given the fact that this study was conducted within the Howard University network, and heavy recruitment took place within the cancer center, it is possible this may have influenced African American males' willingness to engage in biospecimen and cancer genetics research more than women. Men may have understood the study to have physician endorsement and been at greater ease with the recruitment and advertising being conducted in familiar medical spaces.

It is also possible that misperceptions about the biospecimen and cancer genetics research process and its impact on treatment may have influenced males' responses. A finding from a qualitative work of African Americans in the South revealed differences in their misunderstanding and misperceptions of clinical trials compared to those of female participants' understanding.

Table 3 Knowledge about disparities and cancer genetics

	Willingness to provide biospecimen			χ^2	p
	No	Yes	Total		
Cancer risk disparity (% correct)					
African Americans have a greater genetic risk for colon cancer than Whites	7.5%	30.0%	37.5%	0.072	0.789
African American women have a greater risk for breast cancer than Whites	8.5%	32.5%	41.0%	0.006	0.938
African American women are more likely to die from breast cancer than white women	10.0%	46.0%	56.0%	1.516	0.218
African American men have a greater risk for prostate cancer than Whites	8.0%	42.0%	50.0%	3.014	0.083
Cancer mortality disparity (% correct)					
Prostate cancer is the leading cause of cancer death in African American men	4.0%	8.5%	12.5%	2.084	0.149
Colon cancer is the leading cause of cancer death in African Americans	3.5%	17.5%	21.0%	0.602	0.438
Genetics and breast cancer (% correct)					
A woman who does not have altered BRCA1 or 2 genes can still get breast or cancer	3.5%	22.5%	26.0%	2.407	0.121
All women with altered BRCA genes will get breast cancer	2.5%	16.5%	19.0%	1.739	0.187

Men believed clinical trials to be similar to their doctor adjusting their dosage or medication to determine the best form of treatment for prostate cancer (Owens et al. 2013). Since participants in this study reported a personal experience with cancer, it is possible that they may have overinterpreted biospecimen research with treatment options. The results of this research suggest that biospecimen donation for cancer genetics research is another medical research domain in which males are more amenable to participate. However, it is recommended that future studies further unpack reasons that drive this difference in willingness to engage as well as assess understanding of the biospecimen research process.

Overall, African American cancer survivors who expressed a positive regard for research and the desire to participate in research to help future generations were associated with higher levels of willingness to provide biospecimens. Findings from this study revealed that participants who acknowledged the importance of knowledge about genetic causes of cancer and participating in genetics research, as well as those who disagreed that they would not participate in genetics research to help future generation, were more willing to provide biospecimens. These findings are consistent with previous studies that have highlighted the positive association of favorable opinions on engagement in genetics-related health behaviors and interest in participating in biospecimen research (Dang et al. 2014; Igbe and Adebamowo 2012; Luque et al. 2012). These findings also support the fact that positive beliefs of the importance and benefits of genetics research among African Americans influence biobanking intentions and behaviors (Dang et al. 2014; Ewing et al. 2015; Streicher et al. 2011). Subsequent studies should be conducted to evaluate the impact and variation of beliefs on actual biospecimen donation among African American cancer survivors. Additionally, qualitative research efforts could provide contextual information for reasons why African American cancer survivors have positive beliefs about cancer genetics biospecimen research and a willingness to participate, but are underrepresented in current biospecimen studies.

It appears that uncertainty in one's beliefs and acknowledgement of the importance of genetics influenced participants' willingness to provide a biospecimen. Specifically, individuals who were uncertain in their belief about (1) participation in cancer genetic research to benefit future generation, (2) knowledge of the genetic causes of cancer, and (3) the importance of participation in genetic research among African Americans were significantly less likely to indicate willingness to provide biospecimens than those individuals who agreed with these statements. This may suggest that uncertainty among African Americans about the benefits of genetics research is correlated with historical and negative perceptions of African American involvement in medical

research (Gamble 1993; Skloot and Turpin 2010). This level of uncertainty may be a proxy for the phenomenon of mistrust and skepticism of the medical community that exist within various minority populations. Simultaneously, this observation may also highlight the need for interventions to address uncertainty about research within the African American community.

This study is unique in that it sought to understand African Americans' understanding of cancer health disparities and the influence of this knowledge on behavioral intent to provide biospecimens. Although findings were not statistically significant in this population, findings revealed limited knowledge of cancer health disparities and cancer genetics among cancer survivor participants. This suggests that African Americans may not understand the full extent of cancer morbidity and mortality rates. Respondents reporting low levels of knowledge were similar to those in previous studies that revealed genetic misunderstanding among minorities (Bussey-Jones et al. 2009; Hughes et al. 1997; Thurman et al. 2009; Cancer Disparities - National Cancer Institute at the National Institutes of Health 2018). Similarly, another study highlighted low levels of health disparity awareness even among upper-level pharmacy students (Okoro et al. 2012). Other works reveal that even genetics providers vary in their knowledge of changes in the field of cancer genetics resulting from policy changes and research advancements (Cragun et al. 2016). These findings suggest that lack of genetics knowledge and variability in understanding is not unique to populations disproportionately impacted by disease. Additionally, lack of genetic knowledge, among participants as well as providers, may contribute to the underrepresentation of African Americans in cancer genetics research. This knowledge deficit warrants further attention and intervention efforts towards patients and providers. Targeting health care providers with continuing educational efforts may also help to address provider bias leading to perceptions that minority patients are unlikely to take part in research in order to improve recruitment and inclusion efforts. Increasing awareness among health care providers may potentially influence health behaviors and contribute to enhancements in population health outcomes and health service access and utilization.

Limitations A major limitation of this study is that willingness to provide biospecimens may differ in individuals who have been diagnosed with cancer compared to individuals without a personal cancer experience. It is possible that individuals with cancer may be more inclined to participate in cancer genetics research relative to those without a personal encounter with the disease or because they may be more acquainted with cancer health care providers and researchers. It is also possible that individuals may assume that research results will guide the treatment and management of their diagnosis (Halverson and Ross 2012; Nobile et al. 2013). Since this study targeted a convenience sample of cancer survivors at Howard

University, where a significant percentage of providers and patients are racially and ethnically diverse, issues of medical and research mistrust may not be as profound as observed at other institutions where racial concordance between the patient-provider population are similar. Additionally, it is possible that the association with Howard University could have influenced participants' willingness to provide biospecimens. Unfortunately, we did not capture the percentage of participants recruited from the Howard University network compared to those who accessed the survey independently or through membership in a national and/or local cancer support groups. It may also be possible that social desirability bias, or the participants' provision of responses that they assumed the investigators deemed acceptable, may have also influenced participants' responses and impacted a slightly higher response of intent to provide a biospecimen (Krumpal 2013; Johnson and Fendrich 2002). Additionally, compared to national statistics of African Americans, the educational level of African Americans in this sample was higher. It is possible that men and women with higher levels of education in this study were more inclined to participate in research. Therefore, inclusion of a larger and more representative population of African Americans may yield different results. Finally, since this study investigated hypothetical biospecimen research, the results, as it relates to willingness to provide biospecimens for cancer genetics research, could be an overestimation. Future studies could involve a mixed-method approach in cancer genetic studies that involve the option of submitting a specimen for biobanking along with collecting qualitative information.

Conclusions and implications for future research This study highlights pertinent issues in regard to African American willingness to participate in cancer genetics research. The study identified that men and those with favorable beliefs about genetic research are more likely to express an interest in providing biospecimens for cancer genetics research. While we anticipated that one's familial and personal experience with cancer as well as their knowledge of genetic contributions to cancer and health disparities would impact willingness to provide a biospecimen among African American cancer survivors, these factors did not turn out to have a significant association. The study findings should inform research recruitment efforts used by health care professionals to engage African Americans with cancer diagnoses. Identifying avenues that will translate the willingness of African American cancer survivors' willingness to participate in biospecimen research into actual participation will be critical in efforts to reduce cancer health disparities. Interventions that focus on the link between willingness and actual participation may yield more informative results, since willingness is high, but participation rates still remain relatively lower.

Compliance with ethical standards

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

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was not required for this study as identifying information was not obtained. An informational preamble was provided and read by all individual participants included in the study. The Howard University Institutional Review Board approved of this study.

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