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Cancer Research Participation Beliefs and Behaviors of a Southern Black Population: A Quantitative Analysis of the Role of Structural Factors in Cancer Research Participation

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Abstract

Increasing the participation of Blacks in cancer research is a vital component of a strategy to reduce racial inequities in cancer burden. Community-based participatory research (CBPR) is especially well-suited to advancing our knowledge of factors that influence research participation to ultimately address cancer-related health inequities. A paucity of literature focuses on the role of structural factors limiting participation in cancer research. As part of a larger CBPR project, we used survey data from a statewide cancer needs assessment of a Black faith community to examine the influence of structural factors on attitudes toward research and the contributions of both structural and attitudinal factors on whether individuals participate in research. Regression analyses and non-parametric statistics were conducted on data from 727 adult survey respondents. Structural factors, such as having health insurance coverage, experiencing discrimination during health care encounters, and locale, predicted belief in the benefits, but not the risks, of research participation. Positive attitudes towards research predicted intention to participate in cancer research. Significant differences in structural and attitudinal factors were found between cancer research participants and non-participants; however, directionality is confounded by the cross-sectional survey design and causality cannot be determined. This study points to complex interplay of structural and attitudinal factors on research participation as well as need for additional quantitative examinations of the various types of factors that influence research participation in Black communities.

Introduction

In the United States (US), Black communities continue to experience higher rates and slower declines in cancer incidence and mortality as compared to other racial and ethnic communities [1]. Health inequities are systematic differences in health outcomes of different groups, which are a result of unequal access to resources and thus are avoidable and, by inference, unfair and unjust. [2] The causes of racial and ethnic inequities in cancer burden are multifaceted in nature and encompass genetic, behavioral, and environmental factors as well as myriad other factors within the category of social determinants of health. In order to understand the mechanisms through which social determinants of health maintain, and in some cases, increase racial and ethnic inequities in cancer burden, cancer research must be inclusive of and conducted with racially and ethnically diverse populations. Blacks continue to be underrepresented in cancer research, comprising only 11.6% and 5.5% of participants in cancer prevention and treatment trials, respectively [2]. Yet, Blacks represent 13% of the US population and are overrepresented in groups of individuals at risk for and suffering from all major types of cancer [1]. Black's underrepresentation in cancer research trials impedes both the advancement of scientific knowledge regarding the mechanisms

responsible for racial and ethnic inequities in cancer burden and developing strategies to reduce these inequities. Failing to engage members of the Black community in cancer research inhibits the creation of new knowledge concerning racial and ethnic inequities in cancer burden and limits generalizability of findings across the cancer control continuum, both of which tend to perpetuate inequities[3].

Efforts to reduce cancer inequities must include strategies to increase the participation of high-risk groups, including Black communities and other communities of color, in cancer research [4]. Community-based participatory research (CBPR) is a research paradigm that seeks to actively involve community members as partners in the conceptualization, development, implementation, and utilization of health research on topics of importance to these communities [4, 5]. CBPR has the potential to access community knowledge and resources in order to produce scientific knowledge and strategies that are effective in real-world settings [4, 5]. The application of CBPR principles and methods has been effective in engaging Black communities in the development of cancer research agendas to address racial inequities in cancer burden [4]. It is for these reasons that CBPR may be the research paradigm best suited for examining causes and contributors of racial inequities in cancer research participation. Inequities in cancer research participation are complex; a result of an interaction between individual, community, and institutional factors. Yet, the vast majority of literature on this topic focuses on the role of individual-level factors, with little attention to external influences and the interaction of different forms of influence. Previous literature examining potential reasons for Blacks' low rates of participation in cancer research has focused extensively on individual factors, such as attitudes towards research participation and researchers. Many of these studies on which these inferences are based are qualitative and describe how experiences of discrimination during medical encounters and knowledge of historical research abuses have shaped Black's views towards research [6-9]. The influence of structural factors, which encompass system-level influences on health such as educational, health care, and economic systems, are inadequately addressed despite their influence on individuals' attitudes towards research participation[8].

Blacks are more likely to live in communities with fewer educational opportunities, thus limiting opportunities to learn about health research or to participate in studies. Additionally, lack of educational opportunities can lead to lower levels of health literacy, another barrier to meaningful participation in health research [9-12]. Access to quality health care is a structural barrier to participation in health research, as recruitment for many types of cancer research occurs in health care settings. Individuals without access to health care have fewer opportunities to be approached about cancer-related health research [12]. Even those with health care access face barriers to participation as a result of racial discrimination in health care settings [13]. For many individuals, the health care and research fields are indistinguishable, and perceptions of health care directly influence perceptions of research and vice versa. Locale also plays a role in shaping research-related beliefs. Blacks living in urban areas are more likely to be exposed to health research than their rural counterparts [12]. However, Blacks residing in rural areas are less likely to experience discrimination in health care settings than urban residents, which may positively influence rural residents' views of health research [14]. Together these features of the social environment, education

levels, locale, and health care access represent proxy measures of structural factors that have the potential to influence Black's attitudes towards health research.

Structural factors impact the availability of opportunities to participate in health research and have also been linked directly to Black adults' participation in health research. Blacks have been shown to be at least as likely as Whites to enroll in cancer research studies even though they are less likely to be invited to participate in such studies [15, 16]. Together, these findings indicate structural factors influence research participation behavior indirectly through attitudes towards research and directly through opportunities to participate in research; however, few studies have used quantitative methods to examine the role of structural and attitudinal factors in relationship to participation in cancer research.

In this study, we sought to explore the relationship between attitudinal and structural factors related to participation in cancer research in a statewide sample of Black Americans. Specifically, we examined two hypotheses: 1) Structural factors are predictive of attitudes towards participation in cancer research and 2) Structural and attitudinal factors, in combination, are predictive of participation in cancer research among a sample of Blacks in the southeastern US. Understanding the relative importance of attitudinal and structural factors and their contribution to research participation is an important step towards the development of strategies to increase Blacks' participation in cancer research.

Methods

The National Cancer Institute's Center to Reduce Cancer Health Disparities funds 23 Community Networks Program Centers that conduct CBPR and community outreach to address racial inequities in cancer burden [4]. The South Carolina Cancer Disparities Community Network-II (SCCDCN-II) is a Community Networks Program Center focusing on inequities in cancer burden among Blacks in South Carolina in partnership with the faith community. The SCCDCN-II consists of researchers from the University of South Carolina's Statewide Cancer Prevention and Control Program and several community partner organizations, including members of the State Baptist Young Woman's Auxiliary Health Ministry of the Woman's Baptist Education and Missionary Convention of South Carolina (State Baptist YWA) who collaborate to use CBPR to conduct research on, and implement educational initiatives to, address inequities in cancer burden in Black faith communities across the state.

The data used in this analysis were collected as part of an ongoing cancer needs assessment survey. The survey was administered to a convenience sample of 727 adult (18 years and older), male and female members from 28 Black Baptist churches in South Carolina. The purpose of the needs assessment was to collect information about cancer prevention and control behaviors and to determine appropriateness of current and future educational initiatives. The survey included items assessing demographics, health literacy, discrimination, and attitudes towards and participation in cancer research. Regional coordinators from the State Baptist YWA administered the survey from October 2012 to August 2013. The coordinators collected completed surveys and returned them to the

University for data management, entry, and analysis. This study was approved by the University of South Carolina Institutional Review Board as exempt research.

Measures

Demographics—Demographic variables included sex, age, and employment. Sex was reported as male or female. Two items were used to collect age. One item recorded date of birth and an additional item asked respondents to select their age from a list of categories (18-39 years old, 40-49 years old, 50-59 years old, 60-69 years old, 70 years or older). Age was calculated by subtracting the date of survey administration from the respondent's date of birth. Three age ranges were created: 18-39 years old, 40-64 years old, and 65 years or older. If the date of birth was not supplied by the respondent but an age category was selected; the respondent was then included in the appropriate age range. For employment, respondents could indicate multiple responses, including employed for wages, self-employed, out of work, student, homemaker, retired, or unable to work. Respondents were classified as employed if they selected employed for wages or self-employed; all other responses were categorized as not employed.

Structural Factors

Education—Respondents were asked to select their highest level of education completed from six categories; which were further collapsed to three categories: less than high school, high school graduate or equivalent (i.e. GED), and college graduate or higher.

Health Insurance Status—Health insurance options (e.g., employer provided health insurance, private health insurance, Medicaid, Medicare) were listed and respondents were asked to select all applicable options. Respondents selecting at least one health insurance option were coded as having health insurance coverage. For health insurance type, those selecting Medicaid, Medicare, or military insurance were coded as having public health insurance. Everyone else was categorized as having private health insurance.

Locale—Respondents' zip codes were mapped to counties in order to determine whether respondents resided in an urban or rural locale as described by the 2006 National Center for Health Statistics' Urban-Rural Classification Schema for Counties [17]. Counties are given codes from 1 to 6 with 1 representing a large metropolitan statistical area and 6 representing non-core areas. Counties with codes 1-4 were designated as urban, and all remaining counties were designated as rural for this analysis.

Health Literacy—The Single Item Literacy Screener (SILS) was adapted to assess health literacy [18]. Respondents were asked, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?". Response options included 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = Often, 5 = Always. In accordance with the SILS authors' recommended cut point of 2 indicating difficulties in reading printed health material, respondents were grouped into two categories, "low health literacy" (responses 3-5) and "high health literacy" (responses 1-2) [18].

Discrimination—One item assessing discrimination was taken from the Experiences of Discrimination measure [19]. Respondents were asked if they had “Ever experienced discrimination, been prevented from doing something, or been hassled or made to feel inferior in getting medical care because of your race, ethnicity or color?”. Responses to these items included “Yes”, “No”, and “Don't Know”; the response “Don't Know” was recoded as “No” for analytic purposes.

Cancer Research Participation

Attitudes Toward Cancer Research Participation—Respondents were asked to rate the following statements “Participation in clinical research benefits society” and “Participation in clinical research is risky” using a 5-point Likert scale ranging from strongly agree to strongly disagree. Responses were coded so that numerical ratings increased as participants indicated more positive attitudes towards research participation.

Cancer Research Participation Intentions and Behaviors—Participation in cancer research items were adapted from previous work of the authors [20, 21]. Survey respondents were asked one item assessing behavioral intention: “Have you ever been invited to participate in a cancer clinical trial?” and two items assessing research participation behaviors: “If they had ever been invited to participate in a cancer clinical trial?” and “Have you ever participated in a cancer clinical trial?”. Responses to these items included “Yes”, “No”, and “Don't Know”; “Don't Know” responses were recoded as “No” for analytic purposes.

Data Analysis

Survey forms were scanned using Teleform® software and managed in Microsoft Excel. All analyses were conducted using SAS® 9.4 [22]. Demographic characteristics were calculated and reported in Table 1. Spearman rank and Pearson's product moment correlations were computed to examine relationships between demographic characteristics, attitudes toward research participation, and research participation behaviors. Proc GLM was used to construct OLS regression models to determine the influence of demographic and structural factors (education, health insurance coverage, health literacy, discrimination, and locale) on research related attitudes. Logistic regression models were fit to examine the combined influence of demographic, structural and attitudinal factors on cancer research participation behaviors, such as receiving an invitation to participate in a study or participating in a study. After case-wise deletion of respondents with missing data, the resulting number of respondents with research invitations or who were research participants was insufficient to allow the logistic regression models to converge. Fisher exact tests were performed to determine if there were any significant differences between participants and non-participants in cancer research.

Results

Descriptive statistics for the sample are displayed in Table 1. Of the 727 respondents surveyed, over half were female (60.0%) and between the ages of 40-64 years (54.3%). The majority of the sample had at least a high school education (90.9%) and had some form of

health insurance coverage (90.4%). Of those with health insurance coverage, nearly two-thirds had public health insurance (63.8%). The sample was relatively evenly split between those residing in urban areas and rural areas (55% and 45%, respectively). Two-thirds of respondents (67.4%) indicated that they agreed or strongly agreed that participation in clinical research benefits society. Almost half of the sample (45.1%) was unsure about the riskiness of participation in clinical research and about half (51.5%) had no intention of participating in cancer research. Only 9.4% of respondents indicated an intention to participate in cancer research; 6.0% had ever been invited to participate in cancer research; and 3.7% of respondents had participated in cancer research.

Bivariate associations revealed positive associations between the belief in the benefits of clinical research and sex, with females being slightly more likely to express agreement ($r=0.08$, $p=0.03$), as well as education, with more educated respondents being more likely to agree with the statement ($r=0.14$, $p<0.0002$). Intention to participate in cancer research was positively correlated with agreement with the benefits of clinical research ($r=0.21$, $p<0.0001$). Additionally, there was a negative correlation between the benefits of clinical research participation and belief in the riskiness of participation ($r=-0.18$, $p<0.0001$).

The OLS model developed for predicting beliefs about the benefits of clinical research was statistically significant, but the effect size was very small (Cohen's $f=0.004$) [23]. The mean values for each predictor are displayed in Table 2. Experiencing discrimination while accessing health care (4.05 vs 3.80, $p=0.03$) and possessing health insurance coverage (3.84 vs. 2.50, $p=0.01$) were significant predictors of endorsing the benefits of research participation. Respondents living in an urban locale were also more likely to express agreement with the benefits of research participation (3.89 vs. 3.79, $p=0.05$). The model predicting beliefs about the riskiness of research participation was not significant ($p=1.0$) while the model predicting intention to participate in research was ($-2 \log L = 243.05$, $\chi^2 = 25.82$, $p=0.02$). Agreement with the benefits of research participation was the only significant predictor of intention to participate in research (OR = 3.57, 95% CI = 2.03 – 6.31).

We conducted Fisher Exact Tests to examine potential differences between: 1) Those invited and those not invited to participate in cancer research and 2) Research participants and non-participants. No significant differences were found between respondents who did and did not receive an invitation to participate in cancer research, but there were important differences between those with and without a past history of cancer research participation (see Table 3). Respondents with and without a history of research participation differed in terms of age with a higher percentage of older adults participating in research (e.g., 36.0% of research participants were in the 65 to 94 year-old age group compared to 22.5% of non-participants). A larger proportion of participants expressed agreement with the benefits of research participation (e.g., 91.3% of participants vs. 66.4% of non-participants). Additionally, more individuals with a history of research participation displayed intentions to participate in future research studies than those who had never participated in research (77.3% vs. 7.2%). A higher percentage of research participants compared with non-participants had low levels of health literacy (31.6% vs. 14.8%) but this difference fell short of statistical significance ($p=0.06$).

Discussion

In this study, very few (3.7%) respondents had ever participated in cancer research and only 6.0% had ever been invited to participate. However, while the overall proportion of those who were invited to participate in cancer research was low, among those invited, the majority participated in cancer research (62.0%; 26/42). In addition, intention to participate in the future was 9.4%, which is higher than those who had ever been invited to participate in research (6.0%). There is much room for improvement in terms of extending invitations to and enrolling Blacks in cancer research among this study sample and nationally [15, 24]. Just under half (46%) of respondents were uncertain about the risks of clinical research participation. Uncertainty about the risks of clinical research may have influenced decisions to participate but it is unclear how this belief influenced research participation behaviors. In this sample, the association between belief in the risks of clinical research participation and the benefits was only weakly negative ($r=0.18$, $p<0.0001$) an indication that many respondents held both positive and negative attitudes towards research participation.

The first hypothesis was that structural factors predict attitudes towards participation in cancer research. Structural factors examined were education level, health insurance status, locale, health literacy, and discrimination. Health insurance coverage, experiencing discrimination during health care encounter and locale predicted endorsement of the benefits of research participation but none of the structural factors examined predicted beliefs about the risks of research participation. We believe that individuals with health insurance and who live in urban areas are more likely to have increased contact with the health care system and thus have more opportunities to experience health care discrimination [9]. Conversely, this increased contact with the health care system leads to more exposure to research studies and thus results in more positive attitudes towards research participation [12]. Agreement with the benefits of research participation predicted the intention to participate in research. These results point to the complexity of influences on attitudes towards research, wherein structural factors influence certain attitudes (benefits of research) and not others (risks of research participation).

The second hypothesis was that the combination of structural and attitudinal factors is predictive of participation in cancer research. We were unable to determine if structural and attitudinal factors in combination predicted receiving an invitation to participate in cancer research, and actual participation. There were significant differences regarding structural and attitudinal factors between those who had participated previously in cancer research and those who had not participated. A higher proportion of research participations were in the older age ranges (40+ years), believed in the benefits of research participation and intended to participate in cancer research as compared to non-participants. Unfortunately, due to the cross-sectional nature of this study, the temporal direction of these observations is unclear.

Structural factors (e.g., transportation, childcare, life and environmental stressors, health care costs, access to care) have been discussed in previous literature on racial and ethnic inequities in research participation but they have not been identified as key to increasing participation [9, 24]. In this study, we sought to examine the role of structural factors and hypothesized that structural factors would be predictive of attitudes toward cancer research

participation. Our results showed a connection between structural factors and positive attitudes (benefits) towards cancer research but not the negative attitudes (risks). These findings indicate that a focus on structural barriers to research participation may increase research participation in Black communities directly through increased opportunities to be involved in studies and indirectly through promoting positive attitudes towards research.

A strength of this study was the relationship with the Black faith community and positive history of productive research collaborations that precipitated and allowed for the administration of the assessment survey to a statewide population not directly involved with a specific research study. This study allowed for the examination of factors external to the individual in order to examine research participation among Blacks. The sample consisted of fairly equal numbers of males and females. Survey respondents had high levels of education overall and high levels of health insurance coverage, which may have limited our ability to detect differences in outcomes as they relate to education levels and health insurance coverage. Additional limitations of this work include the use of a convenience sample and the reliance on self-reported data to evaluate invitation to participate, actual participation, and intention to participate in cancer research.

This study was nested in a larger needs assessment, and examination of participation in cancer research was not the main focus. This may have limited our ability to collect more detailed data regarding structural factors, as those examined were measured using individual level measures as proxies, e.g., education and health care access. Additionally, respondents' knowledge of research terminology and language used to describe research participation may have resulted in misclassification of survey responses. [25] Despite these limitations, this study contributes to the literature on this topic by exploring the ways in which structures and attitudes are related to each other and influence research participation behaviors. The findings presented add to the small amount of quantitative literature describing the contributors to racial and ethnic inequities in cancer research participation.

In conclusion, examining the role of structural and attitudinal factors in predicting cancer research participation in Black communities is critical to addressing racial inequities in cancer burden. Improved understanding can inform culturally appropriate interventions designed to prevent and control cancer, thus reducing the burden of cancer. Ensuring that approaches for prevention, control, as well as treatment are relevant across population groups demands diversity among cancer research participants. Study results demonstrated associations between structural and attitudinal factors and cancer research participation in terms of intention to participate and actual participation. Additional research is needed to understand further how these different factors work together to facilitate or inhibit research participation behaviors in Black communities and other communities of color. More research assessing the attitudes of individuals prior to and after participation in cancer research studies can provide valuable information as to the source of observed differences between research participants and non-participants. The relationships between structural and attitudinal factors will illuminate how Blacks are exposed to research studies and how they make decisions about participation. Further, CBPR efforts with Black communities may be ideal settings in which to address factors related to participation in cancer research.

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Table 1

Sociodemographic Characteristics, Research Related Beliefs and Behaviors of Survey Respondents n =727

Variable	Frequencies (f)	Percentage (%)
Gender		
Female	440	60.5
Age Range (Years)		
18-39	153	22.3
40-64	372	54.3
65-94	160	23.4
Educational Levels		
Less than HS	63	9.0
HS or GED	456	65.2
College Graduate or Higher	180	25.8
Health Literacy		
High	465	84.1
Employed		
Yes	369	53.2
Health Insurance Coverage		
Yes	620	90.4
Health Insurance Type		
Public	391	63.8
Locale		
Urban	359	55.3
Experienced discrimination while receiving healthcare		
Yes	78	12.1
Belief that research benefits society		
Strongly Agree	170	24.5
Agree	298	42.9
Neutral	186	26.8
Disagree	22	3.2
Strongly Disagree	18	2.6
Belief that participation in research is risky		
Strongly Agree	46	6.7
Agree	164	23.8
Neutral	310	45.1
Disagree	139	20.2
Strongly Disagree	29	4.2
Do you plan on participating in clinical trials in the future?		
Yes	65	9.4
No	358	51.5
Don't Know	272	39.1
Have you ever been invited to participate in a cancer clinical trial?		

Variable	Frequencies (f)	Percentage (%)
Yes	42	6.0
No	652	92.5
Don't Know	11	1.6
Have you ever participated in a cancer clinical trial?		
Yes	26	3.7
No	660	94.6
Don't Know	12	1.7

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Table 2

OLS and Logistic Regression Models Predicting the Belief in in the Benefits of Research Participation, the Risks of Research Participation and Intentions to Participate in Research Among Survey Respondents n =727

Predictors	Benefits of Research Participation	Risks of Research Participation	Intention to Participate in Research
	Mean (Std) ^a	Mean (Std) ^b	OR (CI) ^c
Gender			
Male	3.74 (0.93)	2.93 (0.89)	Ref
Female	3.88 (0.87)	2.91 (0.93)	0.79 (0.37 – 1.69)
Age			
18-39 years old	3.89 (0.82)	2.88 (0.87)	Ref
40-64 years old	3.89 (0.92)	2.90 (0.96)	0.97 (0.39 – 2.43)
65-94 years old	3.65 (0.95)	2.98 (0.83)	0.38 (0.09 – 1.62)
Employment			
Not Employed	3.76 (0.90)	2.95 (0.87)	Ref
Employed	3.88 (0.91)	2.89 (0.94)	0.83 (0.34 – 2.01)
Locale			
Urban	3.89 (0.89)	2.89 (0.91)	Ref
Rural	3.79 (0.92)	2.95 (0.91)	1.06 (0.50 – 2.26)
Education			
Less than High School	3.50 (1.10)	3.04 (1.02)	Ref
High School Graduate	3.81 (0.89)	2.90 (0.92)	2.37 (0.27 – 20.64)
College Graduate or Higher	3.94 (0.90)	2.91 (0.88)	1.03 (0.10 – 10.36)
Health Literacy			
High	3.82 (0.93)	2.91 (0.91)	Ref
Low	3.87 (0.77)	2.92 (0.92)	1.08 (0.37 – 3.17)
Discrimination			
No discrimination	3.80 (0.92) *	2.93 (0.91)	Ref
Discrimination while receiving medical care	4.05 (0.77) *	2.83 (0.91)	2.27 (0.82 – 6.27)
Health Insurance Coverage?			
No	2.50 (0.71) *	2.50 (0.71)	Ref
Yes	3.84 (0.91) *	2.92 (0.91)	>999.99 (<0.00 – >999.99)
Insurance Type			
Public	3.84 (0.92)	2.92 (0.93)	Ref
Private	3.81 (0.90)	2.91 (0.87)	1.12 (0.47 – 2.68)
Agreement with the Benefits of Research Participation			3.57 (2.02 – 6.31) *
Disagreement with the Risks of Research Participation			1.07 (0.75 – 1.53)

Note

^a Mean values for agreement with the perceived benefits of research participation with 1= Strongly Disagree and 5 = Strongly Agree

^b OLS model predicting disagreement with the perceived risks of research participation with 1=Strongly Agree and 5= Strongly Disagree

^c Logistic regression model predicting odds of expressing an intention to participate in research

*
 $p < 0.05$

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Table 3

Differences between Survey Respondents Reporting Participation and Non-Participation in Cancer Clinical Trials n =727

Variables	Participants	Non-Participants
	n (%)	n (%)
Age		
18-39	1 (4.0)	151 (23.0)
40-64	15 (60.0)	351 (54.2)
65-94	9 (36.0)	146 (22.5)
Participation in clinical research benefits society		
Agree	21 (91.3)	440 (66.4)
Disagree	1 (4.4)	39 (5.9)
Unsure	1 (4.4)	184 (27.8)
Intention to participate in future trials		
Yes	17 (77.3)	48 (7.2)
No	5 (22.7)	618 (92.8)