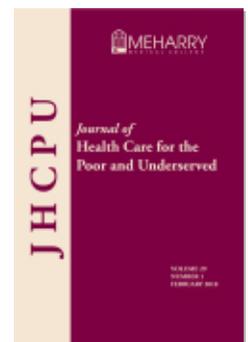




PROJECT MUSE®

Spirituality and Willingness to Participate in Health-Related Research Among African Americans

Elizabeth Ojukwu, Lauren R. Powell, Sharina D. Person, Milagros C. Rosal, Stephenie C. Lemon, Jeroan Allison



Journal of Health Care for the Poor and Underserved, Volume 29, Number
1, February 2018, pp. 400-414 (Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/hpu.2018.0027>

➔ *For additional information about this article*

<https://muse.jhu.edu/article/686974>

Spirituality and Willingness to Participate in Health-Related Research Among African Americans

Elizabeth Ojukwu, MD
Lauren R. Powell, PhD
Sharina D. Person, PhD
Milagros C. Rosal, PhD
Stephenie C. Lemon, PhD
Jeroan Allison, MD, MSc

Abstract: African Americans remain underrepresented in health-related research. We examined the association between spirituality using the Self-Rating Spirituality Scale (range 6–24) and self-reported willingness to participate in health-related research studies among African Americans. Covariates included gender, education level, employment status, and previous research experience. Adjusted associations were calculated with logistic regression models, with multiple imputation to account for missing data. Results from the logistic regression model show that each one-point increase in the Self-Rating Spirituality Scale was associated with a 24% increase in the odds of being very likely to participate in research (OR: 1.24, 95% CI: 1.07–1.44). Those with less than a college degree (OR: 3.59, 95% CI: 1.51–8.54), who were unemployed (OR: 2.34, 95% CI: 1.03–5.33), and had previous research experience (OR: 2.92, 95% CI: 1.22–6.99) reported increased willingness to participate. This work offers new insight for developing recruitment initiatives within African American spiritual communities.

Key words: Spirituality, research participation, African Americans, willingness.

African Americans are disproportionately affected by poor health outcomes ranging from cardiovascular disease, diabetes, and cancer, to stroke.^{1–4} However, only

ELIZABETH OJUKWU is a Pediatric Resident at Monroe Carell Jr. Children's Hospital at Vanderbilt University. LAUREN R. POWELL is a Master of Public Administration Candidate & Sheila C. Johnson Leadership Fellow, Harvard Kennedy School of Government. SHARINA D. PERSON is an Associate Professor in the Department of Quantitative Health Sciences at the University of Massachusetts Medical School. MILAGROS C. ROSAL, PhD is an Associate Professor in the Division of Preventive and Behavioral Medicine. STEPHENIE C. LEMON is Professor of Medicine in the Division of Preventive and Behavioral Medicine and Co-Director of the UMass Worcester Prevention Research Center and of the Community Engagement Core of the UMass Center for Clinical and Translational Science. JEROAN ALLISON is Professor and Vice Chair of the Department of Quantitative Health Sciences at the University of Massachusetts Medical School and Associate Vice Provost for Health Disparities Research. Please address correspondence to Jeroan Allison, MD, MSc, Department of Quantitative Health Sciences University of Massachusetts Medical School, 55 Lake Avenue North, Worcester, Massachusetts 01655 USA; email: jeroan.allison@umassmed.edu., phone: 508-856-5437.

12.6% of African Americans are enrolled in studies funded by the National Institute of Health (NIH).⁵ Furthermore, only about one-third of 86 randomized controlled trials performed in 2009 reported analyses by race or ethnic groups.⁶ This lack of subgroup analyses was mostly attributed to insufficient numbers of participants. In order for research findings to benefit ethnic minorities, adequate representation of diverse populations in health-related research is necessary.⁷⁻¹⁰

Despite efforts to increase minority inclusion in health-related research, the African American population remains underrepresented.¹¹⁻¹⁷ Several studies have proposed potential barriers and facilitators to research participation.^{18,19} Within the African American community, identified challenges include low health literacy, distrust of the health care system, costs of participation, poor access to health care, institutional racism, and inadequate recruitment efforts by investigators.^{18,20,21} Facilitators of African American research participation include perceived future benefits to their community, exposure to newer and improved medications, access to free medications and services, and culturally congruent recruitment.¹⁸

In spite of previous work focused on identifying predictors of research participation, African Americans remain under represented in research, as described above. Novel approaches to improving participation are needed. The role of spirituality in African American populations is a singular dimension with potential for improving research participation. About eight out of 10 African Americans report that religion is very important in their lives,²² despite the fact that a large majority (72%) of African Americans are unaffiliated with a particular faith.²³ Thus, elucidation of how the broader concept of spirituality influences health-related research participation among African Americans in the general community is warranted.

However, the role of spirituality in association with research participation among African American populations has not yet been studied. This is further complicated by the complex multidimensional concept of spirituality and its broad overlap with religion.²⁴ Though there is much controversy over the definition of spirituality, widely used definitions of spirituality include “a sense of transcendence beyond one’s immediate circumstances, and other dimensions such as the purpose and meaning of life, reliance of inner resources, and sense of within-person integration or connectedness.”²⁵[p.1347]

Though spirituality and willingness to participate in health-related research has not been studied specifically, a few studies examining the closely related concept of religiosity show mixed results. One study identified religious fatalistic perceptions as a factor that limits research participation.²⁶ In this study, analysis was limited to patients with cancer and religious belief was measured with a single survey item. Furthermore, the investigation focused on differences between African Americans and Whites,²⁶ which still begs the question of how differences in spiritual or religious beliefs within African Americans affect research participation. In contrast, another study suggested that religiosity is positively correlated with altruism, which facilitates willingness for participation in AIDS-related research.²⁷ Another investigation focused on the role of the church and church-leaders in African Americans’ willingness to participate in health-related research in North Carolina.²⁸ This study found that church members felt prepared to participate in research overall,²⁸ which may support the role of religious and spiritual leaders within the African American church have in encouraging research participation.

Our study examines the association between spirituality and willingness to participate in health-related research studies among African Americans. To the best of our knowledge, this is the first study examining spirituality and willingness to participate in health-related research in a community-based sample of African Americans. Unlike other studies in the past, this study did not limit the study population to only individuals with a particular disease or individuals with an active church membership. By providing insight into the role of spirituality in research participation among African Americans in local communities, appropriate recruitment initiatives may be identified and used to increase research participation among racial/ethnic minorities.

Methods

Sample selection and recruitment. A cross-sectional study design was performed using a purposive sample of 430 adults. Participants were recruited to target diversity with respect to age, race/ethnicity, socioeconomic status, and gender equal representation. Participants were at least 18 years of age, English-speaking, and cognitively able to provide informed consent to complete the survey. The strategic approach for recruitment included engagement with community partners for attendance at community-based events, email blasts, and web-based posts on social media (Twitter, Craigslist). Recruitment took place at various community events in Worcester and Boston, Massachusetts. Subsequent analysis was restricted to individuals who self-identified as African American in response to the question “What is your race?”

Data collection. Participants who were recruited on site completed the survey on paper or via a web-enabled tablet. On-line participants were provided with a private link to complete the survey on a web-enabled personal device. Respondents were provided informed consent prior to study procedures and were compensated with a \$25 card to a Target retail store for their participation. All study procedures were approved by the University of Massachusetts Medical School, Institutional Review Board.

Measures. The outcome variable was based on a single item, “How likely are you to agree to participate in a health-related research study?” Responses were recorded on a five-point Likert scale (Not at all likely, A little likely, Somewhat likely, Likely, Very likely). The main research goal was to examine factors associated with being highly likely to participate in future health-related research. Thus, the outcome was dichotomized to those who were very likely to participate versus those who were less than very likely to participate in health-related research.

The main independent variable was spirituality measured by the Self-Rating Spirituality Scale (SRSS), a validated survey that contains 6 items.²⁹ Items include “It is important for me to spend time in private spiritual thought and meditation,” “I try hard to live life according to my religious beliefs,” “The prayers or spiritual thoughts that I say when I am alone are as important to me as those said to me during services or spiritual gatherings,” “I enjoy reading about my spirituality and/or religion,” “Spirituality helps keep my life balanced and steady in the same ways as my citizenship, friendships, and other memberships do,” and “My whole approach to life is based on my spirituality.” For our study, the neutral option was eliminated to increase the likelihood that participants would choose a response toward one extreme. The final

response options used in our study were: strongly agree, somewhat agree, somewhat disagree, or strongly disagree. A “choose not to answer” option was available for all items. Appropriate item responses measuring spirituality were reverse coded so that higher scores reflected higher spiritual orientation. Those who responded with “choose not to answer” were coded as missing. The mean spirituality score was calculated and then multiplied by 6 to give the total score, resulting in a scale with a range of 6–24. Cronbach’s alpha from our data was 0.91.

Demographic items thought to be associated with spirituality and willingness to participate were measured, which included age (18–34; 35–49; 50–64; 65+), gender (female; male), education level (<9th grade, 8th–12th grade, high school graduate, attended college/tech, college graduate and higher), and employment status (employed, unemployed, homemaker, student, unable to work, retired). Education was dichotomized to more than college vs. less than college. Employment was dichotomized to employed vs. unemployed. Health literacy was determined based on the response to the previously validated screening question, “How comfortable are you filling out medical forms by yourself?” (extremely, quite a bit, somewhat, a little bit, not at all),^{30,31} and was dichotomized to high health literacy (extremely and quite a bit) and low health literacy (somewhat, a little bit, and not at all) for statistical analyses. Perceived income was used to evaluate whether respondents felt that their household income was enough to meet their needs (more than enough, just enough, not enough, don’t know, choose not to answer). Previous history of research participation was inferred from response to the question “Have you ever been in a health-related research study?” (Yes/No) and health status was evaluated in response to the question, “In general, would you say your health is:” (Excellent, Very Good, Good, Fair, Poor).³²

Analytic approach. Frequency distributions were generated to describe the study sample. Bivariate associations with the outcome variable were examined with either the chi-square test or ANOVA for categorical and continuous independent variables, respectively. Non-parametric trend testing³³ was also used to determine the trend of spirituality across willingness to participate. Approximately 9% of respondents had missing data for the spirituality scale, and the level of missingness was less than or equal to 2% for all other covariates. Thus, multiple imputation with chained equations^{34,35} was used to account for missing data. The logistic regression model was adjusted for all covariates found to be statistically significantly associated with willingness to participate in research in bivariate analyses. Based on the multiple imputed logistic regression model described above, we developed predicted probabilities for each of the predictor variables with the inverse logit transformation. For each particular prediction, variables other than the index predictors were set at their overall mean. Spirituality was divided into three categories based on tertiles.

To address the potential impact of dichotomizing the outcome, extensive sensitivity analyses were performed that accounted for the full information available in the native ordinal outcome variable. First, an ordered logistic model was performed to analyze the association between spirituality and willingness as an ordinal categorical variable (as presented in the survey). However, the employment and education variables violated the proportional odds assumption. Therefore, we also developed a partial generalized ordered logit model to allow coefficients of these demographic variables to vary across

strata.³⁶ Additionally, bivariate analyses were performed to determine if the associations between spirituality and willingness to participate were the same between those who completed the survey via paper and online. STATA version 14 was used for all statistical analyses.³⁷

Results

Sample characteristics. The final study sample consisted of 188 African American participants. Demographic characteristics are summarized in Table 1; 57.1% were female, 46.4% were in the 18–34 age category, and 64.3% were employed. Nearly half of participants had more than a college education and reported having at least enough income to meet household bills (52.7% and 53.9% respectively). Most individuals had very good or excellent health (63.93%). The majority of participants had high health literacy and no previous experience with research (80.3% and 75.5% respectively). Bivariate analyses revealed increased willingness to participate in research in females ($p < .05$), those with previous experience with research ($p < .001$), those with less than a college education ($p < .05$), and those who were unemployed ($p < .05$). Thus, these variables were included in the multivariable logistic model described below.

Spirituality and willingness to participate in health-related research. ANOVA and non-parametric trend testing showed an association between spirituality level ($p < .01$) and increased willingness to participate in health-related research ($p < .05$), respectively. Figure 1 shows spirituality scores by willingness to participate in health research. Spirituality (range 6–24) ratings demonstrated a general upward trend moving across categories of increasing willingness to participate in health-related research ($p = 0.002$).

Increased willingness to participate was significantly associated with spirituality, as shown in Figure 2. The logistic regression model controlled for gender, education, employment status, and previous research experience. There was a 24% increase in the odds for being very willing to participate for every one-point increase in spirituality (OR = 1.24, 95% CI = 1.07–1.44, $p < .01$). Increased willingness to participate in research was reported by those with less than a college degree (OR: 3.59, 95% CI: 1.51–8.54), those who were unemployed (OR: 2.34, 95% CI: 1.03–5.33), and those with previous research experience (OR: 2.92, 95% CI: 1.22–6.99). Gender was not significantly associated with willingness to participate in health-related research in the overall model. Our logistic regression model had good discrimination; area under ROC curve was 0.75. Table 2 presents the predicted probabilities for each predictor variable in the previously developed multivariable model. Higher predicted probabilities for research participation were associated with being female, unemployed, less educated, and having past research experience. A gradient of increasing willingness to participate was found across increasing tertiles of spirituality.

Findings persisted with partial generalized ordered logistic regression, indicating that the decision to dichotomize the outcome did not affect the main conclusions. The association between spirituality and willingness to participate in health-related research was of similar magnitude among participants who completed the survey on paper (OR: 1.25, 95% CI: 1.04–1.51) and those who took a web-based survey (OR: 1.19, 95% CI: .98–1.44). Findings did not differ substantively with or without imputation.

Table 1.
CHARACTERISTICS OF 188 AFRICAN AMERICAN/BLACK SURVEY RESPONDENTS BY SELF-RATING
WILLINGNESS TO PARTICIPATE IN HEALTH-RELATED RESEARCH, 2014-2015

Demographic Characteristics	Overall*	Likely (%)				P value**
		Not at all	A little	Somewhat	Very Likely	
Age category, years	178					.092
18-34	83 (46.4)	7.23	13.25	42.17	21.69	15.66
35-49	47 (26.40)	0.00	25.53	31.91	14.89	27.66
50-64	39 (22.10)	7.69	23.08	20.51	25.64	23.08
65+	9 (4.49)	0.00	11.11	66.67	22.22	0.00
Gender	184					.025
Females	105 (57.07)	0.95	18.10	33.33	25.71	21.90
Male	79 (42.93)	11.39	17.72	36.71	17.72	16.46
Education	184					.041
< College Degree	87 (47.28)	6.90	18.39	34.48	13.79	26.44
> College Degree	97 (52.72)	4.12	17.53	35.05	29.90	13.40
Employment						.015
Employed	119 (64.32)	4.20	18.49	35.29	28.57	13.45
Unemployed	66 (35.68)	7.58	16.67	33.33	12.12	30.30
Perceived income	185					.114
More than need	20 (12.12)	10.00	25.00	25.00	30.00	10.00
Just enough	69 (41.82)	1.45	15.94	42.03	27.54	13.04
Not enough	76 (46.06)	5.26	13.16	32.89	19.74	28.95

(continued on p. 406)

Table 1. (continued)

Demographic Characteristics	Overall*	Not at all Likely (%)	A little Likely (%)	Somewhat Likely (%)	Likely (%)	Very Likely (%)	P value**
Health Literacy ^a	183						.296
High	147 (80.33)	4.08	19.05	33.33	23.81	19.73	
Low	36 (19.67)	11.11	13.89	41.67	13.89	19.44	
Health Status	183						
Excellent	41 (22.40)	4.88	14.63	21.95	39.02	19.51	.294
Very Good	76 (41.53)	5.26	19.74	42.11	14.47	18.42	
Good	51 (27.87)	5.88	19.61	31.37	23.53	19.61	
Fair or Poor	15 (8.20)	6.67	13.33	46.67	6.67	26.67	
Previous experience with research	184						< .001
Yes	45 (24.46)	4.44	6.67	17.78	33.33	37.78	
No	139 (75.54)	5.76	21.58	39.57	19.42	13.67	
Spirituality Self-Rating Scale ^b (mean)	19.87 ± 3.94	18.00	19.69	18.66	20.52	21.71	.0032

Notes

*n(%) or mean ± sd.

**p value of Chi-Square Test or ANOVA.

^aHealth Literacy measured by item dichotomized item How comfortable are you filling out medical forms by yourself? (Extremely, Quite a bit, Somewhat, A little bit, Not at all).

^bSpirituality Self-Rating Scale range is 6–24.

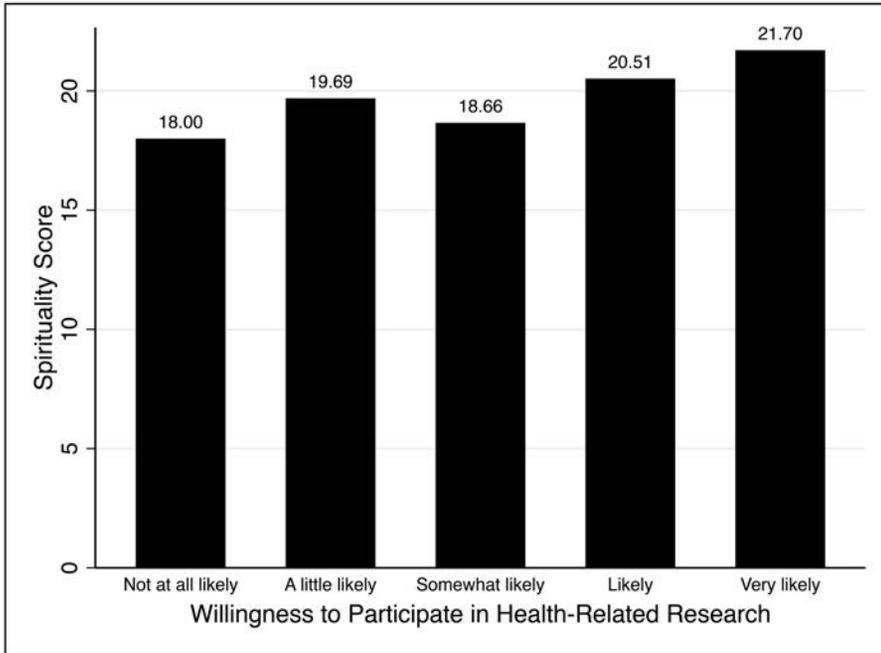


Figure 1. Spirituality Self-Rating Scale Scores by Willingness to Participate in Research among 188 African Americans, 2014–15

Spirituality Score is from Spirituality Self-Rating Scale (Range 6–24), with $p = 0.002$ for non-parametric trend test across levels of willingness to participate in health-related research.

Discussion

To the best of our knowledge, this is the first study that examines the role of spirituality and willingness to participate in health-related research among African Americans. In our study of African Americans from two Massachusetts communities, we identified important new associations between spirituality and willingness to participate in health-related research. We found that spirituality was strongly and significantly associated with self-reported willingness to participate in research. Additionally, those who were unemployed, had less than a college education, or had previous research experience were more willing to participate in health-related research (Table 2). Given that underrepresentation of African Americans in health-related research is a persistent barrier to health equity, our study provides valuable new insights towards increasing research participation in the African American community.

Given that altruism is a common facilitator of health-related research,¹⁸ altruism may explain the connection between spirituality with increased willingness to participate in health-related research. In a multivariate model examining factors affecting African Americans' willingness to participate in AIDS-related research, high levels of religiosity have been associated with increased levels of altruism, which were then associated with increased willingness to participate in AIDS-related research. Interestingly, altruism was the only positive predictor in the multivariate model for willingness to participate in

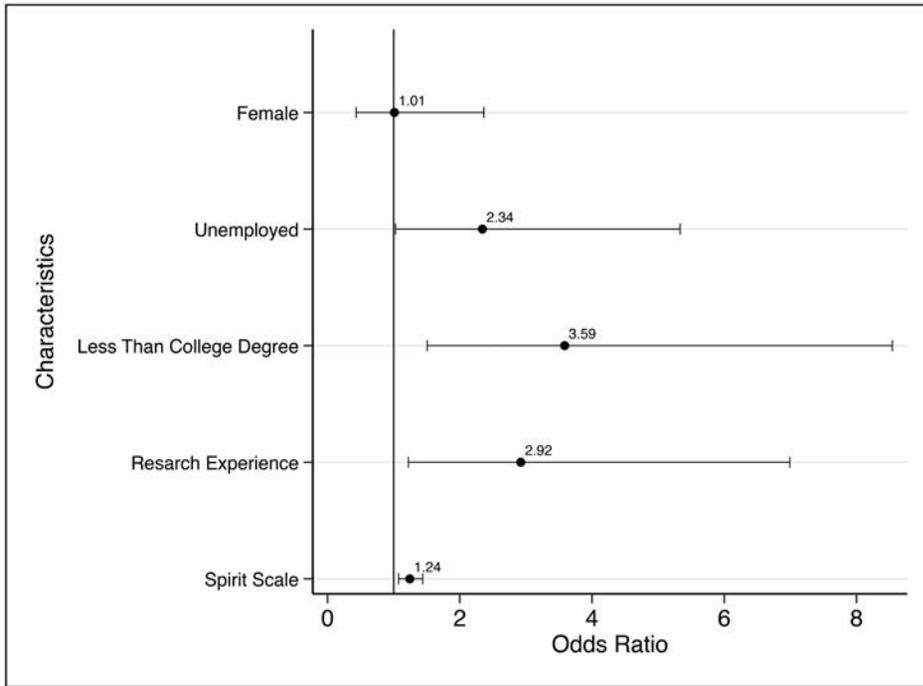


Figure 2. Odds Ratios (95% CI) for Reporting “Very High Likelihood of Future Research Participation” Among 188 African Americans Surveyed.^a

Note: ^aData based on multiple imputation with chained equations for missing values. Spirit Scale is score calculated from Spirituality Self-Rating Scale (Range 6–24). Research Experience is past participation in research.

AIDS-related research in that study.²⁷ However, more studies are needed to investigate the relationship between spirituality, religiosity, altruism, and willingness to participate in health-related research.

Participants in our study were more willing to participate in health-related research if they were unemployed and had less than a college education than otherwise. However, several research studies show that participants with more education and income are more likely to enroll in clinical trials.^{38–47} Our findings suggest that monetary incentives for research participation may drive willingness to participate among those who are unemployed,⁴⁸ although use of monetary incentives to recruit vulnerable populations raises ethical dilemmas.⁴⁹ Additionally, we speculate that those with higher education are more knowledgeable about the historical exploitation of African Americans in health-related research studies, and thus are less willing to participate in research due to underlying mistrust. This awareness further supports previous studies in which participants use historical evidence of racial discrimination in medical research to validate distrust of the medical and research communities.^{38–40} We also found that participants with previous research exposure were three times more willing than others to participate in health-related research. Our findings confirm studies that show that previous research participants and those who are more knowledgeable about research procedures are more likely to agree to research participation.^{50–52}

Table 2.**PREDICTED PROBABILITIES (95% CI) OF “VERY HIGH LIKELIHOOD OF FUTURE RESEARCH PARTICIPATION” AMONG 188 AFRICAN AMERICANS^a**

	Predicted Probability (%)	95% Confidence Interval
Gender		
Male	16.29	0.89–23.68
Female	21.86	14.71–29.01
Employment Status		
Employed	13.45	7.61–19.28
Unemployed	30.30	20.36–40.24
Education		
At least college education	13.32	6.87–19.77
Greater than college education	30.30	18.09–34.54
Past Research Experience		
No	13.57	8.15–18.99
Yes	37.78	24.87–50.68
Spirituality Tertiles		
Low	9.68	3.34–16.02
Intermediate	22.67	16.24–29.10
High	30.63	20.34–40.93

Note

^aBased on the multiple imputed logistic regression model from Figure 1.

While there are some similarities between our results and previous findings, specific results of our study differ from some earlier work investigating the closely related concept of religiosity. For example, a study that recruited only Latinas shows that there is a positive correlation between “religiosity and perceived lack of community support for clinical trials participation.”^{53[p.220]} Although these findings may be unique to the concept of religiosity in the Latina sample studied, they highlight the need for more research that elucidates attitudes about research participation within various spiritual and religious racial/ethnic minority communities. In another study examining patients with malignant disease, more African Americans than White Americans believed that God determined if they would survive their disease, which was correlated with less willingness to participate in cancer clinical trials.²⁶ This suggests the possibility that constructs of spirituality and religiosity associated with lack of personal control may actually be a barrier to research participation. In all, it is important to recognize that multiple factors influence an individual’s decision to participate in clinical research.^{19,27}

Our findings have important implications for increasing diversity in health-related research, which is a persistent barrier to achieving health equity. Spiritual individuals

may not be as readily identifiable as those who share a specific religion. Religion is more readily defined as “an organized system of beliefs, practices, and symbols designed to facilitate closeness to a higher power.”²⁵[p.1346] However, incorporating spirituality as a source of motivation in existing education-based recruitment efforts may be beneficial in recruiting African Americans in the general community. For example, use of educational interventions such as audio-visual aids and computerized animation that incorporate spirituality in African-American communities may not only improve understanding of the research process, but also encourage participation among African Americans who do not necessarily identify with a particular religion.^{54–56} As stated previously, participants with previous research exposure were more willing to participate in health-related research. This suggests that African Americans with previous research experience could serve as culturally congruent storytellers who utilize their spirituality in their spoken narratives to inspire research participation and provide necessary education about the research process. Furthermore, culturally congruent storytellers would serve as individuals who share similar cultural perspectives with other community members and thus decrease the sense of mistrust that some individuals have towards medical and research communities.^{57,58} Additionally, the church and religious leaders within the African American community have demonstrated great potential in engaging African Americans in research.^{28,59–62} Involvement of spiritual or religious leaders to promote a sense of purpose and related spiritual beliefs may further encourage minority participation in health-related research studies.

Our study suggests potential avenues to increase African American participation in health-related research, although it also has limitations worth mentioning. First, the SRSS was used to measure general spirituality. However, the concept of spirituality is broad and multidimensional in nature, thus there is no clear consensus on the definition of spirituality within health-related research.⁶³ Second, our study inquired about hypothetical willingness to participate in health-related research, rather than focusing on actual research participation. It is possible that hypothetical decisions may not reflect actual behavior, as actual research participation could be contingent on established barriers and facilitators to research participation. However, our study is one of several survey-based studies performed on the theory that one’s behavior is determined by one’s intention to perform the behavior.⁶⁴ We have also found that those who have previous research experience have higher spirituality, which again suggests that spirituality is an influential factor in actual research participation. Third, there also may have been a self-selection process by which those least likely to participate did not participate in this study. Thus, our sample may not reflect the entire continuum of likelihood of research participation. Fourth, our study did not distinguish between different types of health-related research. Willingness to participate in low-risk health-related research, such as focus groups or surveys, may be quite different from willingness to participate in higher-risk health-related research, such as drug or device related clinical trials. Fifth, the generalizability of the research findings is limited given that participants analyzed were African Americans located primarily in the Boston and Worcester areas. Finally, due to the cross-sectional nature of the study, causation between the independent variables and outcome cannot be inferred.

Despite these limitations, the findings provide insight about spirituality and its role in

willingness to participate in health-related research. Further research is needed to elucidate the relationship between spirituality and attitudes towards health-related research participation among African Americans. For example, there may be underlying positive beliefs about research participation shared by spiritual individuals. Such beliefs could be fostered within the African American community and utilized in recruitment efforts. Additional studies are needed to determine the effectiveness of recruitment initiatives that leverage spirituality in increasing African American research participation.^{28,59–62,65} Though more studies are needed, our findings underscore the influence of spirituality as it relates to willingness to participate in health-related research.

Acknowledgments

We would like to acknowledge the following individuals for their contributions to the qualitative research and data collection portions of this project (Dr. Heather Lyn-Haley, Dr. Laura Hayman, Dr. Suzanne Cashman, Dr. Carol Bova, Robert Gakawaya) and scholastic contributions to the execution of this manuscript (Ryan D'Sousza). We would also like to thank those community partners and members who welcomed us into their community to conduct focus groups, and administer our survey, including: Mosaic Cultural Complex (Worcester, Mass.); Lawrence Senior Center (Lawrence, Mass.); Reggie Lewis Center (Roxbury, Mass.); Ashmont Neighborhood Association (Ashmont, Mass.); Urban League of Eastern Massachusetts (Roxbury, Mass.); YMCA of Central Massachusetts (Worcester, Mass.); Greendale YMCA (Worcester, Mass.).

Disclosure of funding received for this work: This work was supported by grant funding from the following sources: National Institutes of Health, National Institute on Minority Health and Health Disparities, Grant #: 5 P60 MD006912 Centers for Disease Control and Prevention, UMass Worcester Prevention Research Center, Grant #: 1 U48 DP005031 and 5 U48 DP001933.

Disclosure of potential conflicts of interest for all authors in the past 3 years: None.

References

1. Cruz-Flores S, Rabinstein A, Biller J, et al. Racial-ethnic disparities in stroke care: The American experience: A statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*. 2011 Jul;42(7):2091–116.
2. Peek ME, Cargill A, Huang ES. Diabetes health disparities: A systematic review of health care interventions. *Med Care Res Rev*. 2007 Oct;64(5 Suppl):101S–56S.
3. Pinsky PF, Ford M, Gamito E, et al. Enrollment of racial and ethnic minorities in the prostate, lung, colorectal and ovarian cancer screening trial. *J Natl Med Assoc*. 2008 Mar;100(3):291–8.
4. Roger VL, Go AS, Lloyd-Jones DM, et al. Heart disease and stroke statistics—2011 update: A report from the American Heart Association. *Circulation*. 2011 Feb 1;123(4):e18–e209.
5. Pinn VW, Roth C, Bates AC, Wagner R, Jarema K: Department of Health and Human Services. National Institutes of Health; 2009. Monitoring adherence to the NIH policy on the inclusion of women and minorities as subjects in clinical research. Comprehensive report: Tracking of human subjects research in fiscal year 2007 and fiscal year 2008. . 2009.

6. Geller SE, Koch A, Pellettieri B, et al. Inclusion, analysis, and reporting of sex and race/ethnicity in clinical trials: Have we made progress? *J Womens Health (Larchmt)*. 2011 Mar;20(3):315–20.
7. Allmark P. Should research samples reflect the diversity of the population? *J Med Ethics*. 2004 Apr;30(2):185–9.
8. Britton A, McKee M, Black N, et al. Threats to applicability of randomised trials: Exclusions and selective participation. *J Health Serv Res Policy*. 1999 Apr;4(2):112–21.
9. Freedman LS, Simon R, Foulkes MA, et al. Inclusion of women and minorities in clinical trials and the NIH revitalization act of 1993—the perspective of NIH clinical trialists. *Control Clin Trials*. 1995;16(5):277–85.
10. Hussain-Gambles M. Ethnic minority under-representation in clinical trials. whose responsibility is it anyway? *J Health Organ Manag*. 2003;17(2):138–43.
11. Medicare clinical trial policies. ;2016(2/23).
12. Evelyn B, Toigo T, Banks D, et al. Participation of racial/ethnic groups in clinical trials and race-related labeling: A review of new molecular entities approved 1995–1999. *J Natl Med Assoc*. 2001 Dec;93(12 Suppl):18S–24S.
13. Food and Drug Administration. Modernization act of 1997. ;2016(2/23).
14. Ford JG, Howerton MW, Lai GY, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer*. 2008;112(2):228–42.
15. National Institutes of Health. NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research. . October 1, 2001;2016(2/23).
16. Spiker CA, Weinberg AD. Policies to address disparities in clinical trials: The EDICT project. *Journal of Cancer Education*. 2009;24(S2):S39–49.
17. Bolen S, Tilburt J, Baffi C, et al. Defining “success” in recruitment of underrepresented populations to cancer clinical trials. *Cancer*. 2006;106(6):1197–204.
18. George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among african americans, latinos, asian americans, and pacific islanders. *Am J Public Health*. 2014 Feb;104(2):e16–31.
19. Rivers D, August EM, Sehovic I, et al. A systematic review of the factors influencing african americans’ participation in cancer clinical trials. *Contemporary clinical trials*. 2013;35(2):13–32.
20. Ford ME, Siminoff LA, Pickelsimer E, et al. Unequal burden of disease, unequal participation in clinical trials: Solutions from african american and latino community members. *Health Soc Work*. 2013 Feb;38(1):29–38.
21. Huang H, Coker AD. Examining Issues Affecting African American Participation in Research Studies. *Journal of Black Studies*. 2010; 40(4): 619–636.
22. Shuman JJ, Meador KG. *Heal thyself: Spirituality, medicine, and the distortion of christianity*. Oxford University Press; 2002.
23. Pew Research Center. A religious portrait of african-americans. . 2009;2016(2/23).
24. Koenig HG. *Spirituality and health research: Methods, measurements, statistics, and resources*. Templeton Foundation Press; 2012.
25. Monod S, Brennan M, Rochat E, et al. Instruments measuring spirituality in clinical research: A systematic review. *J Gen Intern Med*. 2011 Nov;26(11):1345–57.
26. Advani AS, Atkeson B, Brown CL, et al. Barriers to the participation of african-american patients with cancer in clinical trials: A pilot study. *Cancer*. 2003 Mar 15;97(6):1499–506.
27. Sengupta S, Strauss RP, DeVellis R, et al. Factors affecting african-american participation in AIDS research. *JAIDS J Acquired Immune Defic Syndromes*. 2000;24(3): 275–84.

28. Odulana A, Kim MM, Green M, et al. Participating in research: Attitudes within the african american church. *Journal of religion and health*. 2014;53(2):373–81.
29. Galanter M, Dermatis H, Bunt G, et al. Assessment of spirituality and its relevance to addiction treatment. *J Subst Abuse Treat*. 2007;33(3):257–64.
30. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *health*. 2004;11:12.
31. Wallace LS, Rogers ES, Roskos SE, et al. Brief report: Screening items to identify patients with limited health literacy skills. *Journal of general internal medicine*. 2006;21(8):874–7.
32. Stewart AL, Hays RD, Ware JE. The MOS short-form general health survey: Reliability and validity in a patient population. *Med Care*. 1988;26(7):724–35.
33. Cuzick J. A wilcoxon-type test for trend. *Stat Med*. 1985;4(4):543–7.
34. Raghunathan TE, Lepkowski JM, Van Hoewyk J, et al. A multivariate technique for multiply imputing missing values using a sequence of regression models. *Survey methodology*. 2001;27(1):85–96.
35. van Buuren S. Multiple imputation of discrete and continuous data by fully conditional specification. *Stat Methods Med Res*. 2007 Jun;16(3):219–42.
36. Williams R. Generalized ordered logit/partial proportional odds models for ordinal dependent variables. *Stata Journal*. 2006;6(1):58–82.
37. StataCorp. *Stata statistical software: Release 14*. . 2015.
38. Dula A. African american suspicion of the healthcare system is justified: What do we do about it? *Cambridge Quarterly of Healthcare Ethics*. 1994;3(03):347–57.
39. Gamble VN. A legacy of distrust: African americans and medical research. *Am J Prev Med*. 1993;9(6 Suppl):35–8.
40. Gamble VN. Under the shadow of tuskegee: African americans and health care. *Am J Public Health*. 1997 Nov;87(11):1773–8.
41. Avis-Williams A, Khoury A, Lisovicz N, et al. Knowledge, attitudes, and practices of underserved women in the rural south toward breast cancer prevention and detection. *Fam Community Health*. 2009 Jul–Sep;32(3):238–46.
42. Baquet CR, Commiskey P, Mullins CD, et al. Recruitment and participation in clinical trials: Socio-demographic, rural/urban, and health care access predictors. *Cancer Detect Prev*. 2006;30(1):24–33.
43. Brown DR, Topcu M. Willingness to participate in clinical treatment research among older african americans and whites. *Gerontologist*. 2003;43(1):62–72.
44. Germino BB, Mishel MH, Alexander GR, et al. Engaging african american breast cancer survivors in an intervention trial: Culture, responsiveness and community. *Journal of Cancer Survivorship*. 2011;5(1):82–91.
45. Gooden KM, Carter-Edwards L, Hoyo C, et al. Perceptions of participation in an observational epidemiologic study of cancer among african americans. *Ethn Dis*. 2005;15(1):68–75.
46. Gross CP, Filardo G, Mayne ST, et al. The impact of socioeconomic status and race on trial participation for older women with breast cancer. *Cancer*. 2005;103(3):483–91.
47. O'Malley AS, Forrest CB, Feng S, et al. Disparities despite coverage: Gaps in colorectal cancer screening among medicare beneficiaries. *Arch Intern Med*. 2005;165(18):2129–35.
48. Bentley JP, Thacker PG. The influence of risk and monetary payment on the research participation decision making process. *J Med Ethics*. 2004 Jun;30(3):293–8.
49. Grant RW, Sugarman J. Ethics in human subjects research: Do incentives matter? *J Med Philos*. 2004;29(6):717–38.

50. Ellis PM, Butow PN, Tattersall MH, et al. Randomized clinical trials in oncology: Understanding and attitudes predict willingness to participate. *Journal of Clinical Oncology*. 2001;19(15):3554–61.
51. Ohmann C, Deimling A. Attitude towards clinical trials: Results of a survey of persons interested in research. *Inflammation Res*. 2004;53:S142–7.
52. Trauth JM, Musa D, Siminoff L, et al. Public attitudes regarding willingness to participate in medical research studies. *J Health Soc Policy*. 2000;12(2):23–43.
53. Daverio-Zanetti S, Schultz K, del Campo, Miguel A Martin, et al. Is religiosity related to attitudes toward clinical trials participation? *Journal of Cancer Education*. 2015;30(2):220–4.
54. Montalvo W, Larson E. Participant comprehension of research for which they volunteer: A systematic review. *Journal of Nursing Scholarship*. 2014;46(6):423–31.
55. Norris D, Phillips M. Using instructive videotapes to increase patient comprehension of informed consent. *Journal of Clinical Research and Pharmacoepidemiology*. 1990;4(4):263–8.
56. Ryan RE, Prictor M, McLaughlin KJ, et al. Audio-visual presentation of information for informed consent for participation in clinical trials. *Cochrane Database Syst Rev*. 2008;1(1).
57. Houston TK, Allison JJ, Sussman M, et al. Culturally appropriate storytelling to improve blood pressure: A randomized trial. *Ann Intern Med*. 2011 Jan 18;154(2):77–84.
58. Houston TK, Cherrington A, Coley HL, et al. The art and science of patient storytelling—harnessing narrative communication for behavioral interventions: The ACCE project. *J Health Commun*. 2011 Aug;16(7):686–97.
59. Felix Aaron K, Levine D, Burstin HR. African american church participation and health care practices. *Journal of General Internal Medicine*. 2003;18(11):908–13.
60. Markens S, Fox SA, Taub B, et al. Role of black churches in health promotion programs: Lessons from the los angeles mammography promotion in churches program. *Am J Public Health*. 2002 May;92(5):805–10.
61. Reed PS, Foley KL, Hatch J, et al. Recruitment of older african americans for survey research: A process evaluation of the community and church-based strategy in the durham elders project. *Gerontologist*. 2003;43(1):52–61.
62. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. *Annu Rev Public Health*. 2006;27:1–28.
63. Moberg DO. Assessing and measuring spirituality: Confronting dilemmas of universal and particular evaluative criteria. *Journal of Adult Development*. 2002;9(1):47–60.
64. Ajzen I, Fishbein M. *Understanding attitudes and predicting social behavior*. Englewood Cliffs, NJ: Prentice Hall; 1980.
65. Mitchell-Beren ME, Dodds ME, Choi KL, et al. A colorectal cancer prevention, screening, and evaluation program in community black churches. *CA: a cancer journal for clinicians*. 1989;39(2):115–8.