Promoting Retention: African American Older Adults in a Research Volunteer Registry

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Abstract

Objectives: The objectives of this study were to evaluate the capability of a research volunteer registry to retain community-dwelling African American older adults, and to explore demographic and health factors associated with retention. **Method:** A logistic regression model was used to determine the influence of demographics, health factors, and registry logic model activities on retention in a sample of 1,730 older African American adults. **Results:** Almost 80% of participants active in the volunteer research registry between January 2012 and June 2015 were retained. Employment, being referred to research studies, a higher number of medical conditions, and more follow-up contacts were associated with an increased likelihood of retention. Older age, more months in the registry, and more mobility problems decreased the likelihood of retention. **Discussion:** These results suggest the Michigan Center for Urban African American Aging Research logic model promotes retention through involving older African American adults in research through study referrals and intensive follow-up. The loss of participants due to age- and mobility-related issues indicate the registry may be losing its most vulnerable participants.

Keywords

research volunteer registry, retention, African American, older adults

Introduction

African American older adults are underrepresented in health-related research. This lack of inclusion affects the generalizability of study results and may contribute to the lack of progress in eliminating health disparities between African Americans and other racial and ethnic groups. Older African Americans suffer higher morbidity and mortality rates from various diseases compared with non-Hispanic Whites (Brown & Topcu, 2003; Centers for Disease Control & Prevention, 2013). African Americans also report higher levels of hypertension and diabetes than any other racial or ethnic group (Centers for Disease Control & Prevention, 2013; Federal Interagency Forum on Aging-Related Statistics, 2010) and have higher incidence and death rates for strokes, coronary heart disease, and certain cancers compared with non-Hispanic Whites (Centers for Disease Control & Prevention, 2013). Life expectancy for African Americans is 74 years, whereas for non-Hispanic Whites it is 78.5 years (Centers for Disease Control & Prevention, 2013). For these reasons, more than 20 years ago, the National Institute of Health (NIH) issued the Public Health Service Act Sec. 492B, 42

U.S.C. Sec. 289a-2, a policy aimed at increasing the inclusion of women and minorities as subjects in clinical research. In response to this policy, the National Institute on Aging (NIA) created the Resource Centers for Minority Aging Research (RCMAR) "to address the infrastructure development intended to reduce health disparities among older adults" (Sood & Stahl, 2011, p. S5). A primary goal of the RCMAR program is to "conduct research on recruitment and retention of community-dwelling older adults for research addressing behavioral, social, and medical issues" (Sood & Stahl, 2011, p. S6).

Since implementation of the NIH inclusion policies for research, a growing scientific literature has focused on identifying recruitment strategies that aim to increase the participation of ethnically diverse older adults in

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research, including African Americans (Bishop, Tiro, Craddock Lee, Bruce, & Skiner, 2011; Bishop, Tiro, Sanders, Craddock Lee, & Skinner, 2015; Chadiha et al., 2011; Hatchett, Holmes, Duran, & Davis, 2000; Lang et al., 2013; Mody et al., 2008; Yancey, Ortega, & Kumanyika, 2006). Limited research, however, is available on creating and maintaining health registries designed to retain community-dwelling older African Americans in research. Scientific literature indicated that registries of patient populations may facilitate creating effective subject pools of research volunteers (Beskow, Sandler, & Weinberger, 2006; Jefferson et al., 2011; Johnson, Mueller, Williams, & Gutman, 2014; Saunders et al., 2014; Schwartz, Brecher, Whyte, & Klein, 2005). Thus, more research is warranted to understand how registries of community-dwelling older African Americans may contribute to creating and retaining subject pools of these adults.

In 2011, faculty from the Michigan Center for Urban African American Aging Research (MCUAAAR), a Center funded through an NIA program for minority aging research, published a work on the creation of, and recruitment to, a research registry (see Chadiha et al., 2011). This article on retention extends the work on recruitment by Chadiha et al. (2011) and describes the process and outcomes in maintaining an effective registry for recruiting older African American adults into health-related research.

The purpose of the current study was to identify factors associated with the retention of community-dwelling older adult African Americans who volunteered to participate in health-related research. Findings about these factors may facilitate the identification of best practices for retaining older African American adults who are not recruited directly through a patient population into health-related research. We will review some of the issues related to research and health disparities, followed by an overview of empirical work on research registries. Finally, we will present our Logic Model for the current efforts at participant retention. We will first review recruitment approaches used with diverse populations and then discuss the role of research registries as one important vehicle for recruiting broad-based research participation, and not just as single studies or single disease registries.

Community outreach is identified as the most viable recruitment effort for enrolling minorities into a research registry (Green et al., 2013). Findings from Chadiha et al. (2011) support community outreach as a viable recruitment effort, noting the Healthier Black Elders Center (HBEC) research registry grew 10-fold during the first 7 years the annual health reception, a community outreach event, was held. The most effective community outreach efforts are carried out in the form of using outreach workers from the targeted population and the inclusion of minority investigators to overcome the trust barriers to recruitment (Yancey et al., 2006). African American and Hispanic respondents in a study

by Napoles-Springer et al. (2000) were in high agreement that they would be more willing to participate in a study if they shared race or ethnic identity with the researchers. In general, successful recruitment of older adults into clinical trials has been linked to building relationships with community-based organizations, making face to face contact with potential participants, and providing needed services as an access point for possible participants (McHenry et al., 2015).

When recruitment efforts yield desired results, researchers must then implement the best methods to retain participants. We have found the following to be effective practices for retention when working with minority participants: intensive follow-up and contact, having the same interviewers and staff over time, having staff from the targeted community, providing social support, having accessible locations for data collection, and timely incentive payments (Yancey et al., 2006). There is also a correlation between the number of retention strategies used to keep participants engaged and decreasing percentages of participants loss to follow-up (Robinson, Dennison, Wayman, Pronovost, & Needham, 2007). Empirical analysis has found a disconnected telephone, refusal to participate in follow-up, and severe cognitive impairment to be the most frequent reasons for loss to follow-up for older African Americans (Dreer, Weston, & Owsley, 2014).

Various researchers have also provided empirical analysis on the predictors of retention or loss to follow-up. Very few differences in basic demographic factors (age, gender, marital status, education, etc.) between participant's loss to follow-up and those retained were identified among African American elders participating in a community-based study. However, those retained were healthier than those lost to follow-up (Hudson, Leventhal, Contrada, Leventhal, & Brownlee, 2000). The number of group and individual sessions attended, frequency of all activity, and higher scores on an active coping scale (measuring the ability to successfully respond to stressful events) have been identified as predictors for the retention of African American elders in a lifestyle-based health intervention program (Carlson et al., 2014).

The Role of Research Registries

Research registries have been identified as a viable strategy to involve underrepresented groups in health-related research. One study found there were no differences in the percentage of African American and non-Hispanic Whites who agreed to enroll in a rehabilitation research registry (Phipps et al., 2004). Registry participants have also been found to be more likely to enroll in research projects than individuals contacted through other methods (Rogers et al., 2007). Several studies have demonstrated the effectiveness of recruiting minority populations for cancer research via research registries (Beskow et al., 2006; Bowen, Vu, & Kasten-Sportes,

2008; Skinner et al., 2008). Empirical analysis has also found that supporting recruitment through registries assists researchers in freeing resources and personnel to be reallocated to other research related tasks (Schwartz et al., 2005) There is, however, very little information available on how well registries catering to older African Americans retain participants.

MCUAAAR

The MCUAAAR is a collaborative research and administrative effort coordinated by the University of Michigan and Wayne State University. It is one of six confederated centers across the country under the leadership of a RCMAR coordinating center at the University of California, Los Angeles. The MCUAAAR implements research, training, and community-based education through its three central cores: Community Liaison Core, Investigator Development Core, and the Administrative Core. The mission of the MCUAAAR is to promote high quality, scholarly research and community based interventions focused on the health promotion among older racial and ethnic minorities. The MCUAAAR carries out this mission through supporting and training minority researchers and encouraging older, racial ethnic minorities to participate in various research projects.

HBEC

The HBEC is the community outreach component of the MCUAAAR. The HBEC operates under the community core arm of the MCUAAAR and has an overall goal of enhancing the health of older African Americans through health education. The HBEC hosts year-round community events where they disseminate information on a variety of topics in health and aging and provide health screenings to audiences of older adults in the Metro Detroit area at no cost to the public. The speakers for these community events include experts on various topics in aging drawn from MCUAAAR scholars, graduate students, and professors, who share their research using clear, common language.

In addition to the overall goal of the HBEC to enhance the health of older African Americans through health education, the HBEC also has a key objective of strengthening the numbers of older African Americans participating in health research. For this reason, the Participant Resource Pool (PRP) was developed. This research volunteer registry is accessed by scholars conducting health-related research and desiring access to African American participants 55 years of age and older who meet their study criteria (e.g., persons with diabetes above the age of 70 years).

The logic model in Figure 1 serves as the framework for the MCUAAAR's Community Liaison Core under which the HBEC operates. The logic model

serves to identify the relationship between retention promoting activities of the HBEC and the retention of individuals in the research volunteer registry. Retention promoting activities include follow-up telephone interviews with registry participants every 18 months, invitations to free health learning series open to the public, and referrals of research volunteer registry members to health-related research studies of which they meet the recruitment criteria. We have found that these efforts directly contribute to the immediate and short-term outcomes of increasing the retention rates of registry participants.

The Present Study

As mentioned previously, the purpose of the current study was to identify factors associated with the retention of community-dwelling older adult African Americans who volunteered to participate in health-related research; two distinctive research questions were formulated:

> **Research Question 1:** How well does the model introduced by the MCUAAAR in 2007 promote retention among participants of the research volunteer registry?
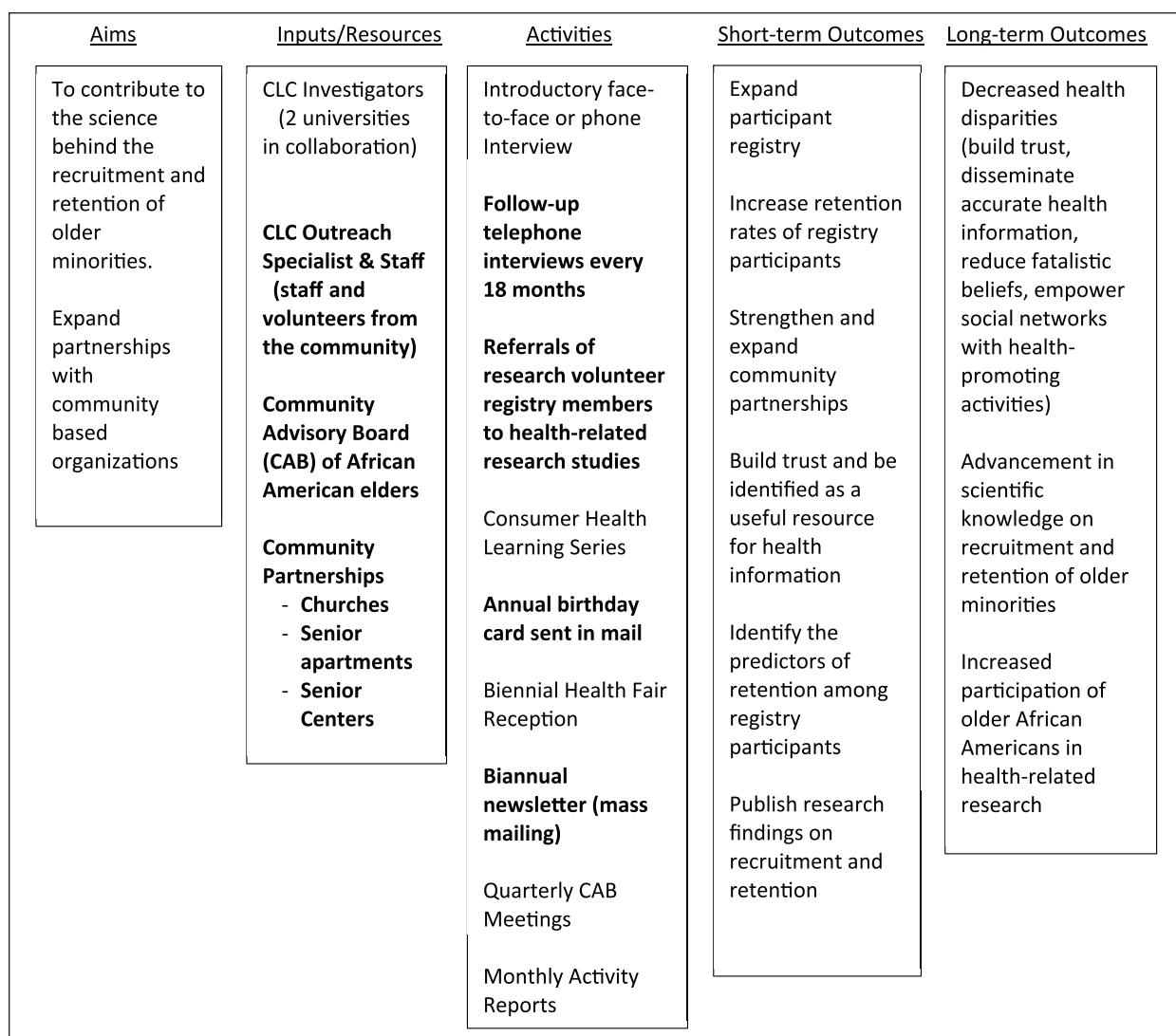> **Research Question 2:** What demographic and health factors are most strongly associated with participants being retained by the participant registry?

Method

Data

Participant registry. Data for the analysis were collected from the HBEC's research volunteer registry. Research volunteer registry enrollees are recruited through community health forums and other community outreach events. An introductory health questionnaire is completed face-to-face or by telephone before an individual is enrolled into the registry. The questionnaire consists of a variety of items covering standard demographic measures, self-reported health status, mobility, and medical conditions. Older adult volunteers administer follow-up surveys (same version) every 18 months, through telephone interview, to participants in the registry. All surveys are entered into a FileMaker Pro database.

The data for this study included all participant registry members who were active as of January 2012, or who became enrolled members following that date. The data were extracted from the most recent research volunteer registry telephone survey completed for participants before June 2015. The original data set for this study contained 1,767 participants. Thirty-seven deceased participants were deleted from the data set leaving a total of 1,730 participants.

Aims	Inputs/Resources	Activities	Short-term Outcomes	Long-term Outcomes
To contribute to the science behind the recruitment and retention of older minorities. Expand partnerships with community based organizations	CLC Investigators (2 universities in collaboration) **CLC Outreach Specialist & Staff (staff and volunteers from the community)** **Community Advisory Board (CAB) of African American elders** **Community Partnerships** - **Churches** - **Senior apartments** - **Senior Centers**	Introductory face-to-face or phone Interview **Follow-up telephone interviews every 18 months** **Referrals of research volunteer registry members to health-related research studies** Consumer Health Learning Series **Annual birthday card sent in mail** Biennial Health Fair Reception **Biannual newsletter (mass mailing)** Quarterly CAB Meetings Monthly Activity Reports	Expand participant registry Increase retention rates of registry participants Strengthen and expand community partnerships Build trust and be identified as a useful resource for health information Identify the predictors of retention among registry participants Publish research findings on recruitment and retention	Decreased health disparities (build trust, disseminate accurate health information, reduce fatalistic beliefs, empower social networks with health-promoting activities) Advancement in scientific knowledge on recruitment and retention of older minorities Increased participation of older African Americans in health-related research

Figure 1. Michigan Center for Urban African American Aging Research Community Liaison Core (CLC) logic model.

Participant characteristics. This full registry sample was 100% African American and majority being female (86.3%). The mean age of the sample was 74.8 years, and the vast majority of participants were retired (87.4%). The largest percentage of participants had some college education or technical/trade school (41.1%), with the next largest percentage (28.8%) being college graduates. Over one third of participants were widowed (35.2%), approximately a third were divorced or separated (29.5%), 23.5% were married, and the remainder reported having never married (8.7%) or being "single" (refusing to clarify their marital status; 3.1%). Participants were members of the research volunteer registry for 4.3 years on average and completed an average of 2.5 registry follow-up surveys. Almost half of the participants (44.3%) reported being in good health on a self-reported health measure. Details of demographic characteristics are found in Table 1.

Measures

Mobility scale. A scale was created to assess the level of mobility-related concerns among the study sample. The mobility scale items were based on questions used in the Established Populations for Epidemiologic Studies of the Elderly (EPESE, "a longitudinal study of community-dwelling elders age 65 designed to oversample AA elders" (Ficker, Lysack, Hanna, & Lichtenberg, 2014, p. 475). Research volunteer registry participants are asked to assess their difficulty level in the following eight domains of mobility: heavy housework (e.g., washing windows, shoveling snow), walking up and down a flight of stairs without help, walking a half mile without help, pulling or pushing large objects (a piece of furniture), stooping crouching or kneeling, lifting or carrying weights over 10 lbs (e.g., a heavy bag of groceries), reaching or extending arms above shoulder level, and handling or fingering small objects (e.g., writing) during the telephone survey process. A 5-point scale

Table 1. Participant Characteristics: Univariate Analysis (*N* = 1,730).

	Total PRP database
	% (*n*) or *M* (*SD*)
Age	74.8 (8.8)
Sex	
Male	13.7% (237)
Female	86.3% (1,493)
Marital status	
Married	23.5% (406)
Widowed	35.2% (605)
Divorced/separated	29.5% (507)
Never married	8.7% (149)
Single	3.1% (53)
Employment status	
Retired	87.4% (1,501)
Employed	7.6% (131)
Unemployed	5.0% (86)
Education	
Less than high school	5.9% (102)
High school graduate	24.2% (415)
Some college	41.1% (706)
College graduate	28.8% (495)
Self-reported general health	
Excellent	5.5% (95)
Very good	21.0% (361)
Good	44.3% (763)
Fair	24.7% (426)
Poor	4.5% (77)
PRP status	
Active	78.5% (1,358)
Inactive	21.5% (372)
Number of months in registry	51.6 (31.1)
Number of studies referred	0.8 (1.0)
Medical problems total	2.8 (1.7)
Mobility conditions scale	17.6 (8.0)
Self-reported general health	3.0 (0.9)
Follow-up survey count	2.5 (1.2)

Note. PRP = Participant Resource Pool.

was used to rate participant responses (1 = *no difficulty at all*, 2 = *a little difficulty*, 3 = *some difficulty*, 4 = *a lot of difficulty*, and 5 = *just unable to do it*). Scores ranged from 8 to 40 with a mean score of 17.6 for the research volunteer registry sample.

Medical problems total. The medical problems total was created using participants responses to a variety of medical conditions on the PRP survey. During the telephone survey, participants were asked to respond to whether they were currently experiencing, had ever experienced, or ever were told they had a diagnosis of a variety of medical conditions. Each medical condition was given a value of "1" and added together to calculate a total score for medical conditions. Participants were asked whether they had diabetes (type I, II, or unknown type = 1), arthritis (rheumatoid, osteoarthritis, or unknown

type = 1), osteoporosis (1), cancer (colon, lung, breast, prostate, or other = 1), bladder control problems (1), kidney problems (1), liver problems (1), lung problems (asthma, Chronic Obstructive Pulmonary Disease (COPD), or other = 1), high blood pressure (1), heart attack (1), bypass surgery (1), other heart problems (1), stroke (1), seizures (1), Parkinson's (1), Alzheimer's or other dementia (1), nerve damage (1), or other neurological problems (1). Scores ranged from 0 to 12 with a mean score of 2.8 for the research volunteer registry full sample.

Self-reported health. General health was a self-reported measure. Participants were asked, "Would you say your general health is….?" and were given the answer options of excellent, very good, good, fair, poor during the participant registry introduction and follow-up survey process. Responses were coded on a 5-point scale (1= *poor* to 5 = *excellent*). Self-reported general health had a mean score of 3.0 for the research volunteer registry sample.

Data Analysis

At the initial step of the analyses, chi-square tests and ANOVAs were performed to ascertain how retained research volunteer registry participants differed from those who were no longer active in the registry. Chi-square tests were used for the demographic measures sex, marital status, employment status, and education, and ANOVAs were used to examine the relationship between age, number of months in the research volunteer registry, number of completed follow-up surveys, number of research studies referred, medical problems total, mobility conditions scale total, self-reported general health, and the outcome measure of active versus inactive research volunteer registry status. Logistic regression was used as the final step in the analysis, to gauge how well demographic measures, age, number of months in the research volunteer registry, number of completed follow-up surveys, number of research studies referred, medical problems total, mobility conditions scale total, and self-reported general health independently predicted ongoing research volunteer registry status.

Results

From the period of January 2012 through June 2015, 78.5% of the participants remained active in the research volunteer registry. The outcome measure of PRP Status was separated into three distinctive categories (Active, No Longer Interested, and Lost Contact). Analysis of the full sample showed of the 21.5% of Inactive participants, 6.2% informed the registry that they were No Longer Interested, and 15.3% had a status of Lost Contact. Thus, only 6% of the registry participants actively dropped out.

Table 2. Correlation Matrix Full Sample.

	1	2	3	4	5	6	7	8	9
1. Education	1								
2. Self-reported general health	.14***	1							
3. Age	−.15***	−.02	1						
4. Number of studies referred	.07**	.01	.06*	1					
5. Number of months active in registry	.01	−.02	.25***	.17***	1				
6. Mobility scale total	−.19***	−.44***	.18***	−.02	.10***	1			
7. Medical problems total	−.07**	−.33***	.05*	.05	.03	.42***	1		
8. Follow-up survey count	.05*	−.02	.22**	.21**	.79**	.05*	.07**	1	
9. PRP status	.09***	.05*	−.07**	.26***	.09***	−.08**	.12***	.33**	1

Note. PRP = Participant Resource Pool.
*p < .05. **p < .01. ***p < .001.

Correlations were performed for the full sample to determine whether relationships existed between measures, and if so, what the strength of those relationships was. As shown in Table 2, correlations for the full sample revealed a strong, statistically significant positive correlation between the number of months in the registry and survey count (.79). Moderate positive correlations were found between medical problems totals and mobility scale totals (.42), and PRP status and survey count (.33). Moderate negative correlations were found between mobility scale totals and self-reported general health (−.44), and medical problems totals and self-reported general health (−.33).

Bivariate

Chi-square analysis. Chi-square analyses were performed to gauge the differences between demographic measures among those who were still active in the registry and those who were no longer active. Chi-square analysis for the full research volunteer registry sample revealed no significant associations between gender or marital status and research volunteer registry status ($p \geq .05$). Statistically significant associations were found between employment status and registry status ($p \leq .001$). Active participants were more likely to be retired and less likely to be employed for wages or consider themselves unemployed. A significant association was found between the level of education and participant registry status ($p \leq .001$). College graduates and individuals with some college/technical or trade school were more likely to be active, whereas individuals with less than a high school education and high school graduates were more likely to be inactive.

One-way ANOVA analysis. One-way ANOVA analysis with post hoc testing was performed to ascertain whether there were statistically significant mean differences between the research volunteer registry groups, that is, Active, No Longer Interested, and Lost Contact categories.

Full-sample ANOVA analysis. ANOVA testing for the full sample revealed age, $F = 3.86$, $p \leq .05$, number of months in the participant registry, $F = 7.71$, $p \leq .05$, average number of participant registry follow-up surveys completed, $F = 106.50$, $p \leq .05$, number of studies registry members were referred, $F = 63.70$, $p \leq .05$, medical problems totals, $F = 12.10$, $p \leq .05$, mobility scale totals, $F = 5.77$, $p \leq .05$, and self-reported health scores, $F = 12.10$, $p \leq .05$, were statistically significant between research volunteer registry status groups. Post hoc tests revealed which groups had statistically significant mean differences among these seven measures.

The Active group had a statistically significant higher average number of months in the registry, average number of surveys completed, average number of studies referred, and medical problem totals than the No Longer Interested and Lost Contact groups. The Active group also had a significantly higher self-reported health rating than the No Longer Interested group. The No Longer Interested group had a significantly higher average age than the Active group, whereas the Lost Contact group had a statistically significant higher average age and mobility scale totals than the Active group.

Multivariate

Logistic regression analysis. A logistic regression analysis was conducted to examine the independent contributions of the significant predictors of participation found in the ANOVA analyses. The logistic regression model was statistically significant, $\chi^2(15) = 575.754$, $p < .05$. The model explained 45.2% (Nagelkerke R^2) of the variance in participant registry status and correctly classified 86.4% of cases. Similar to the univariate ANOVA analyses, the measures which predicted a significantly higher likelihood of remaining active in the research volunteer registry were being employed for wages, having higher self-reported general health, number of studies referred, medical problems totals, and follow-up survey count; while increases in age, mobility scale total score, and number of months active in registry predicted a less likely outcome of remaining active (see Table 3 for details).

Table 3. Logistic Regression Predicting PRP Status (Active vs. Not Active).

	β	SE	Wald	OR
Marital status				
Married	Ref.	Ref.	4.38	Ref.
Widowed	−0.04	0.44	0.01	0.97
Divorced/separated	0.04	0.43	0.01	1.04
Never married	−0.25	0.43	0.33	0.78
Just single	−0.46	0.47	0.96	0.63
Employment status				
Retired	Ref.	Ref.	6.07	Ref.
Employed for wages	0.66	0.29	5.19*	1.94
Unemployed	0.33	0.37	0.82	1.40
Sex				
Female	Ref.	Ref.	Ref.	Ref.
Male	−0.02	0.22	0.01	0.98
Education	0.08	0.09	0.79	1.08
Self-reported general health	0.19	0.09	4.57*	1.20
Age	−0.05	0.01	24.17***	0.95
Number of studies referred	1.00	0.12	66.21***	2.73
Mobility problems scale	−0.03	0.01	7.89**	0.97
Medical problems total	0.25	0.05	19.96***	1.28
Number of months in registry	−0.05	0.01	123.86***	0.95
Follow-up survey count	2.23	0.16	197.24***	9.27

Note. Full Retention Dataset Logistic Regression: The logistic regression model was statistically significant, $\chi^2(15) = 575.754$, $p < .05$. The model explained 45.2% (Nagelkerke R^2) of the variance in PRP Status and correctly classified 86.4% of cases. PRP = Participant Resource Pool; OR = odds ratio.
*$p < .05$. **$p < .01$. ***$p < .001$.

Discussion

The main goal of this study was to determine the efficacy and efficiency of the Logic model introduced by the MCUAAAR in 2007 in retaining participants in the volunteer research registry. The MCUAAAR logic model promotes involving older African American adults in research through study referrals and intensive follow-up through telephone surveys conducted by older adult volunteers as viable inputs for positive retention outcomes in the research volunteer registry. Our findings support the assumptions that referrals to research studies and intensive follow-up are activities that promote retention in a research volunteer registry. Both measures were found to increase the likelihood of remaining active in the research volunteer registry. We shared the study results with all members of the registry through our lay person newsletter which is mailed to each registry member.

During the period of January 2012 through June 2015, researchers conducting a total of 28 studies used the registry to recruit participants. A total of 3,096 research volunteer registry participants were referred to various studies, with 1,041 indicating that they accepted the offer to participate. Individuals were found to be more likely to remain active in the registry with each research study to which they were referred. These findings support the assumption that the MCUAAAR model introduced in 2007 promote retention of participation in

the registry through the activity of referring participants to research studies using the registry for recruitment. Although individual-level data were not available on individuals agreeing to participate, the mere act of keeping individuals engaged through study referrals and opportunities to participate in research is a key element in retaining participants in the registry. The referral of participants to studies leads to contact from researchers, and although individuals may not consent to being involved in studies with each recruitment attempt, these contacts reinforce a positive benefit of being a member of the registry.

In addition to the number of studies individuals were referred to for recruitment providing evidence of the MCUAAAR model in 2007 promoting retention of participation in the registry, the number of follow-up surveys administered to participants was also shown to have a positive influence on individuals remaining active in the registry. The MCUAAAR logic model highlights follow-up surveys as a retention-promoting activity and coincides with previous literature on retention findings that identify intensive follow-up and contact as a viable strategy for promoting retention. Intensive, constant follow-up contact serves to promote retention in two ways. First, constant contact keeps older adults engaged in the research volunteer registry through the reminders that they are involved in a group where they will have the opportunity to participate in research. Second, contact reduces the risk of losing

participants due to outdated contact information. At the time of the follow-up, phone survey participants are asked for any changes to email or address information, and if telephone surveyors fail to reach participants by telephone after three attempts, a reminder card is mailed to the last address on file for the individual, asking them to call and update their contact and health information with the registry.

There are some findings from our study that can be applied to recruitment and retention of African American participants in less well-established organizational settings. First, use of an advisory board is critically important for entry into the community. Second, offering knowledge as well as time to share that knowledge is a key ingredient to community research. Third, having an organized and easy process of sign up and permission to follow-up is helpful. Finally, sharing information both about the investigators and the study results helps establish lasting credibility.

Limitations

The main limitations of the study include generalizability. Research volunteer registry participants were recruited from only one geographical area (metro Detroit); recruitment of all participants for the registry only occurred at community outreach events. It is possible that retention rates and outcomes would have differed if research volunteer registry participants were recruited through flyers or phone calls in the community.

Demographic and medical/functional measures were related to retention. As participants' ages increased, they were less likely to remain active. Age also showed small, positive correlations with mobility scale totals and medical problems totals, and a negative correlation with education. As with age, higher scores on mobility limitations were found to have an inverse relationship with research volunteer registry retention. Individuals with more mobility-related issues were less likely to remain active in the research volunteer registry. Increased mobility limitations, medical problems, and lower levels of education increased the risk of vulnerability for older participants. This loss of participants due to age may be due to effects of social isolation (which may be an outcome of increased mobility-related issues and medical problems) and seems to be an area which needs further investigation. With older age comes more vulnerability, and it is important to understand why the registry is losing its most vulnerable participants.

Summary

This study provides a robust test of the Healthier Black Elders model of community engagement and research registry participation and retention. Retention was high in this longitudinal study, and although there were demographic and medical factors related to retention,

these were modest and indicate that retention was generally high for each age group and for those with disease and disability challenges.

References

Beskow, L. M., Sandler, R. S., & Weinberger, M. (2006). Research recruitment through U.S. central cancer registries: Balancing privacy and scientific issues. *American Journal of Public Health*, *96*, 1920-1926.

Bishop, W. P., Tiro, J. A., Craddock Lee, S. J., Bruce, C. M., & Skiner, C. S. (2011). Community events as viable sites for recruiting minority volunteers who agree to be contacted for future research. *Contemporary Clinical Trials*, *2*, 369-371.

Bishop, W. P., Tiro, J. A., Sanders, J. M., Craddock Lee, S. J., & Skinner, C. S. (2015). Effectiveness of a community research registry to recruit minority and underserved adults for health research. *Clinical and Transitional Science*, *1*, 82-84.

Bowen, D. J., Vu, T., & Kasten-Sportes, C. (2008). Increasing minority participant enrollment into a cancer family registry: The cancer genetics network. *Community Genetics*, *11*(4), 191-192.

Brown, D. R., & Topcu, M. (2003). Willingness to participate in clinical treatment research among older African Americans and Whites. *The Gerontologist*, *43*, 62-72.

Carlson, M., Jackson, J., Mandel, D., Blanchard, J., Holguin, J., Lai, M., . . . Clark, F. (2014). Predictors of retention among African American and Hispanic older adult research participants in the Well Elderly Randomized Control Trial. *Journal of Applied Gerontology*, *33*, 357-382.

Centers for Disease Control and Prevention. (2013). CDC Health Disparities and Inequalities Report—United States, 2013. *Morbidity and Mortality Weekly Report*, *62*(3). Retrieved from http://www.cdc.gov/mmwr/pdf/other/su6203.pdf

Chadiha, L. A., Washington, O. G., Lichtenberg, P. A., Green, C. R., Daniels, K. L., & Jackson, J. S. (2011). Building a registry of research volunteers among older urban African Americans: Recruitment processes and outcomes from a community-based partnership. *The Gerontologist*, *51*(Suppl. 1), S106-S115.

Dreer, L. E., Weston, J., & Owsley, C. (2014). Strategic planning for recruitment and retention of older African Americans in health promotion research programs. *Journal of Health Disparities Research and Practice*, *7*(2), 14-33.

Federal Interagency Forum on Aging-Related Statistics. (2010). *Older Americans 2010: Key indicators of well-being*. Retrieved from http://agingstats.gov/docs/PastReports/2010/OA2010.pdf

Ficker, L. C., Lysack, C. L., Hanna, M., & Lichtenberg, P. (2014). Perceived cognitive impairment among African American elders: Health and functional impairments in daily life. *Aging & Mental Health*, *18*, 471-480.

Green, M. A., Kim, M. M., Barber, S., Odulana, A. A., Godley, P. A., Howard, D. L., & Corbie-Smith, G. M. (2013). Connecting communities to health research: Development of the Project CONNECT minority research registry. *Contemporary Clinical Trials*, *35*(1), 1-7.

Hatchett, B. F., Holmes, K., Duran, D. A., & Davis, C. (2000). African Americans and research participation: The recruitment process. *Journal of Black Studies*, *31*, 664-675.

Hudson, S. V., Leventhal, H., Contrada, R., Leventhal, E. A., & Brownlee, S. (2000). Predicting retention for older African Americans in a community study and a clinical study: Does anything work? In S. E. Levkoff, P.R. Thomas, & P.F. Weitzman (Eds.), *Recruitment and retention in minority populations: Lessons learned in conducting research on health promotion and minority aging* (pp.67-78). New York, NY: Springer.

Jefferson, A. L., Lmabe, S., Chaisson, C., Palmisano, J., Horvath, K. J., & Karlawish, J. (2011). Clinical research participation among aging adults enrolled in an Alzheimer's disease center research registry. *Journal of Alzheimer's Disease*, *23*, 443-452.

Johnson, K. J., Mueller, N. L., Williams, K, & Gutman, D. H. (2014). Evaluation of participant recruitment methods to a rare disease online registry. *American Journal of Medical Genetics, Part A*, *164*, 1686-1694.

Lang, R., Kelkar, V. A., Byrd, J. R., Edwards, C. L., Pericak-Vance, M., & Byrd, G. S. (2013). African American participation in health-related research studies: Indicators for effective recruitment. *Journal of Public Health Management & Practice*, *19*, 110-118.

McHenry, J. C., Insel, K. C., Einstein, G. O., Vidrine, A. N., Koerner, K. M., & Morrow, D. G. (2015). Recruitment of older adults: Success may be in the details. *The Gerontologist*, *55*, 845-853.

Mody, L., Miller, D. K., McGloin, J. M., Div, M., Freeman, M., Marcantonio, E. R., . . . Studenski, S. (2008). Recruitment and retention of older adults in aging research. *Journal of the American Geriatrics Society*, *56*, 2340-2348.

Napoles-Springer, A. M., Grumbach, K., Alexander, M., Moreno-John, G., Forte, D., Rangel-Lugo, M., & Perez-Stable, E. J. (2000). Clinical research with older African Americans and Latinos. *Research on Aging, 22*, 668-691.

Phipps, E., Harris, D., Brown, N., Harralson, T., Brecher, A., Polansky, M., & Whyte, J. (2004). Investigation of ethnic differences in willingness to enroll in a rehabilitation research registry: A study of the Northeast Cognitive Rehabilitation Research Network. *American Journal of Physical Medicine & Rehabilitation*, *83*, 875-883.

Robinson, K. A., Dennison, C. R., Wayman, D. M., Pronovost, P. J., & Needham, D. M. (2007). Systematic review identifies number of strategies important for retaining study participants. *Journal of Clinical Epidemiology*, *60*, 757-765.

Rogers, J. L., Johnson, T. R. B., Brown, M. B., Lantz, P. M., Greene, A., & Smith, Y. (2007). Recruitment of women research participants: The Women's Health Registry at the University of Michigan. *Journal of Women's Health*, *16*, 721-728.

Saunders, K. T., Langbaum, J. B., Holt, C. J., Chen, W., High, N., Langlois, C., . . . Tariot, P. N. (2014). Arizona Alzheimer's Registry: Strategy and outcomes of a state-wide research recruitment. *The Journal of Prevention of Alzheimer's Disease*, *1*, 74-79.

Schwartz, M. F., Brecher, A. R., Whyte, J., & Klein, M. G. (2005). A patient registry for cognitive rehabilitation research: A strategy for balancing patients' privacy rights with researchers' need for access. *Archives of Physical Medicine and Rehabilitation*, *86*, 1807-1814.

Skinner, C. S., Schildkraut, J. M., Calingaert, B., Hoyo, C., Crankshaw, S. S., Fish, L., . . . Reid, L. (2008). Factors associated with African Americans' enrollment in a national cancer genetics registry. *Community Genetics*, *11*, 224-233.

Sood, J. R., & Stahl, S. M. (2011). Community Engagement and the Resource Centers for Minority Aging Research. *The Gerontologist, 51*, S5-S7.

Yancey, A. K., Ortega, A. N. & Kumanyika, S. K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1-28.