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Recruiting Black Americans in a Large Cohort Study: The Adventist Health Study-2 (AHS-2) Design, Methods and Participant Characteristics

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Abstract

Objective—The goal of the prospective Adventist Health Study-2 (AHS-2) was to examine the relationship between diet and risk of breast, prostate and colon cancers in Black and White participants. This paper describes the study design, recruitment methods, response rates, and characteristics of Blacks in the AHS-2, thus providing insights about effective strategies to recruit Blacks to participate in research studies.

Design—We designed a church-based recruitment model and trained local recruiters who used various strategies to recruit participants in their churches. Participants completed a 50-page self-administered dietary and lifestyle questionnaire.

Participants—Participants are Black Seventh-day Adventists, aged 30–109 years, and members of 1,209 Black churches throughout the United States and Canada.

Results—Approximately 48,328 Blacks from an estimated target group of over 90,000 signed up for the study and 25,087 completed the questionnaire, comprising about 26% of the larger 97,000 AHS-2-member cohort. Participants were diverse in age, geographic location, education, and income. Seventy percent were female with a median age of 59 years.

Conclusion—In spite of many recruitment challenges and barriers, we successfully recruited a large cohort whose data should provide some answers as to why Blacks have poorer health outcomes than several other ethnic groups, and help explain existing health disparities.

Keywords

Blacks; African Americans; Cohort Study; Cancer; Recruitment; Adventists

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Introduction

In the past, Blacks have been reluctant to participate in research studies for a number of reasons: fear of exploitation, mistrust of White researchers, time and hassle involved in participation, and perception of little benefit.¹⁻³ Researchers often fail to target Blacks because of perceived difficulty of recruitment and costly incentives sometimes required.^{2,3}

The development of a large nationwide cohort study in 2002 – known as Adventist Health Study-2 (AHS-2) – provided the opportunity to enroll Blacks. The study is the third major cohort study of Seventh-day Adventists (SDA or Adventists) in the United States. The Adventist church espouses a lifestyle that includes proscribed items (ie, no alcohol, tobacco, and pork), as well as regular physical activity. Members are also encouraged to eat a vegetarian diet, which usually contains modest quantities of eggs or dairy products.⁴

Previous Adventist Health Studies

Two earlier longitudinal studies, the Adventist Mortality Study (1958–1966),⁵ and the Adventist Health Study-1 (1976–1988)⁶ conducted in California have provided many helpful insights into diet-disease connections. Findings from these studies showed that non-Hispanic White Adventists have lower risks of heart disease, various cancers, diabetes, hypertension and arthritis than the general population.^{4,7} Compared to their California counterparts, Adventist men live 7.3 years longer, and Adventist women live 4.4 years longer with vegetarian Adventists living even longer.^{4,8}

Unfortunately, because of low demographic representation of Black Adventists in California at the time and recruitment barriers, very few Blacks enrolled in these earlier studies. Thus, researchers were unable to adequately investigate this group.

Current Adventist Health Study

The Adventist Health Study-2 was initially funded by the National Cancer Institute, and relates diet and lifestyle to cancer outcomes. Major aims are to investigate the associations between dietary soy, dairy, calcium, and long chain fatty acids, and the risk of prostate, colon, and breast cancers. We will also compare dietary patterns and other lifestyle risk factors, between racial groups, hoping to explain health disparities across populations. The objectives and general methodology of AHS-2 are described elsewhere in more detail.^{9,10}

The study has enrolled approximately 97,000 individuals aged ≥ 30 years from the United States and Canada. We made special efforts to recruit a large proportion of Blacks, and they represent 26% of the cohort. This article describes the methodology, strategies, successes, and challenges involved in recruiting Black Adventists throughout the United States and Canada.

In this article, we primarily use the term “Black” to refer to all individuals of African descent; however, we also use the term “African American” particularly when citing published studies.

Methods

Because the selected cohort was all Seventh-day Adventists, we chose local Adventist churches as the primary unit for participant recruitment. In the Black community, the church is the center of faith, community life, weekly activities, and social interactions. Local Adventist churches range in size from about 50 adult members to more than 1,000. Moreover, the majority of the 1,175 predominantly Black churches in the United States are organized and administered in regional units called regional conferences or regional

fellowships. While the local pastor remains very influential in his church, the somewhat hierarchical structure facilitates networking and communications. The nine regional conferences are located throughout the South, the Northeast and Mid-America; and on the West Coast, there are seven regional fellowships. The major concentration of Black churches and membership is in the Northeast and Southern regions of the United States (See Table 1). There are 34 churches in Ontario, Canada, whose memberships include a large majority of West Indians.

Pilot Studies of Recruitment Methods

The recruitment process and strategies were based on very limited experience with Blacks in previous Adventist studies in California and two more recent pilot studies.

The first of these pilot studies was conducted in three predominantly Black Adventist churches three years prior to AHS-2.² This study consisted of personal interviews and focus groups where the opinions of participants were solicited and recorded. These churches differed in size (300–1,200) and the socioeconomic make-up of their respective memberships; two were in California and the third in Pennsylvania. Various promotion and recruitment strategies and questionnaire collection approaches were evaluated and we obtained feedback from pastors, church leaders, church members, and a recruiter specializing in Black studies.

The findings of this pilot study mirror those of other Black research studies. Recruitment barriers identified were mistrust, fear of exploitation by White researchers, little perceived benefit for participation, and experiences of disrespectful treatment by educational and health care institutions.^{1–3} Issues of high importance were confidentiality, concerns about the use of social security numbers, respectful and culturally appropriate treatment of participants, meaningful and more motivating incentives, and on-going sharing of results in a way that highlighted and credited Black participation at every level of the study.

The second pilot study in Black Adventists was a dietary validation study. One challenge facing nutritional epidemiology is to measure long-term intake of nutrients accurately, including vitamins and minerals. Biological measurements are valuable and sometimes used to validate diet information obtained using food frequency questionnaire (FFQ). Validation studies of FFQ data in White populations have been published, but few are available among Black populations. Our goal in this validation study was to enroll 160 Black participants living in San Diego, Los Angeles, and San Francisco to complete a questionnaire, and of these, 100 would also be enrolled in a clinic and provide biological specimens. The successful experience^{2,11} of motivating pastors and members of these 30 Black churches to attend a clinic and complete an FFQ was a valuable introduction to the recruitment issues that we would face in AHS-2.

Overview of the AHS-2 Recruitment Plan and Philosophy

These pilot studies guided us in the development of a personalized recruitment plan involving the local church congregation, and a promotional model directed at the regional church administrative structure. The recruitment protocols and materials continued to be refined, based on experience and feedback, during the first year of recruitment to AHS-2.

The Loma Linda University (LLU) recruitment personnel were Black researchers familiar with the target population, the church structure, and barriers to recruitment. Two of the senior researchers traveled extensively, promoting the study, and conducting training programs for volunteer recruiters from local congregations. Three to five research assistants based at LLU kept in weekly email and telephone contact with the local church volunteer

recruiters. The research staff established and maintained a database of church personnel, and monitored the schedule and progress of enrollment in each church.

In order to build trust, respect, and inclusion, we solicited the support of the regional church administrators in planning the recruitment strategies and communications with churches. However, the pastor and his chosen volunteer recruiter were key persons for successful study recruitment in each church as they provided a face for the study to their congregation, and were contact persons for the recruitment team.

Early in planning we realized the importance of including and collaborating with a sister institution, Oakwood University in Alabama, from which the majority of Black Adventist pastors graduate with training in pastoral ministry. We established a research support office at Oakwood with an AHS-2 study co-investigator. The Oakwood alumni network was helpful in the AHS-2 study promotion and the recruitment of participants.

The Loma Linda University institutional review board approved all consent procedures, research protocols, materials, and questionnaires.

The Recruitment Goal

The overall AHS-2 recruitment goal was 105,000 participants, of which the Black cohort goal was 35,000 participants aged ≥ 30 years with no upper age limit. Limited data are available on the demographic make-up of the one million adult Adventists church members in the United States and Canada. At the start of the study, official church records estimated that there were approximately 250,000 Black/African American church members. After taking into account those aged < 30 years and those who did not attend church we estimated our target group, who were both age-eligible and regularly attending English-speaking members in Black Adventist churches, was approximately 90,000.

Based on the return rate of questionnaires in the validation pilot study and in consultation with local church pastors, we suggested specific church enrollment goals based on their estimates of weekly church attendance. On average, the enrollment goal in each church was about 18% of the listed membership, corresponding to about 50% of adult regular attendees.

The Main Recruitment Model

Promotional Resources—We developed training and promotional resources for the in-church recruitment campaign, including information brochures, posters, goal charts, sample announcements and presentations, and a 14-minute and a 3-minute video featuring key Black church leaders affirming the value of the study for improving Black health. Pastors and local volunteer recruiters received a training manual containing recruitment protocols and methods, motivation strategies, sample presentations, frequently asked questions and confidentiality and consent information. We updated this manual several times during the five-year recruitment period.

Recruitment Staging—We staged recruitment geographically over a four-year period from 2002 through 2006. In the United States, recruitment started on the West Coast and proceeded progressively to the East, and then to the South, conference-by-conference, and church-by-church.

Prior to the start of recruitment in each region, we obtained the endorsement from the regional conference president, who sent a personal letter to all pastors under his administration. Then we directly solicited the support of these local pastors, followed by their training and that of local volunteer recruiters from their churches. In each church

congregation, the main recruitment model included two weeks of preparation and ten weeks of enrollment and follow-up activities (See Table 2).

Buy-In and Support from Pastors—The pilot study taught us how vital the pastor's support was for recruitment and long-term follow-up; thus, we sought to reach each pastor personally to get his buy-in and support for the study. This support included the pastor making supportive announcements and allowing the church recruiters to show videos and otherwise promote the study during the church service time. The majority of pastors recognized the importance of the study and gave their support.

Pastors' Training—We arranged with conference administrators to schedule training times at one of the regular conference-initiated mandatory pastors' meetings. This provided the opportunity to talk to the pastors personally about what their endorsement of the study meant, and how their church could participate. We asked them for the names of possible local volunteer recruiters, and negotiated their church enrollment goal and recruitment start date. Pastors later received an agreement in the mail stipulating their church enrollment goal, details of a prorated monetary incentive of \$350, based on the percent of goal achieved, and their three-month recruitment timeline. We trained pastors who were unable to attend the pastors' meeting over the telephone.

Training Local Volunteer Recruiters—Volunteer recruiters received a letter and a phone call inviting them to attend a training session scheduled in their geographical area led by the same Black researchers who trained the pastors. Protocols and motivational strategies were reviewed. Recruiters who were unable to come to the training program received training by telephone. Each recruiter received the training manual, sample promotional resources, and a questionnaire.

Recruiters learned how to respond to some frequently asked questions such as: how we guard participant confidentiality, why we request social security numbers (SSNs) and how we use and protect SSNs. Recruiters also received agreements stipulating a monetary incentive of between \$100 and \$200 depending on the size of their church, and prorated against their church goal.

Pre-Enrollment Activities—Three weeks prior to their promotion or Celebration Day, we sent the recruiter the promotional resources and a supply of questionnaires. The research staff kept in contact with the recruiter to provide encouragement and answer questions. In the two-week lead-up to the start day, recruiters displayed the posters in the church foyer, printed announcements in the church bulletin, gave oral announcements, and showed the 14-minute video.

Celebration Day—On Celebration Day, to start enrollment, the short 3-minute video was shown, and the pastor was encouraged to preach a health sermon. At the close, the pastor invited all members aged ≥ 30 years to enroll in the study. The recruiter distributed questionnaires to all eligible participants and asked them to complete the enrollment card (name, address, name of church) on the front page of the questionnaire, which was then collected and mailed to the research office. Enrollment was complete when the participant mailed the completed questionnaire to the research office. A \$10 incentive was promised on completion of the questionnaire.

After the sermon on Celebration Day, recruiters were encouraged to organize a church potluck meal to provide a group atmosphere while participants independently began completing their questionnaires. This setting provided the opportunity for the recruiter to support, clarify, and give directions. Church members later completed their questionnaire at

home as it required them to look in their cupboards and check brand names for various food items and supplements.

Enrollment Follow-Up—During the next 8–10 weeks, the recruiter, through personal interaction with church members and announcements in church, continued to enroll members and encourage completion of the questionnaire. The research team stayed in telephone and email contact with the recruiter and pastor during the follow-up period. Weekly progress enrollment results were also sent, to be shared with each congregation. At intervals of four, seven and ten weeks following the distribution of the questionnaires, the research staff mailed reminder post cards to participants who had not yet returned the questionnaires. During active recruitment, the senior researchers attended regionally organized gathering of pastors and church members where participation in the study could be encouraged and its importance emphasized.

When a completed questionnaire was received, a letter of thanks was mailed to the participant, along with the previously promised \$10.

National Media Promotion—In 2004, a national church media campaign enhanced the main recruitment model. We promoted the study on Adventist national TV, in church publications and individual church newsletters. In addition, the first edition of the annual newsletter was sent to all enrollees and non-respondents starting year two. The newsletters gave updates on the study's progress, featured key health issues in the Black community (ie, obesity, prostate cancer), gave health tips, recipes, and featured Black Adventist seniors aged >95 sharing their secrets to longevity.

We evaluated a number of different recruitment strategies between February 2004 and October 2006, some across all Regions and other strategies limited to specific groups.

The Self-Administered Questionnaire

The self-administered comprehensive diet and lifestyle questionnaire was quite long (50 pages) and took, on average, 1.25–3.5 hours to complete. It consisted of nearly 2000 data fields divided into sections for medical history, diet, physical activity, female history, demographics and lifestyle, vitamin and mineral supplement use, and vegetarian food consumption. The food frequency component was the largest section.

Each questionnaire packet contained a cover letter, a pictorial food-serving chart to help with selecting standard serving sizes, a pencil and, a large and a small postage paid return-addressed envelope. The large envelope was for mailing the completed questionnaire and the smaller one was for mailing the tear-out back page of the questionnaire, which contained all personal data and the consent form. The main part of the questionnaire was identified only by number to preserve participant confidentiality.

Results

Demographic Characteristics of Participants

Table 3 reports demographic characteristics for 25,662 Black participants; 18,003 females ranging in age 30–105 with a mean age of 59.1 years old; and 7,659 males ranging in age from 30–109 with a mean age of 58.8 years old.

Regional Participation

The researchers trained and endeavored to keep in contact with more than 1,057 pastors and 1,175 local volunteer recruiters from the 1,209 churches during the recruitment campaign.

Of the 48,328 members of Black churches who signed up and received the questionnaire, nearly 25,087 returned a completed questionnaire. In addition, there were 575 Black study members who belonged to churches without an ethnic identity, and these members were recruited following a somewhat different promotion process.⁹ Overall, this represented 72% of the enrollment goal of 35,000 Black participants. Table 1 shows participants by region and the response rates. The percent return rate varied by region, with an average return rate of 51.9%. The highest returns were in the Lake Region (60.0%), Central States (59.6%), and Southwest Region (58.3%). The geographical distribution of participants very much reflects the distribution of Black Adventist church members across the United States. A large number of respondents lived on the East and Southeast Coast (NEC, SCC, SEFLC, ALEC, and ALWC [11,259]), with fewer on the West Coast (PAC and NPAC [3,063]), Mid-America (CSC & LRC [3,063]), and 5,484 from the South (SAC and SWRC). This excluded 1,743 members in other Black churches (OBC), who joined under a different promotional model,⁹ and 475 Blacks from Canadian churches (CC) (Table 1).

Approximately 413 of the 1209 churches (18%) attained more than 100% of their individual church goal or more. The smaller churches (<100 members) tended to have greater participation achieving on average 58.0% of their goals; medium sized churches (100–299 members) 55.0% of their goals; and large churches (300 + members) 49.1% of their goals (Table 4).

Whether the pastor and the local volunteer recruiter participated fully in the study made a difference to the overall church's response. In churches where the pastor both enrolled and returned the questionnaire, there was an average return rate for the church of 55.2%, compared to 38.7% in churches where the pastor did not complete enrollment by returning his questionnaire. Likewise, in churches where the recruiter both enrolled and returned his or her questionnaire, the average return rate was 59.2% compared to 35.4% where the recruiter enrolled but did not return his or her questionnaire. However, in the churches where neither the pastor nor the church recruiter enrolled in the study, there was an average return for the church of 35.8%; whereas when both the pastor and the church recruiter fully participated the average return was 67.3% (Table 4).

Discussion

While we did not reach our initial goal of 35,000 enrollees, we were satisfied with the 72% response as our target group from which we recruited was most likely only approximately 90,000 active and age-eligible church members, vs the 125,000 persons that we had first believed to be available for recruitment. Nationwide, membership lists kept by churches simply were not as accurate as we assumed based on local pilot studies. In fact, more than half (48,328) of the estimated eligible members, were interested and motivated enough to sign up for the study, though only half of these returned the completed questionnaire.

We have established a large and viable cohort of Black participants and collected extensive lifestyle and dietary data, sufficient to effectively address the aims of the study. We have demonstrated that it is possible to enroll a large number of Blacks in spite of the challenges and barriers that we faced. Many of those barriers encountered led us to valuable lessons learned and helped us build a strong recruitment approach that is the basis of what we hope to be an effective long-term strategy for follow-up of this cohort.

Our baseline questionnaire provides information about lifestyle characteristics and the prevalence of many medical disorders. Incidence data for cancer and other disorders will soon be collected and should provide numbers adequate for analysis by 2012.

Existing health disparities suggest an urgent need for a better understanding of the mechanisms behind the higher incidence of colon cancer, prostate cancer, and lower survival rates for breast cancer in Blacks compared to Whites.¹² Once this is achieved preventive strategies can be devised. We anticipate that AHS-2 will play a part in the resolution of these health disparities.

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Table 1

Regional conferences and fellowships: enrollments and responses

Region	Churches	Membership	Enrollment	Returns	% Returns
Pacific (PAC)	72	28,505	5,603	2,773	49.5
North Pacific (NPAC)	13	2,772	593	290	48.9
Lake Region Conference (LRC)	81	22,687	3,668	2,200	60.0
Southwest Region Conference (SWRC)	106	17,894	3,313	1,931	58.3
Central States Conference (CSC)	42	10,068	1,449	863	59.6
Allegheny West Conference (ALWC)	54	10,895	1,833	1,004	54.8
South Central Conference (SCC)	142	28,942	3,655	1,923	52.6
Allegheny East Conference (ALEC)	113	27,885	5,062	2,803	55.4
Southeastern Florida Conference (SEFLC)	138	28,032	4,218	2,138	50.7
Northeastern Conference (NEC)	157	44,171	7,100	3,391	47.8
South Atlantic Conference (SAC)	121	29,947	6,172	3,553	57.6
Other Black churches (OBC)	136	26,055	3,885	1,743	44.0
Canadian Conference (CC)	34	11,530	1,777	475	26.7
	1,209	289,383	48,328	25,087	51.5

Table 2

Local church recruitment schedule and activities

Weeks 1–2 Preparation	Week 3 Start of enrollment and “Celebration Sabbath”	Weeks 4–10 Intensive promotion and motivational activities	Weeks 11- until goal reached or the end of promotion Momentum continued
Poster in foyer	Health Sermon	Bulletin announcements	Weekly reports to recruiters & pastors
Bulletin	3 minute video	Verbal announcements	Reminder postcard
Announcements	Distribution surveys	3 minute video	Telephone calls
Bulletin fliers	Potluck for completing surveys	Group sessions	
Verbal announcement	Sunday brunch	Tag-team battle stations in foyer	
14 minute video	Announcements continue	Reminder phone calls & postcards	

Table 3Demographic characteristics of the AHS-2 Black cohort - *n* (% %)

Demographic	Men	Women
<i>N</i> =25,662	7,659 (29.85%)	18,003 (70.15%)
Age		
Range/Mean	30–109/58.82	30–105/59.13
30–39	492 (6.42%)	1177 (6.54%)
40–49	1624 (21.20%)	3755 (20.86%)
50–59	2147 (28.03%)	4856 (26.97%)
60–69	1658 (21.65%)	3972 (22.06%)
70–79	1112 (14.52%)	2627 (14.59%)
80–89	530 (6.92%)	1310 (7.28%)
90–99	84 (1.10%)	274 (1.52%)
100 +	12 (.16%)	32 (.18%)
Personal income of people who work		
<\$20,000	1176 (21.11%)	3508 (30.15%)
\$21,000–\$50,000	2775 (49.81%)	5704 (49.03%)
\$51,000–\$100,000	1358 (24.38%)	2194 (18.86%)
>\$100,000	262 (4.70%)	228 (1.96%)
Personal income of people who do not work		
<\$20,000	416 (75.50%)	1896 (82.15%)
\$21,000–\$50,000	118 (21.42%)	350 (15.16%)
\$51,000–\$100,000	16 (2.90%)	42 (1.82%)
>\$100,000	1 (.18%)	20 (0.87%)
Personal income of retired people		
<\$20,000	431 (46.44%)	1234 (64.30%)
\$21,000–\$50,000	412 (44.40%)	611 (31.84%)
\$51,000–\$100,000	76 (8.19%)	64 (3.34%)
>\$100,000	9 (.97%)	10 (0.52%)
Education		
No high school diploma	964 (12.84%)	2203 (12.54%)
High school diploma or associate degree	3616 (48.17%)	9590 (54.60%)
Bachelors	1350 (17.99%)	3213 (18.29%)
Graduate	1576 (21.00%)	2559 (14.57%)
Marital Status		
Married	5946 (78.89%)	8820 (50.18%)
Single, divorced, separated, widowed	1591 (21.11%)	8755 (49.82%)
Place of birth		
United States/Canada	4590 (60.49%)	11475 (64.32%)
Caribbean Islands	2076 (27.36%)	5089 (28.53%)
South Africa/other Africa	512 (6.75%)	401 (2.25%)
Other	410 (5.40%)	875 (4.90%)

Demographic	Men	Women
All the distributions are based on data without missing value for each variable		
Missing number and percentage are listed as following:		
Personal Income: 2234(9.75%)		Education: 591(2.30%)
Marital Status: 550(2.14%)		Origin of Birth: 234(0.91%)

Table 4

Recruitment response based on church size, pastor, and local recruiter participation

Church size	# churches (%)	% goal for sent Qs	% goal for returned Qs	Combined % for returned and sent Qs
<i>Effect of church size</i>				
Small: <100	535 (44.3%)	95.4	55.3	58.0
Medium: 100–299	379 (31.4%)	89.3	49.2	55.0
Large: ≥300	295 (24.4%)	85.1	41.8	49.1
Total or average	1209	87.5	45.4	51.9
<i>Effect of pastor participation</i>				
Not participate (enrolled)	544 (53.4%)	85.6	44.9	52.4
Q not returned	242 (23.7%)	80.5	38.7	48.1
Q returned	233 (22.9%)	98.0	55.2	56.4
Total or average	1019	87.4	45.9	52.5
<i>Effect of local volunteer recruiter participation</i>				
Not participate (enrolled)	595 (52.5%)	86.1	45.1	52.4
Q not returned	140 (12.3%)	79.2	35.4	44.7
Q returned	399 (35.2%)	107.9	59.2	54.8
Total or average	1134	89.2	47.2	53.0
<i>Effect of non-participation of pastor and local volunteer recruiter</i>				
Neither pastor or church recruiter participated (enrolled)	193	73.2	35.8	48.9
Both pastor and church recruiter enrolled and returned Q	120	114.9	67.3	58.6
Total or average	313	89.7	48.3	53.8

Q=questionnaire