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African American Men's and Women's Perceptions of Clinical Trials Research: Focusing on Prostate Cancer among a High-Risk Population in the South

Otis L. Owens, MPH, Dawnyéa D. Jackson, MS, Tracey L. Thomas, MA, MPH, Daniela B. Friedman, PhD, and James R. Hébert, ScD

Otis Owens, Dawnyéa Jackson, and Tracey Thomas are PhD candidates and Daniela Friedman is Associate Professor in the Department of Health Promotion, Education, and Behavior at the University of South Carolina (USC). Daniela Friedman is also a Core Member of the Statewide Cancer Prevention and Control Program at USC. James Hébert is Health Sciences Distinguished Professor and Carolina Trustee Professor in the Department of Epidemiology and Biostatistics and Director of the Statewide Cancer Prevention and Control Program at USC

Abstract

While African Americans are at significantly higher risk for developing certain cancers, they also have low rates of participation in cancer research, particularly clinical trials. This study assessed both African American men's and African American women's (1) knowledge of and participation in cancer-related clinical research and (2) barriers to and motivations for participating in clinical research. Data were collected from a total of 81 participants. Phase I of this research consisted of qualitative focus groups (all 81 participants). Phase II included quantitative pre/post survey data from an education program (56 participants). Findings from the study revealed that African American men and women had poor knowledge about clinical trials and the informed consent process, limited experience in participating in clinical trials, and they feared and mistrusted cancer research. Participants identified incentives, assurance of safety, knowledge and awareness, and benefiting others as motivators to participate in clinical trials research.

Keywords

African Americans; clinical trials; cancer research; participation; barriers; motivators

African Americans are more likely to develop and die from cancer than any other racial or ethnic group, in part owing to being diagnosed at later stage.¹⁻⁴ While African Americans are at significantly higher cancer risk,¹ they also have low rates of participation in cancer research, particularly clinical trials.⁵⁻⁷ Prostate cancer incidence and mortality are significantly higher in African-American men compared with White men; with incidence approximately 60% higher and mortality approximately 150% higher than in Whites.¹ In

Please address correspondence to: Daniela B. Friedman, PhD, Department of Health Promotion, Education, and Behavior, Arnold School of Public Health, University of South Carolina, 915 Greene Street #235, Columbia SC, 29208.

Conflicts of interest:

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Contributors:

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All authors had (and have) full access to all of the data in the study and take full responsibility for the integrity of the data and the accuracy of the results presented.

addition, the burden of this disease in the state of South Carolina is $\approx 50\%$ higher than the national average.^{8–10} Despite this, the two largest prostate cancer clinical trials to date included almost no African-American men.^{11,12} The results of these two studies indicated that screening using prostate-specific antigen (PSA) does not have a substantial effect on reducing the prostate cancer mortality rate, while leading to significant side effects. These findings, along with other scientific evidence, have led to the U.S Preventive Services Task Force's recommendation against routine PSA screening.¹³ The American Cancer Society (ACS), however, recommends that men make an informed decision with their doctor about whether or not to screen for prostate cancer.^{14,15} Participation in educational programs and clinical trials can help patients make more informed decisions by gaining knowledge about a particular health condition.^{16–18}

Despite federal mandates to include women and racial/ethnic minorities in clinical trials,^{19,20} African Americans generally represent <10% of participants in National Cancer Institute (NCI)-sponsored cancer prevention²¹ and treatment^{22,23} trials. Barriers to African Americans and other underserved groups' participation in cancer research and clinical trials have been documented widely at the patient, provider, and systems levels.^{24–26} At the patient level, barriers include mistrust of the medical system and of research,^{6,27–34} too-strict study eligibility criteria,^{27,35} low-socioeconomic status,^{7,27,36} lack of health insurance coverage,^{22,37} and limited education about trials.^{38–41} Providers' limited awareness or lack of referral to clinical trials also serve as barriers,^{41–44} and there has been evidence of institutional^{44,45} and structural⁴⁶ barriers to African-American recruitment and participation. Studies have also shown that African Americans express a need for race/ethnicity-specific disease risk information,^{47,48} and an appreciation of their unique beliefs, values, attitudes, and preferences.

Much of the research on the barriers and facilitators of African Americans' participation in cancer-specific trials has focused primarily on African-American women.^{6,7,34,38} Therefore, more research involving African-American men is warranted. Using CBPR principles,^{49,50} best practice recruitment methods, and culturally and linguistically appropriate communication strategies^{51,52} this pilot research project assessed the knowledge and attitudes of African-American men and female spouses, family members, or significant others regarding participation in prostate cancer research.

Methods

Phase 1: Formative focus groups

Twenty-two 90- to 120-minute focus groups (half with men and half with women), were conducted with a total of 81 participants (43 men, mean age 51.0 and 38 women, mean age 50.3) at a local public library in the southeast United States (i.e., South Carolina) (see Table 1 for participant demographics). Men and women were recruited with the assistance of clinical and community partners using various methods such as providing study announcements through media outlets (e.g., radio and newspaper), distributing flyers at facilities such as barber/beauty shops and churches, and spreading the message through word-of-mouth in the community.⁵³ Women were included in this study because prior research has shown that African-American women play an active role in finding health information for spouses and male relatives and in the health-related decisions of African-American men.^{54–56}

The focus groups aimed to assess participants': 1) current knowledge about and participation in clinical trials, 2) perceptions about clinical trial participation, 3) barriers and incentives for participation in clinical trials, and 4) preferred methods for receiving information about clinical trials. To assess these domains, five questions were included on a 19-item discussion

protocol that was co-developed by the research team, National Cancer Institute Community Cancer Centers Program partners, and the community advisory panel. All focus groups were audio-recorded and professionally transcribed.

Qualitative coding and thematic analysis—Transcripts were uploaded and organized into NVivo® 9,⁵⁷ a qualitative software program. Prior to the thematic analysis, a codebook was developed by members of the research team through an open-coding process.⁵⁸ This comprehensive list of codes was used to re-code all transcripts and facilitate the axial coding process conducted by two authors (DBF, OLO).⁵⁸ Axial coding is a process used to identify any thematic relationships that exist between codes.⁵⁸ Additionally, researchers implemented a constant comparison method by which themes were compared and contrasted across groups (men vs. women).⁵⁸

Prior to the focus group discussions, participants also were administered an 18-item survey with questions on demographics (e.g., sex, race, employment, marital status, income), and current, preferred, and feasible sources for health/cancer information (e.g., regular doctor, radio, email, text message). The data from the survey were analyzed using SPSS® 18.0⁵⁹ and nonparametric frequencies/percentages were calculated.

Phase 2: Pilot education intervention

The pilot education intervention, developed based on information gained from the community during the phase-1 focus groups, consisted of four one-hour education sessions. Fifty-six of the 81 focus group participants from phase-1 participated in the education sessions which were held in one week intervals over one month.⁵³ Sessions included topics that provided men and their female family members and friends with information related to prostate cancer and participation in clinical research such as: What are Risk Factors and Symptoms of Prostate Cancer? and What are clinical trials? Prior to and following the four education sessions, participants also were asked to complete a 75-question survey to assess potential changes in prostate cancer and clinical trial-related knowledge, perceptions, and behaviors. There were 39 questions that specifically assessed clinical trial attitudes and behaviors which were developed based on information from ClinicalTrial.gov's "Understanding Clinical Trials" article,¹⁸ research participation barriers from published literature, and information gained from the phase 1 focus groups. A total of 49 participants (or 87.5%) completed both pre- and post-test surveys, receiving a monetary incentive following the completion of both the pre- and post-test.

Pre/Post survey analysis—Nonparametric frequencies/percentages were calculated. The Wilcoxon Rank-Sum Test was used for assessing significant pre/post differences for all questions with Likert response options.⁶⁰ The McNemar–Bowker test, appropriate for non-binary responses,^{61, 62} was used to assess the significance of changes between pre- and post-tests for those items with response options of “yes, no, I don’t know.” All pre/post differences were considered statistically significant at $p < .05$.

Results

Phase 1: Focus group themes

Findings from the African-American men's and women's focus groups revealed a number of themes that fell into three categories: (1) knowledge, participation, and perception of clinical trials, (2) barriers to participation in clinical trials, and (3) motivation for participating in clinical trials. A ranking of themes and subthemes by gender has been provided in Table 2 to provide a comparative summary of how frequently various themes emerged based on the focus group composition (men versus women).

Knowledge, participation, and perceptions of clinical trials—Overall, male and female participants had limited knowledge about or previous participation in clinical trials, though many reported familiarity with the term “clinical trials.” Despite their lack of specific knowledge about clinical trials, both male and female participants had varying perceptions of what types of activities constitute clinical trials.

Men most often perceived clinical trials as experimental in nature and commonly referred to the term “guinea pig” when interpreting their perceptions of clinical trials. Women also perceived clinical trials as experimental, but less frequently than male participants. Female focus group participants also most often perceived clinical trials to be a type of research and described the research as pertaining to a specific disease or health condition. Men less often referred to clinical trials as research and their perceptions of research were typically not tied to any specific diseases or health conditions.

Both women and men perceived clinical trials to be associated with drugs/prescription medications, but their perceptions differed slightly. Women often perceived clinical trials as activities leading to the invention of new prescription drugs, general advancements in medicine, and the testing of a medication prior to being released into the marketplace. Men also associated prescription drugs with clinical trials, but instead perceived a clinical trial as a process by which new medications are issued to individual patients by their physicians in an effort to identify the most adequate treatment for a specific disease. For example, one man said, “I think of like [what] medicine doctors use, just test medicine, like if I was going to switch medications.”

Barriers to participation in clinical trials—When asked specifically why they believed African Americans have low participation in clinical trials research, both men and women most often discussed fear and mistrust of clinical research. Fear was commonly associated with the uncertainty, lack of knowledge, perceptions about the safety of clinical trial procedures, and the physical discomfort of participating in clinical trials. Mistrust was most often attributed to the historic, cultural stigma related to early unethical research studies performed on African-American communities (e.g., Tuskegee Syphilis Study). Female and male participants had similar views regarding mistrust being a barrier to African-American participation in clinical trials. For example, one female participant stated, “I just think the younger you are, in the Black community, the more likely you probably are going to participate. But older people that grew up during that time we heard more about the Tuskegee experiments and stuff and what happened to those men and their families.... I think it’s just mistrust and fear.”

The time commitment/schedule fit also was expressed by both male and female participants equally as a key barrier to participation in clinical trial research among African Americans. Comments related to participants’ individual experiences and their thoughts on why they feel that people in their community also do not participate in research. These time constraints were commonly linked to family obligations such as serving as a caretaker for a family member or work commitments.

Motivators for participation in clinical trials—When asked what incentives would motivate participants and people in their community to participate in clinical trials research, the most commonly reported incentives included money, assurance of safety while participating in the clinical trial, education regarding clinical trial procedures, the potential for the research to benefit someone in their family or community, encouragement from peers, and free healthcare. Male and female participants most often mentioned money as the most promising incentive for motivating community members to participate in clinical research.

Male participants asserted that safety and full disclosure of potential adverse effects would play an exceedingly important role in whether they or others in their communities would participate in a clinical trial. When asked what would motivate him and other African-American men to participate in a clinical trial, one male participant stated, “I think most of us would like to hear something like ‘no risk.’” Men also reported that having full disclosure of any procedures and potential side effects of prescribed treatments may motivate them to participate in a clinical trial. Women did not mention safety as a motivator for clinical trial participation.

After monetary incentives, women felt that helping someone in their family or community would be the strongest motivator for encouraging African Americans to participate in clinical research, particularly if it could “save the life” of someone they knew. Male participants less often mentioned helping someone as a motivator for promoting clinical trial participation. Male and female participants both reported that making the community more aware of clinical trials, and their specific protocols, would be a potential motivator for their participation.

Female participants reported peer encouragement as a stronger motivator for persuading them or others to participate in clinical trials than male participants. These women and men reported that encouragement could occur through the personal experience of an acquaintance (e.g., friend had a positive clinical trial experience) or through social support provided by family or friends. For example, a female participant commented on the persuasiveness of peer support to convince a person to participate in a clinical trial. She stated, “You know, you could say [to a peer], ‘Well, you know ... I’m going to a prostate study,’ ... You know, they might listen.”

Some male and female participants reported not having access to healthcare and therefore indicated that receiving free medications and/or other medical services could serve as an incentive for motivating African Americans to participate in clinical trials. These resources were reported less often in female and male groups compared with the other incentives. See Table 2 for a ranked list of themes and subthemes.

Phase 2: Education program survey results

The reported results are based on those items that exhibited the most meaningful changes between pre- and post-tests (see Table 3). Few met conventional criteria for significance study (and should not be expected to). Overall, these results fall into two categories: (1) clinical trial participation and (2) barriers to clinical trial participation. The participation category included information about participants’ previous involvement in clinical trials and their openness to participating in clinical trials in the future. The barriers to participation section included themes (e.g., distrust), which have been demonstrated in previous literature to have hindered African Americans from participating in clinical research.²⁴

Participation in clinical trials—The majority of participants reported never participating in a clinical trial and never being asked by their doctor to participate in clinical research. However, most male and female participants said that they would be open to being involved in a cancer clinical trial in the future. Following the four-week education intervention there was a slight, but non-significant, increase in participants’ openness to participate in a clinical trial in the future.

Men and women expressed similar likelihoods of participating in clinical trials at both pre- and post-test. Men, however, reported being open to participating in clinical trials in the future more often than women prior to the educational intervention. Following the intervention, both men and women reported being about equally open to participating in

clinical trials in the future. Additionally, male and female participants either strongly agreed or agreed that they would be willing to participate in clinical trials if they have a good understanding about why the trial is being done. These numbers were similar at post-test. Furthermore, there was a decrease from the pre- to the post-test in the number of men who believed that medical experiments can be done without them knowing about it.

Barriers to participation in clinical trials—The largest barrier reported by all respondents for not participating in a clinical trial in the past was time commitment/schedule fit followed by transportation, mistrust, poor compensation, informed consent being too complicated, and pressure from researchers. When stratified by sex, male respondents ranked transportation as the largest barrier to clinical trial participation at pre-test followed by time commitment/schedule fit, mistrust, poor compensation, informed consent being too complicated, and pressure from researchers. At post-test most men indicated time commitment/schedule fit as the top barrier. Other barriers included: mistrust, informed consent too complicated, transportation, compensation, and pressure from researchers.

At pre-test, the majority of women respondents reported transportation as a barrier to clinical trial participation. Mistrust, poor compensation, time commitment/schedule fit, and a too-complicated informed consent process were also reported as barriers. Pressure from researchers was not reported as a barrier at either pre-test or post-test. At post-test, time commitment/schedule fit was reported as the most common barrier to clinical trial participation among women. Other-barriers were less often reported. Table 3 presents a summary of barriers to participation in clinical trials.

Discussion

Our study assessed African-American men and women's 1) knowledge of and participation in clinical research and 2) barriers to and motivations for participation in clinical research. This study is one of few mixed methods studies to be conducted with African-American men and also one of the first to be conducted with both African-American men and women.³⁴ Determining to what extent African-American men and women understand and participate in clinical research and the barriers and motivators to their participation researchers can determine the most optimal strategies for engaging high-risk African-American communities in clinical research. It is essential that researchers, clinicians, and other stakeholders work together to eliminate barriers that can increase African Americans' participation in clinical trials research if we are to answer important questions about racial differences in what drives their high burden of cancer.¹ African Americans' involvement in clinical research could lead to advancements in medicine and public health practice that result in reducing health disparities. For example, a recent statement by the U.S. Preventive Services Task Force recommends that healthy men should not receive PSA screenings.¹³ However, the research evidence on which these recommendations were based includes virtually no African-American men, and none from high-risk groups in the American South (who have the highest prostate cancer rates in the world and who represent 55% of all Americans of African descent).^{8-12, 65, 66}

The findings from our study reveal many common themes among African-American men and women regarding clinical research; however, emphasis on particular themes varied. Overall, both male and female participants had poor knowledge about clinical trials and the informed consent process and reported only limited participation in clinical trials. When asked about the term "clinical trials," few participants had a clear idea of what constitutes a clinical trial. Some participants, instead, provided researchers with their personal perceptions of clinical research or what information they had learned from sources such as the media or other community members. Many times these perceptions were either incorrect

or negative (e.g., African-American men commonly confused the “trial and error” process of finding the correct medication dosage with their enrollment in a clinical trial), but likely stemmed from limited resources to inform the community about clinical trials and from the “guinea pig” stigma that permeates through the African-American community. Our qualitative data demonstrates that fear and mistrust were considered the most commonly reported themes followed by time commitment/schedule fit. These themes emerged similarly in male and female focus groups. Fear was typically associated with participants’ lack of knowledge about clinical trials and some of the misperceptions about clinical trials. Mistrust has stemmed from the history of African Americans who have participated in research, particularly the Tuskegee Syphilis study.⁶⁷ Mistrust and fear also have been shown as limiting factors in other studies which have examined barriers to African-American participants in clinical research.^{32, 68, 69} For example, Williams and colleagues found that mistrust was a “fundamental reason” why African Americans did not participate in Alzheimer’s Disease biomarker research.³²

Through our qualitative analysis, we also found that mistrust was a commonly reported barrier. However, mistrust was reported much less often in our quantitative findings at pre-test (8%) and post-test (15%) than the most commonly reported barrier (i.e., time commitment/schedule fit), which was reported by 32% of respondents at pre-test and 55% at post-test. Despite the differences in our qualitative and quantitative findings regarding the most commonly reported barriers, mistrust, fear, and time are the three prevailing barriers among our African American study participants.

Male and female participants reported a number of incentives that could help motivate African Americans to participate in clinical trials. Money was reported most often as a motivator for encouraging African Americans to participate. In a recent systematic review of 397 papers (37 studies), which discussed recruitment strategies, money was shown to significantly improve recruitment of patients into clinical trials.⁷⁰ Other studies also have shown money to be a motivating factor.^{71, 72} However, no prior studies found that money alone increased the recruitment of African Americans. In addition, other research shows that using money to recruit subjects is unethical because of undue coercion of an individual to participate or remain in a study because of the incentive as opposed to the potential risks or benefits.^{72–74}

The second most reported motivator by men was the assurance of safety, while women reported wanting general awareness and education. The third most reported motivator by men was receiving education. The third most reported motivator by women (4th most commonly reported among men) was helping someone such as a friend or family member. This finding is consistent with previous studies showing that individuals participated in clinical research because they knew it would benefit a family member or society as a whole.^{75, 76} Peer encouragement also was cited as a strong motivator by men and women, particularly when opinion leaders such as pastors and friends provided assurance regarding the safety and importance of clinical trials. Prior research has indicated that pastors and peers do play an influential role in African Americans’ participation in research and the adoption of healthier behavior.^{77, 78}

Finally, free healthcare was least often mentioned by men and women as a motivator for participation in clinical trials; however, lack of health insurance was demonstrated as an issue among this group. Prior research has shown that free healthcare may motivate African Americans’ participation in research,⁷⁹ particularly because there is a disparity in health insurance coverage among African Americans compared to their White counterparts.^{75, 79} Colon-Otero and colleagues specifically noted that national healthcare reform that ensures

universal healthcare coverage will diminish barriers to cancer clinical trial enrollment that uninsured and underinsured patients encounter.⁷⁹

The legacy of slavery, segregation, and unequal civil rights that spanned into the late 20th century give African Americans apprehension about trusting a predominantly White establishment.⁶ Furthermore, socioeconomic factors related to education, employment, and health insurance status also limit enrollment of African Americans into medical research.⁶ Our study demonstrates that many of the aforementioned barriers do, in fact, hinder African Americans from participating in cancer-related clinical trial research (e.g., mistrust, fear, time), but these barriers can be ameliorated or overcome through a combination of strategies which include culturally appropriate education, informing the community about eligible clinical research, clear disclosure about study procedures and benefits of research, schedule accommodation, and monetary incentives.

Based on our findings (Table 2) that men and women demonstrated similar overall clinical trial knowledge and types of barriers to participation, educational content and efforts to eliminate barriers to participation/recruitment (e.g., flexible hours) should be similar. However, educational content for men, in particular, should focus more on ameliorating their perception of clinical trials as guinea pig experiments, whereas education efforts for women should focus on improving their understanding of clinical trials beyond their knowledge of the term being related to research. Furthermore, institutions should keep the community informed about the successes of research that materialize through various studies. Lastly, clinical researchers should encourage those African Americans who do participate in clinical trials to share their experience with others and encourage them to become involved in future research. By striving to implement some of the aforementioned strategies using a community-engaged approach, we believe that cancer researchers can increase the participation of African Americans in their clinical studies.

Limitations

This mixed-methods study has limitations. The sample consisted of a small number of African-American men and women from one mid-sized city in a southern state. Therefore, the results from this study may not be generalizable to African-American men and women in the state or other regions of the U.S. In addition, the results cannot be generalized to other racial and ethnic groups. Despite these limitations, this study provided valuable information that can contribute to the future development of culturally appropriate strategies to recruit African-American men and women for participation in cancer-related clinical trials research. The mixed methods approach greatly strengthened the study design because it allowed us to use data from our formative qualitative research to customize an intervention that was appropriate for our participants and provided us with expansive information about barriers to clinical trial participation that we would otherwise have not received through the utilization of a strictly quantitative survey approach. In addition, including both men and women in our study provided us with a holistic, family-centered perspective on African Americans and clinical trials and provided a shared learning environment where men and women could participate in cancer-focused dialogue that we encouraged to extend beyond the education program.

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Table 1

Focus Group Participant Demographics and Cancer Information Seeking Behaviors (N=81)

GENDER	Men (N=43)		Women (N=38)	
AGE (years)	51.9 ± 9.8		50.3 ± 12.5	
MARITAL STATUS	Freq *	Percent	Freq *	Percent
Single	15	35.9%	10	26.3%
Married	21	48.8%	17	44.7%
Separated	2	4.7%	1	2.6%
Divorced	4	9.3%	4	10.5%
Widowed	1	2.3%	6	15.8%
EMPLOYMENT STATUS				
Full-Time	20	46.5	16	42.1%
Part-Time	5	11.6	3	7.9%
Retired	7	16.3	6	15.8%
Not Employed	11	25.6	13	34.2%
INCOME LEVEL				
<20,000/year	16	38.1	11	29.7%
\$20,000 to \$39,999	11	26.2	19	51.4%
\$40,000 to \$59,999	6	14.3	5	13.5%
\$60,000 to \$79,999	5	11.9	1	2.7%
\$80,000 to \$99,999	1	2.3	0	-
Over 100,000	3	7.1	1	2.7%
HIGHEST EDUCATION LEVEL				
Less than high school	8	19.5	3	8.1%
High School/GED	15	36.6	14	37.8%
Some college	10	24.4	14	37.8%
Bachelor's Degree	7	17.1	4	10.8%
Advanced/Graduate Degree	1	2.4	2	5.4%
SOURCES OF HEALTH/CANCER INFORMATION **				
Doctor	26	70.3%	18	62.1%
Health Educator	6	16.2%	10	34.5%
Family member/Friend	2	5.4%	0	-
Internet	2	5.4%	0	-
Radio	0	-	0	-
Newspaper	1	2.7%	0	-
Magazine	0	-	0	-
Television	0	-	0	-
Other	0	-	1	3.4%
PREFERRED METHOD FOR RECEIVING CANCER INFORMATION				

GENDER	Men (N=43)		Women (N=38)	
AGE (years)	51.9 ± 9.8		50.3 ± 12.5	
MARITAL STATUS	Freq *	Percent	Freq *	Percent
Doctor	26	70.3%	18	62.1%
Health Educator	6	16.2%	10	34.5%
Family member/Friend	2	5.4%	0	-
Internet	2	5.4%	0	-
Radio	0	-	0	-
Newspaper	1	2.7%	0	-
Magazine	0	-	0	-
Television	0	-	0	-
Other	0	-	1	3.4%

* Totals in each section vary due to missing responses and multiple selections

** Participants were asked to provide multiple answers if applicable

Table 2

Frequency of Mention of Phase 1 Focus Group Themes and Subthemes* (N=81)

FOCUS GROUP THEMES AND SUBTHEMES**	Ranking (Men)	Ranking (Women)
1. Clinical Trial Perceptions		
General Research	2	1
Prescription Drug Invention/Testing	3	3
Experimental/Guinea Pig	1	2
2. No Clinical Trial Participation	1	1
3. Lack of Clinical Trial Knowledge	1	1
4. Barriers to Participation in Clinical Trials		
Mistrust	1	1
Fear	2	2
Time Commitment/Schedule Fit	3	3
5. Motivation for Participation in Clinical Trials		
Money	1	1
Safety	2	-
Education	3	2
Help Someone	4	3
Peer Group Encouragement	5	4
Free Healthcare	6	5

* Table provides a comparison of the prominence of each theme or subtheme by gender.

** Each major theme is ranked separately. Major themes only display a ranking if they have no subthemes.

Table 3
 Barriers to Participation in Clinical Trials Research: Phase 2 Survey Results (Pre/Post Pilot Education Survey)

	All Participants (N=49) [*]		Men (N=25)		Women (N=24)	
	Pre-Test ^{**}	Post Test ^{**}	Pre-Test ^{**}	Post Test ^{**}	Pre-Test ^{**}	Post Test ^{**}
BARRIERS^{***}						
The time of the clinical trial did not fit my schedule	10/31 (32.3%)	18/33 (54.5%)	4/18 (22.0%)	11/20 (55.0%)	5/12 (41.6%)	6/12 (50.0%)
I did not have transportation to attend	7/25 (28.0%)	3/25 (12.0%)	6/15 (40.0%)	2/14 (14.3%)	7/9 (77.7%)	1/10 (10.0%)
I did not trust the researcher	2/25 (8.0%)	4/26 (15.4%)	2/10 (20.0%)	3/14 (21.4%)	8/14 (57.0%)	1/11 (9.1%)
The compensation was not good enough	2/25 (8.0%)	3/27 (11.1%)	2/10 (20.0%)	1/14 (7.1%)	7/14 (50.0%)	2/12 (16.6%)
The informed consent was too complicated	2/29 (7.0%)	3/26 (11.5%)	1/16 (6.3%)	2/13 (15.4%)	1/12 (8.3%)	1/12 (8.3%)
Researchers pressured me	1/24 (4.0%)	-	1/14 (7.1%)	-	-	-

^{*} 56 individuals participated in the education program. 49 people completed both pre/post surveys. Data from the 49 participants are reported here.

^{**} Totals in each section vary due to missing responses and multiple selections

^{***} Participants were asked to provide multiple answers if applicable