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# Perceptions of cancer clinical research among African American men in North Carolina

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## Abstract

**Objective—**The problem of cancer health disparities is substantial. Clinical trials are widely advocated as a means of reducing disparities and bringing state-of-the-art care to the broader community, where most cancer care is delivered. This study sought to develop a better understanding of why disproportionately few African American men enroll in clinical trials given their substantial cancer burden.

**Design—**This study applied community-based participatory research (CBPR) methods to design and conduct four focus groups of African American male cancer survivors and their caregivers in North Carolina.

**Results—**Among major themes, participants expressed confusion about the relationship between clinical trials, treatment, and research, signifying patient confusion and misinterpretation of common clinical trial terminology. Social norms including gender barriers and generational differences remain problematic; participants often reported that men do not talk about health issues, are unwilling to go to the doctor, and exhibit misapprehension and distrust regarding trials. Participants perceived this as detrimental to community health and expressed the need for more clarity in clinical trials information and a more fundamental social openness and communication about cancer detection and treatment.

**Conclusion—**Findings indicate the importance of clinical trials education in both traditional provider referral to trials and also in general patient navigation. To dispel pervasive misapprehension regarding placebos, clinical trials information should emphasize the role of standard care in modern cancer treatment trials. Many participants described willingness to

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participate in a trial upon physician recommendation, suggesting merit in improving patient-physician communication through culturally competent terminology and trial referral systems.

**Keywords**

Racial disparities; cancer; community-based participatory research; clinical research; African Americans

## Introduction

In the United States, compared to Caucasians, African Americans are diagnosed with more advanced cancer, experience a 23% higher cancer mortality rate, and have 5-year survival rates that are as much as 34% lower among the cancers of greatest incidence [1]. In North Carolina, the disparity is even more stark: compared to Caucasians, African Americans have a 52% greater colon cancer mortality rate, a 40% greater breast cancer mortality rate, and nearly three-fold greater prostate cancer mortality rate [2, 3]. Given these differences and the fact that African Americans comprise nearly one quarter of the state's population, [1, 4] the problem of cancer disparities in North Carolina is particularly acute.

A large portion of these acute racial differences is attributed to racial barriers to high-quality medical care and disparities in treatment [1, 5-7]. Clinical trials have been widely advocated by the Institute of Medicine and others as a means of reducing such disparities and bringing state-of-the-art care to individuals living in the broader community, where the majority of cancer care is delivered [8-10]. However, it is estimated that only 2% to 5% of the adult cancer population receives treatment through a National Cancer Institute (NCI)-sponsored clinical trial despite 80% of adults expressing an interest, half of whom indicate a willingness to enroll [11-14]. The acute cancer health disparities in North Carolina and elsewhere in the United States further suggest that greater African American participation in clinical trials is needed for this population to benefit from advances in cancer research [9].

The North Carolina Comprehensive Cancer Program has recognized the importance of cancer clinical trials and is addressing clinical trial enrollment as a part of the *State Cancer Control Plan*. [15] It is suspected that patterns of trial enrollment follow the concentrated patterns of health care resource availability in the state, which is fragmented and sees regions and populations substantially underserved, likely disproportionately affecting minorities [16]. However, despite the promise of clinical trials and the rising interest in facilitating access to them, little is known about the characteristics of individuals enrolling in cancer trials in North Carolina.

A recent examination by the North Carolina Comprehensive Cancer Program found that overall statewide enrollment rates in NCI trials were comparable with the national estimates, though rates were lowest among African American men [11, 13, 14]. In several counties, African American men had no enrollment whatsoever. The racial differences in the enrollment rates are particularly troubling as there are three medical schools, multiple major academic medical centers, and a provider-based cancer research network, and all offer clinical trials.

This study examined clinical trial enrollment among cancer patients in an eight county region in central North Carolina. To gain a better understanding of why the proportion of African American men enrolling in clinical trials is substantially lower than Caucasian men, we met with focus groups of African American men and their caregivers to understand their thoughts regarding clinical trials and perceived barriers to participation.

## Methods

### Conceptual model and approach

The study was guided by the Lay Health Advisor model, Flaskerud and Winslow's vulnerable populations framework, and the Behavioral Model for Vulnerable populations [17-19]. These were integrated to be comprehensive of the multiple, inter-relating characteristics associated with the health, health behaviors, and health service utilization of vulnerable populations. Combining frameworks allows us to move beyond individual-level factors that influence willingness to participate, to include the role of social networks and communities. The resulting framework allows us to explore and collect data on a variety of factors that may influence willingness to participate in research. Prior studies have shown that these factors exist on many levels and include those that are trial-related (e.g., unwillingness to enroll on a trial with a placebo arm, burdensome/time-intensive requirements), [12, 20, 21] patient-related (e.g., age, race, preferences, uncertainty, logistical concerns, education, additional cost), [22-24] physician-related (e.g., time constraints, protocol compliance issues, protocol incompatibility with normal practice, access to/ awareness of trials), [25-27] organization-related (e.g., distance to facility, staff resources, organizational support systems), [28-30] and environment-related (e.g., competition, local health policies, social norms including trust/distrust of research) [30-33].

This study applied community-based participatory research (CBPR) methods and was conducted within the context of the Carolina Community Network (CCN), the Community Networks Program in North Carolina funded by the NCI Center to Reduce Cancer Health Disparities (CRCHD).[1] The CCN is a regional cancer network aimed at reducing cancer disparities among adult African Americans in North Carolina.[2] CCN community research advocates (CRAs) and Community Advisory Board members affiliated with the CCN collaborated with academic researchers to develop study materials, recruit participants, analyze findings, and communicate them back to their communities.

### Focus groups and participants

Focus groups capture how participants think about an issue and articulate it in their own words, which is often enhanced by the interactive nature of the group [34-35]. A focus group moderator's script was developed, informed by the conceptual framework and the literature. In keeping with the CBPR approach, the focus group moderator guide was further refined through incorporating feedback from the CRAs. The final script addressed perceptions of participation in clinical trials, practical barriers to trial participation, experience with clinical trials and medical decision making, and treatment preferences. Although the same moderator's guide was used in all four groups, the moderator interactively adapted her approach and emphasis to be responsive to each group's needs and observations. The study

focused on male, African American cancer survivors in central North Carolina. Eligibility criteria included being an adult of any age who is physically and cognitively capable of participating, with a history of any cancer regardless of cancer treatment approach, actual participation in a randomized clinical trial, or year of diagnosis – though participants may not be undergoing treatment at the time of the focus groups. Four focus groups of 5 to 11 participants were conducted at various times and locations convenient for participants. Participants included cancer survivors and their caregivers or loved ones, who were included in order to both gain their insight and also to help participants feel more comfortable in the focus group setting. Participants were recruited and focus groups were conducted over a three-month recruitment period in mid-2009. Recruitment occurred through county and hospital employee emails, churches, male civic organizations, health fairs, and newspaper media, as well as by word-of-mouth through community research partners. Each group lasted approximately two hours, and was audio taped and transcribed verbatim. Each participant received a $60 gift card. Information on resources available at local cancer programs was provided, as were NCI materials on clinical trials and cancer treatment.

### Data analysis

A coding scheme was developed based on the conceptual framework and literature. New codes were added based on themes that emerged during the analysis process. All transcripts were first coded using Atlas.ti software by a member of the research team. Again, through CBPR methods, three CRAs each reviewed all four manuscripts. The CRAs contributed their in-depth knowledge of the community to help identify themes specific to the study population. They coded paper copies of the transcripts and returned them to the investigators. All four coded versions of each transcript were reviewed to identify areas to reconcile codes and recognize themes identified by the CRAs. A debriefing session was held after all transcripts had been coded to give all five CRA members an opportunity to reflect on the experience of coding, share the results of the focus groups, and discuss next steps and recommendations.

## Results

Overall, the four focus groups included thirty participants, including fourteen cancer survivors and sixteen caregivers (See Table 1). Eleven of the cancer survivors had been diagnosed with and treated for prostate cancer, two were colon cancer survivors, and one was an oral cancer survivor. None of the cancer survivors were currently undergoing treatment.

Each of the four focus groups touched on a variety of topics in their discussion, but four major themes were collaboratively identified with the CRAs as being most relevant among all groups: understanding of research terminology, trial protocol and perception of research, relationships with physicians, and social norms (See Table 2). Upon analysis, the perspectives of the male cancer survivors and their caregivers were not systematically different, and differentiating responses between these groups of participants was not perceived to change the findings or the conclusions we have drawn from them.

### Theme 1: Understanding of research terminology

There was confusion among participants in all four focus groups about the relationships between treatment, research, and clinical trials, as well as inconsistency in interpretation of clinical trials terminology. At the beginning of each focus group, the moderator introduced several terms including “clinical research,” “medical research,” “research study,” “comparative research,” and “comparative examination,” among others. The moderator asked participants to describe their definitions of these terms and decide by consensus which they wanted to use to refer to clinical trials during the session. There was no consensus among groups as to the meaning of any single term, and each group chose a different preferred term. “Clinical trial,” “medical research,” and “research study” were perceived both positively and negatively by different groups, while “comparative research” and “comparative examination” were generally perceived neutrally. Although the moderator explained these terms at the beginning of each session, there were many instances where participants used them incorrectly, especially during discussions about willingness to participate in trials. While few expressed an initial willingness to consider participating in a clinical treatment trial, in general, participants were more willing to consider clinical treatment trials as the discussion progressed. Most seemed willing to participate in a trial if it only involved giving information.

Participants indicated an increased willingness to enroll in a trial if doing so was recommended by their health care provider. When asked if recommendation from a doctor would change the willingness to participate in a cancer research study for cancer treatment, one participant expressed:

> “It would depend on what all was involved in it. You say research but you’re not saying trial or clinical trial because if it’s just research then that doesn’t involve a clinical trial then maybe so.”

The following exchange from another group highlights the perceived difference between clinical trials and treatment:

> P1: “When I hear associating clinical trial with treatment, and I don’t associate a clinical trial…with a treatment.”
>
> Moderator: “What do you think of instead of treatment?”
>
> P1: “Well it’s a trial to find out what method might be best for a treatment.”

### Theme 2: Clinical trial protocol and perception of research

Almost all participants believed that placebos (i.e., receiving no treatment, sugar pills) were in use in most cancer treatment trials, and that use of placebos is completely unacceptable. As one participant said in response to why she would not participate in a treatment trial:

> “Well one thing is … this placebo thing. I’m not a big believer in that and I think it’s sort of cruel.”

The Tuskegee Syphilis Study came up often, particularly in regard to the use of placebos and research ethics. From 1932 to 1972 the Tuskegee study examined the progression of untreated syphilis in poor black men. It is synonymous with controversial research ethics

because participants believed they were receiving free health care though they were denied treatment for syphilis despite contemporary knowledge of cures for the disease. Participants were not necessarily clear on the details of the Tuskegee study, but were quick to associate clinical trials with it. A related theme of experimentation emerged, and participants did not want to be "experimented on." When asked about the risks of participating in a research study, one participant expressed his distrust:

> "Well one of the risks is first of all if you're a guinea pig if they use a drug as an experimentation – so they don't know what the reaction is going to be so you may get some medical repercussions from it and that way too one of the risks you might be signing away your life, waiving your rights to your life."

Participants expressed their concern about what would be involved in participation, both in terms of treatment and their own commitment. They worried that they would be forced to continue an ineffective treatment if they participated and that they would lose control over treatment decisions. Several participants expressed unwillingness to participate in trials that required the cessation of other prescription drugs, as illustrated in the following exchange:

> P1: "I was trying to look for some new medications that might possibly help. In that search for different things, I've considered these studies just for that purpose alone and part of the reason why I didn't participate… is because of the kind of stuff they have you sign off on that they say you can't do in order to participate in these studies… ."
>
> Moderator: "What are some of the reasons you didn't participate?"
>
> P1: "What I just mentioned before. The fact that they make you say that you can't take certain medications, your current medication. They make you list, tell them what you're taking…and they said, 'well, for the purpose of this study you can't take any medication other than what we give you in order to find out if this works or not…' and then…you may have a placebo or they're giving you the new stuff. You won't know. [Agreement from group members.] But then all the time you're struggling with what…you have and sometimes, especially what I have, it's not a comfortable thing and not getting medication or treatment or whatever to help you."

Some participants were distrustful of clinical trials in general. In one group, one man stated that he believed that all trials, even those run by the National Cancer Institute, were backed by pharmaceutical companies and designed to get approval for new drugs to increase revenue streams. Almost all participants in that particular group agreed with this belief, and many further believed that this led to skewed results.

### Theme 3: Relationship with physicians

In general, participants expressed great trust in their physicians. Few participants had discussed clinical trial participation with their doctor, but no one felt it would be inappropriate for their doctor to bring up the topic. There was some variation in how participants wanted their doctors to introduce trials and the types of information they wanted their physicians to provide. When asked how they would respond if their doctor suggested

participation in a clinical treatment trial, most participants said they would be open to participation if their doctor thought it was a good idea. One man stated:

> "I have confidence in [the doctor] and I assume that he would have confidence, he's for my welfare and if he said somebody else could do better [offer a better treatment], I would do it."

There was lack of agreement on whether physicians should receive incentives for enrolling patients in clinical trials as well as whether disclosure of incentives would affect their relationship with their physician. Roughly half of the participants expressed wariness of their physician's motives for enrolling them in a trial if they were being compensated by study sponsors. Although one participant felt that physicians' motives could be so skewed as to encourage them to misdiagnose patients, most participants simply felt that monetary incentives for physicians could result in misplaced priorities. As one participant shared:

> "When the doctor begins getting compensation I think they may lose your best interests. They may start thinking more about themselves when they're being compensated. Like the more patients I can get to do this trial then the more money I'm going to get so they may begin to lose their patients' best interest."

Others suggested that such compensation would not be a concern if their doctor was upfront and honest with them. As one participant stated:

> "It wouldn't bother me because I have so much more appreciation for doctors now, nurses…the reason I'm still here is because of the doctor who operated on me so I wouldn't care if they gave him the whole Fort Knox."

### Theme 4: Social norms

When asked who participated in clinical trials, participants said "whites," "Anglos," "Caucasians," and "women." They also agreed that some participants were like themselves, though most were not. They generally acknowledged that Caucasians and African Americans may respond differently to a treatment. For example, when asked why African American men might not want to participate in a trial, one participant said:

> "Like you said, it's clear that a lot of African Americans don't participate in clinical trials so even though my doctor is sitting here telling me that you know it has great promise for the type of cancer I have, how many people like me have you actually tested? How do you know it's going to work on someone like me?"

Participants brought up generational differences as a barrier to trial participation. They expressed the idea that men do not want to talk about their medical problems and that older generations of men especially would not be comfortable discussing treatment with family. One participant said that black men will not go to the doctor so they may "miss out" on opportunities for education and preventive care, while another participant felt that discussing cancer with a family member who was receiving cancer treatment was "off limits."

Participants recognized that this silence related to disease and treatment was detrimental to the health of their community. They talked freely about their specific treatments and

diagnoses and encouraged each other to have these conversations in public to educate others. As one participant reflected:

> "More of like my grandfather, you know, he wouldn't sit around a table like this and talk about it because it was just something they were not taught to do but as we come on now and go and things are changing we're more [likely] to open up because from my standpoint of being concerned that if I can learn something, if I have to go through something and then whatever I go through and learn, I want to help someone else."

## Discussion

In the face of stark racial differences in cancer clinical trial enrollment rates, this qualitative study sought to understand reasons for the relatively low enrollment of African American men given their substantial cancer burden. Through in-depth focus groups with African American male cancer survivors and their caregivers, several major and consistent themes emerged (Table 2). Among them, there was confusion about the relationship between clinical trials, treatment, and research, signifying that the common terms researchers and physicians use to describe clinical trials often have a different meaning to patients. Participants expressed confusion about trial protocols and assumed that all cancer treatment trials involve a placebo, the fear of which was clearly identified as contributory to participants' unwillingness to participate in trials. Despite this somewhat misapprehensive disfavor, participants expressed great trust in their physicians, suggesting that physician recommendation may be a powerful tool in overcoming the historical legacy of discrimination African Americans have experienced in medical research [36, 37]. Other factors such as generational differences suggest that the barriers to clinical trial participation are multidimensional, which must be considered when developing strategies to improve enrollment.

Defining and discussing the various clinical research terms at the beginning of each focus group was intended to ensure all participants had similar baseline knowledge and related terminology about the topic area. The finding that participants were confused and unable to agree upon the terminology for clinical trials was unexpectedly insightful, though is consistent with prior research [38] and indicates that physicians and researchers must be conscious of how their chosen term for clinical trials is received by patients, as some terms may elicit negative reactions or increase confusion. Patients' ability to make informed decisions about cancer trials may be severely impaired if they enter the discussion on unstable footing with confusion regarding terminology and misperception of trial protocols. Discussion and interpretation of findings with CRAs revealed a concern over the low health literacy demonstrated by participants, echoing prior research [39]. The CRAs, and the research team by extension, had erroneously presumed that patients with experience in the cancer care system would have been better informed about clinical trials than those who have not been through cancer treatment. These findings suggest merit in emphasizing clinical trials education in patient navigation.

Whereas participants did not come to consensus about trial terminology, they expressed initial confusion though came to general agreement about trial protocol. Two of the four groups brought up the Tuskegee Syphilis Study and spoke of fear of being "experimented on" or being used as a "guinea pig," consistent with prior related studies [37, 40-42]. Participants' substantial concern regarding placebos in the first focus group necessitated amending subsequent focus group scripts to educate remaining groups' participants early in the sessions about contemporary cancer clinical trials. This misconception of placebo use likely arises from lack of education about trial design, which has previously been shown to be a barrier to clinical trials enrollment among African Americans [41]. Clearly, providing information about contemporary trial design should be a component of any future intervention or trial promotion literature.

Considering participants' high-level of distrust in research, the high-level of trust in their physicians was somewhat unexpected. Previous studies have reported that distrust of physicians is a barrier to research participation, [36, 37] but this finding has not been consistent [43]. Although some participants had misgivings about their physician receiving compensation for enrolling patients in trials, they generally believed that their physicians were acting in their best interest. Establishing a patient-physician trust relationship and obtaining physician referral have been identified as important points for increasing clinical trial enrollment among other cancer populations, [44, 45] and are likely also relevant in this population since many participants described increased willingness to participate in a trial if their physician recommended it.

It is important to consider that the positive patient-physician relationship we observed could be a function of our study population, half of whom were cancer survivors. Moreover, none of the participants were actively receiving cancer treatment – they had received treatment and were presumptively "cured." This may have created more trust and faith in their physician than they would have had if treatment had not been successful, they had not yet initiated treatment, or they had never been diagnosed with cancer. Future focus groups with patients who are actively undergoing treatment for cancer or with healthy men without a cancer diagnosis may shed light on the baseline status of the positive patient-physician relationship we observed.

The focus groups revealed that social norms associated with gender and age remain barriers to African American men's participation. Participants consistently reported that men in the community do not talk about health issues. Generational differences may further hinder communication, as older men more often indicated that they were unwilling to go to the doctor or talk about health issues, a finding which may contribute to the fact that older patients are less likely to enroll in clinical trials [46]. This was discussed as detrimental to community health, and participants expressed the need for more open communication about cancer detection and treatment. Participants perceived communication as a valuable way to spread information and dispel myths about trials, and increase individuals' awareness of their health. Given that this perspective came from individuals who were sufficiently willing to discuss their cancer experience that they volunteered to participate in our study, this finding may be more prevalent in our study population than the general population. Regardless, enthusiasm for talking about their experience has been identified as valuable in

promoting outreach, opening communication, and enhancing research participation elsewhere in the African American community [40, 41].

This study clearly demonstrates the value of CBPR. Multiple elements of this study were strengthened as a function of community-members' familiarity with the study population and the community at large. Most notably, our community collaborators were superior in identifying and richly characterizing the theme of social norms across multiple groups and contexts. Greatly enhanced through their interpretation, this theme underscores the need for community education to change attitudes towards care-seeking behaviors, and is an exemplar for strengthening future research.

In addition to limitations noted earlier, generalizability of study findings may be limited by the geographic area in which the research was conducted. All participants lived in counties that were within close proximity to major academic medical centers, and most received their cancer treatment from local cancer providers. Thus, individuals receiving care within this community may have different experiences within the health care system compared to those living in other areas with limited access to care, and this may be associated with their perception of clinical trials. Given that our sample size that was small, though typical of a focus group study, we are well-served to validate study findings through additional research to strengthen the general recommendations for how study findings may be acted on. Current research is addressing this through focus groups among African American women and in other areas of the state, and will also examine differential perspectives of survivors and caregivers, which may further refine how to inform future interventions to improve clinical trial access and enrollment.

Regardless of these limitations, our findings point to several recommendations for increasing clinical trial enrollment among African American men in North Carolina. The findings clearly indicate the need for basic information and education about cancer clinical trials. As such, a top priority for promoting enrollment in clinical trials in this community should be education of not only community members, but also physicians and researchers, including terminology that resonates with the local population. Further research on the preferred terms for clinical trials is needed to help facilitate physicians tailor their discussions to improve patient-physician communication. Information about clinical trials delivered through pamphlets, fliers, or interpersonal communication should emphasize the role of standard care in modern cancer treatment trials to dispel placebo-related fears.

Finally, identifying optimal points of intervention to educate the African American community should be evaluated. While this study did not center on organization-related characteristics, one of our conceptual models suggests merit in their examination. Indeed, several of the issues raised in these focus groups may be addressed through enhancing organizational support systems and staff training. Refining the approach and timing of patient referral to a trial may contribute to greater patient receptivity. On a larger, community level, given the willingness to participate in non-treatment trials and the altruism shown by participants in the current study, perhaps non-treatment trials can be used to establish familiarity with clinical trials in general and increase acceptability of treatment trials within the community. Ongoing studies such as the NCI-funded pilot study *Community*

*Bridges to Cancer Clinical Trials*, will help further inform the cancer research community regarding these and related issues of community knowledge and favorable attitudes towards clinical trials [47].

In conclusion, the findings from this study provide the foundation for developing culturally competent interventions to increase cancer clinical trial enrollment among African American men in North Carolina, which may contribute to a reduction in the severe racial disparities in incidence and mortality. These findings will directly and immediately inform the North Carolina Comprehensive Cancer Program and other regional efforts aimed at enhancing minority cancer clinical trial accrual, and will be informative to other clinical research stakeholders nationally.

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**Table 1**

Characteristics of focus group participants

| Characteristics | n | (%) |
|---|---|---|
| Total Participants (n) | 30 | |
| -Cancer Survivor | 14 | (47%) |
| -Caregiver | 16 | (53%) |
| Age, years (mean) | 57.0 | |
| Male (%) | 21 | (70%) |
| Work full-time (%) | 12 | (40%) |
| Married (%) | 20 | (67%) |
| College graduate (%) | 15 | (50%) |
| Household Income >40k (%) | 20 | (67%) |
| Have regular source of care (%) | 27 | (90%) |

## Table 2

Summary of key findings and recommendations

| | |
|---|---|
| **1** | Understanding of research terminology: Focus groups consistently expressed confusion and were unable to reach consensus about the relationship between clinical trials, treatment, and research, signifying that common terminology used to describe clinical trials often has a different meaning to cancer patients and their caregivers. |
| | – These findings suggest merit in emphasizing clinical trials education in not only traditional provider referral to cancer clinical trials, but also broader patient navigation. |
| **2** | Perception of research and clinical trial protocol: Pervasive misperception that placebos are a central part of clinical research remains a major source of distrust and concern regarding clinical research. |
| | – To dispel pervasive misapprehension regarding the use of placebos, clinical trials information should emphasize the role of standard care in modern cancer treatment trials. |
| **3** | Relationships with physicians: Focus groups expressed great trust in their physicians, and many participants described greater willingness to participate in a trial if their physician recommended it. |
| | – Establishing trust in the physician-patient relationship could be an effective leverage point for increasing trial enrollment |
| **4** | Social norms: Social norms including generational and gender barriers remain problematic - participants often reported that men in the community do not talk about health issues. Generational differences appear relevant, as older men more often indicated unwillingness to go to the doctor or talk about health issues, and also exhibited more misapprehension and distrust regarding clinical trials. |
| | – Participants perceived this as detrimental to community health, and expressed need for greater social openness and communication about cancer detection and treatment as a more fundamental component to improving clinical trial participation. |