CancerSupportCommunity.org
Uniting The Wellness Community and Gilda’s Club Worldwide
Clinical Trials Information Needs of Black & African American Cancer Patients & Caregivers

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Learning Objectives

- Understand the information needs about clinical trials among Black and African Americans.
- Identify perceptions, attitudes, and beliefs about clinical trials among Black and African Americans.
- Identify two barriers to participation in clinical trials among Black and African Americans.
Cancer Support Community

OUR MISSION:
To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.
Frankly Speaking About Cancer®

- High quality, evidence-based educational programming for cancer patients, survivors, caregivers, and health care professionals
- Frankly Speaking About Cancer (FSAC)
  - Provide easy to understand in-depth coverage of topics relevant to those affected by cancer
  - To educate and to empower cancer patients, survivors, caregivers, and health care professionals
  - Topics are tumor type-specific (e.g. melanoma, lung, metastatic breast, liver, colorectal, multiple myeloma) or cross-tumors (e.g. immunotherapy, clinical trials, treatments and side effects)
  - Provide up-to-date content and reflect new advances in knowledge
CSC’s Frankly Speaking About Cancer: Clinical Trials Educational Materials

Photo Narrative

• **innovative, award-winning publication** that takes a **photojournalistic approach** to refreshing the conversation about clinical trials

• features **real patients talking with their families and health care teams** about the issues they face when considering a clinical trial

• **debunks myths** about clinical trials in patients’ own words and highlights the importance of becoming an active partner with one’s health care team.

• after culturally adapting this for Spanish speakers in the US, CSC wanted to ensure that our materials were culturally-relevant for Blacks & African Americans in the US.

Clinical Trials booklet

• provides **deeper information** to learn about clinical trials as a treatment option and what participation in a clinical trial entails

• Both are available in print and downloadable PDF formats
Participation of African Americans in Clinical Trials

• Fewer than 6% of cancer clinical trial enrollees are Black and African American, although they comprise 12% of the U.S. population

• Potential barriers to cancer clinical trials participation among Black and African Americans include, among others:
  – Fear, suspicion, and mistrust of researchers and medical research
  – Fear of possible side effects or procedures
  – Logistical concerns such as lack of transportation, family and work commitments, financial burdens

• Potential barriers to cancer clinical trials among the medical community include, among other:
  – Time to find clinical trials that patients are eligible to participate in
  – Researcher bias exist in their assumption related to the willingness of minorities to participate in research
Addressing Clinical Trials Participation Barriers among African Americans

- CSC is committed to increase and improve minority and underserved populations’ access to comprehensive, culturally appropriate cancer education, information and services.

- Use of culturally sensitive approaches to enhance ethnic minorities’ participation is important for advancing cancer care and eliminating health disparities.

- With the impact of low clinical trials participation among AAs in mind, CSC conducted community research to gain insights about the information needs of African Americans about clinical trials.
CSC’s Community Research Purpose

• Understand the information needs of Black and African American cancer patients and caregivers to support the development of culturally sensitive health education programs

• Increased understanding about effective ways to communicate with Blacks and African Americans to:
  – Raise awareness about clinical trials
  – Provide context about the importance of research and how clinical trials impact outcomes both on a personal and societal level, and
  – Provide tools to foster an open dialogue with their healthcare team
Methodology

• In 2019, Cancer Support Community (CSC) facilitated three in-person focus groups with Black and African American cancer survivors and caregivers in Florida, New York and Tennessee

• Each group discussion was led by the same facilitator. The discussion guide explored participants’ unmet educational needs about clinical trials

• The discussions were transcribed; thematic content was categorized and coded, and frequencies of categories were tabulated

• In total 29 patients and caregivers participated in the focus group. FL (N=12), NY (N=9), and TN (N=8). All participants self-identified as Black or African American with a few identifying as Caribbean American
Participants Characteristics

- Caregiver: 7 (Florida: 2, Tennessee: 5, New York: 0)
- Patient: 6 (Florida: 5, Tennessee: 1, New York: 0)
- Patient and Caregiver: 7 (Florida: 3, Tennessee: 1, New York: 2)

Total # of Participants: 29
Participants Characteristics

Total # of Participants: 29

Florida: 12 (1 Male, 11 Female)
Tennessee: 9 (0 Male, 9 Female)
New York: 8 (0 Male, 8 Female)
Main Themes: Important Topics for the African American Population

- Being Black/African American
- Medical Ethics/Mistrust
- Spirituality
- Support
- Understanding Clinical Trials
## Sub Themes for Being Black/African American

<table>
<thead>
<tr>
<th>Trust/Experiences (ie testimonials)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
</tr>
<tr>
<td>Emotions (e.g., fear, anger, etc)</td>
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I would like to hear what other groups of Black folks think. Not only Afro-American, Caribbean, different Blacks, not only one different group within the Black community. (FL)

There’s a lot of communities in which you say the word C, it is a death trap, it took me four-and-a-half years to realize why I was so upset and angry. And I had an epiphany; it’s because everybody I knew that had cancer died, and I’m the only one surviving. (NY)
Sub Themes for Medical Ethics/Mistrust

Past Experiences

Transparency

Even though a lot of the younger generation doesn’t know about it, the older generation knows about Tuskegee and what they did to those men and everything. So, that was a clinical trial. It wasn’t termed as a clinical trial, but it was a clinical trial. That’s why there is this fear amongst especially the African American community about clinical trials. (TN)

In the beginning of last year I was told, oh, you have to take this chemo, the liquid chemo, because six months you’re gonna be cured. Turned out to be a lie. (NY)
Sub Themes for **Spirituality**

**Religion/Church**

**Hope/Faith**

*I trust God more than I trust a lot of this medicine. (NY)*

*Everything with the hope is with white people, Black culture is nurturing. We have faith. (FL)*
Sub Themes for Support

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Family

Most times, specifically in the African American Community, it’s a family decision. It’s a family conversation, that conversation about what to do next. (FL)

I would have never joined the clinical trial without the support from my family. Well, I may have joined, but I would have dropped out after the first week if it wasn’t for them. (NY)
Sub Themes for **Understanding Clinical Trials**

**Process/Protocol**

**Purpose:**

Well and sometimes, the doctor don’t have – you want to know the process before you go. Sometimes you want to know what it’s gonna encompass along the way. (TN)

I would consider it if I had more evidence, more factual evidence, and stuff in my face to show me what you trying to tell me would benefit me would be suffice. (NY)
Summary of Findings

When engaging African Americans/Blacks for the purpose of increasing participation in cancer clinical trials, the following should be addressed in oral and written form:

• Use terminology that validate emotions regarding the medical experiences of African Americans/Blacks and abuses from the past

• Trust is a relevant cultural value, inclusion of testimonials from Black and African Americans who have had positive experiences participating in clinical trials is imperative

• Information about participation rates, and outcomes (both positive and negatives) increases transparency and builds trust

• Inclusion of facts about clinical trials is important. Allowing individuals to assess personal risks increases transparency
Implications

Key findings suggest that educational materials about clinical trials should:

• Explain why is important for racial minorities to participate in clinical trials

• Address barriers to participation such as: mistrust of the medical community, fear of side effects, disparities in access to healthcare, and lower socio-economic status

• Provide information related to clinical trials that involved Black and African Americans and the outcomes of those studies on the lives of participants

• Provide a list of questions about clinical trials to ask the health care team, this should include questions about cost of participation, financial support, and how to find clinical trials
Conclusions

• These findings suggest the need to construct culturally tailored messaging around clinical trials for Black and African Americans.

• Many participants were previously unaware of many of the topics discussed during the sessions but became more open to the idea of clinical trials after the discussion.

• Additionally, there is a need to work towards clear concepts and terminology to talk to Black and African American patients about clinical research and its benefits.
Next Steps

• Development of educational materials about clinical trials to ensure that Black and African American communities have access to cultural appropriate educational materials about clinical trials

• Ensure we test new materials with Black & African American men, since they were inadequately recruited for the focus groups.
Next Steps: Patient/Provider Discussion Tool

- Development of educational materials about clinical trials to ensure that African American communities have access to cultural appropriate educational materials about clinical trials

- Those include a patient/provider discussion tool and a factsheet for racial minorities

- Once finalized, materials will be printed, posted online, and offered to health care providers and partner organizations
THANK YOU!

For More Information, contact Owen Renault at orenault@cancersupportcommunity.org

To order Frankly Speaking About Cancer materials visit:
Orders.CancerSupportCommunity.org
888-793-9355