How Do Black People with Cancer View Clinical Research?

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Findings from a small study suggest that more Black than White, Asian, or patients of other races distrust medical research and have spiritual beliefs about medical research. The study asked about 100 people being treated for cancer whether they agreed with certain statements about research.

The findings may help research staff talk with and recruit more Black patients for clinical trials, said the study's leader, Charlyn Gomez, a medical student at the University of Maryland School of Medicine.

Black people make up about 14% of the U.S. population but only 5% to 7% of clinical trial participants. Clinical trial participation is important because it provides people with the opportunity to access emerging cancer treatments, tests, and approaches to improving cancer care.

More Black than non-Black participants of the new study agreed with statements like, "medical research is designed to harm minorities," and "God determines wellness, not research," Ms. Gomez reported October 1 at the American Society for Radiation Oncology (ASTRO) annual meeting in Washington, D.C.

The findings "give us insight into what people may be thinking," said Chika Madu, M.D., medical director of Florina Cancer Center at Staten Island University Hospital and chair of ASTRO's Community Engagement and Advocacy Committee.

But "there are so many reasons why patients may not enroll in clinical trials," added Dr. Madu, who wasn't involved in the research. These include external barriers to enrollment that may be inadvertently imposed by the clinical trials themselves, she said.

However, for new advances in cancer treatment or prevention to provide the most benefit to people from different racial and ethnic groups, she said, people from those groups must be involved in the studies that produced those advances.

And while diversity in clinical trial enrollment has improved slightly over the years, "there's a lot of

work that needs to be done," Dr. Madu said.

Spiritual beliefs and mistrust of clinical research

To better understand the factors influencing the decision to participate in clinical research, Ms. Gomez and her colleagues designed a 45-question survey that captures beliefs and perceptions related to medicine and research.

From October 2023 to February 2024, they gave the survey to people with cancer who had completed radiation treatment at one of two Baltimore hospitals. A total of 97 patients completed the survey, including 27 Black patients (28%).

There were no differences in age or insurance status between Black and non-Black patients. Black patients were more likely to be female, unmarried, and have a lower household income. Also, a similar percentage of Black and non-Black patients had previously participated in a clinical trial (16% versus 18%).

More Black than non-Black patients agreed with statements like:

- God determines wellness, not research (27% versus 8%).
- Research is designed to harm minority groups (20% versus 0%).
- Research could provide personal health information that they don't want to know about (25% versus 4%).
- Their community wouldn't gain anything if they participated in research (30% versus 6%).

The researchers are still collecting survey data, and it's not yet clear how heavily these beliefs and values would influence participants' decision to join a trial, Ms. Gomez noted. Studies have found that despite hesitations, Black patients are interested in participating in research.

The results indicate that doctors and trial coordinators should be prepared to talk with patients about their spiritual beliefs and mistrust of research, Ms. Gomez explained. And they should share information on what clinical research entails and the benefits it can provide to individuals and communities.

However, medical professionals need better training and resources on these topics, she acknowledged.

Why clinical trial participation is important

There are potential risks and benefits of joining a clinical trial. An individual may not benefit personally from joining a trial, but their participation can benefit other patients, especially those in

their population group.

So, when Black people participate in clinical trials, it can help ensure that the treatments, tests, or interventions being studied work well for the Black community.

For instance, in a meta-analysis of four trials in which nearly 20% of the participants were Black, researchers found that radiation therapy for prostate cancer worked better for Black men than for White men.

“If you didn’t have that much enrollment of Black patients in that study, you would’ve never figured that out,” Dr. Madu said.

But on the flip side, when trials have low enrollment of Black patients, their results can fall short for the Black community.

For example, relatively few Black women were included in clinical studies of a genetic test used to guide treatment decisions for early-stage breast cancer. It was later found that the genetic test may be less accurate for Black women than for White women.

Understanding patient perspectives and engaging others with shared experiences

Black patients’ spiritual beliefs and mistrust aren’t the only reasons why they are underrepresented in clinical trials, Dr. Madu said.

A major barrier for many underrepresented patients is simply that they are never asked to join a trial. Some doctors make assumptions that some patients wouldn’t be interested in or couldn’t join a trial, Dr. Madu explained, so they don’t ask.

“It is not our job [as doctors] to make that determination,” she said. “Give [the patient] the opportunity. Ask them and let them decide whether or not they want to enroll in the clinical trial.”

Other barriers include the costs of participating in trials, such as for doctors’ visits and transportation to appointments. And the criteria for taking part in trials often prohibit enrollment of patients with certain health conditions, which is more likely to be the case for people from certain racial or ethnic groups.

If a Black patient is hesitant to enroll due to mistrust, it’s important to understand that their stance is justified, Dr. Madu continued. Centuries of unethical research practices and inequitable medical care, structural racism in current health care systems, and personal experiences with discrimination by medical providers have eroded the trust of Black Americans, she stressed.

When it comes to talking with Black patients about clinical trials and understanding their concerns, having a diverse workforce and having patient advocates who have participated in a trial

themselves speak with patients are helpful, Dr. Madu added. Community leaders and community groups are also great resources for speaking to people about participating in clinical research, she said.

“Humans are more likely to take the advice of someone who’s walked in their shoes,” she said.

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