Spiritual Themes, Distrust May Factor Into Black Patients' Reluctance to Participate in Cancer Clinical Trials

Surveys from two Baltimore medical centers shed light on what may be fueling enrollment declines.

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Spiritual beliefs and a historically-based distrust of clinical research may factor into Black patients' decisions about whether to participate in cancer trials, according to surveys of patients treated at two Baltimore medical centers. Findings were presented at the American Society for Radiation Oncology (ASTRO) Annual Meeting.

This cross-sectional, descriptive study found lingering distrust in clinical research among Black patients, despite their self-reported trust in their cancer medical teams. The surveys sought to shed light on what might be contributing to the growing underrepresentation of Black people in cancer trials and identify ways in which researchers might improve recruitment efforts so their findings can be generalizable to more diverse populations.

"When you offer someone participation in a clinical trial, the conversation has to go beyond the consent form," said Charlyn Gomez, lead author of the study and a medical student at the University of Maryland School of Medicine in Baltimore. "If we want to improve recruitment of underrepresented people in clinical research, we cannot just talk about trial goals. We have to look beyond that to understand where the patient is coming from and what their priorities are."

"Our research has identified some really important themes that should be discussed with patients as part of the recruitment process, such as spirituality or faith, as well as recognizing the elephant in the room that is a justifiable mistrust stemming from structural racism and historical practices in clinical trial programs," she said. "But on the positive side, we also found there is trust in the medical care team and perhaps we can build from there."

Clinical trials in the U.S. historically have been populated almost exclusively by white, male participants. In 1993, Congress directed the National Institutes of Health (NIH) to establish guidelines for the inclusion of women and minority populations in all government-funded clinical research so that study populations would more accurately reflect real-world populations. Despite these mandates, however, inclusion of racial and ethnic minority populations in cancer trials has

remained low; one study found that among the cancer clinical trials reporting race, only 7.2% of participants were Black, even though Black people make up 14% of new cancer diagnoses. More recently, research shows that the gap in participation between Black and white patients grew even wider among people diagnosed with cancer during the COVID-19 pandemic.

Underrepresentation of diverse populations in clinical research can have serious consequences, Gomez said. Seeking to identify key psychosocial factors that may be playing a role, she and her colleagues developed a questionnaire from two previously validated surveys and gave it to patients who completed definitive radiation treatment for curative gastrointestinal, thoracic, gynecological, and head and neck malignancies. Between October 2023 and February 2024, 97 patients – 30% of whom were Black – were asked if they would participate in a clinical trial and to fill out surveys describing the factors they might consider when making this decision. They were asked to complete the surveys while waiting to see their cancer physicians.

There were no differences in insurance coverage, education, employment status, cancer stage or cancer treatments between Black and non-Black participants. And within both groups, at least 90% of participants said they trusted their cancer doctors.

Black patients were more than five times as likely to agree with statements that death or illnesses were determined by God's will (55.5% vs.10%; $p=0.001$) and that God, not research, determined wellness (59.1% vs.11.6%; $p<0.001$), compared to patients who were not Black. Twenty percent of Black people said they agreed that research harmed minority populations, compared to zero non-Black patients ($p<0.001$).

One-third of Black patients said they felt research would provide information about their health they would rather not know about, compared to 4% of non-Black participants ($p=0.037$). Black people were 10 times more likely than their non-Black peers to say they felt they individually (20% vs. 2%; $p=0.038$) and their community (40% vs. 6%; $p=0.031$) had nothing to gain from participating in clinical research.

At least some of that distrust stems from historically unethical research practices that harmed Black people, Gomez said. From 1932 to 1972, the U.S. Public Health Service failed to obtain informed consent or explain the risks of a study of untreated syphilis among Black men in Tuskegee, Alabama.

Researchers also withheld penicillin treatment from the 399 study participants with syphilis when it became available in 1945, causing preventable illness and death among study participants and their family members. This led to the creation of the Belmont report, establishing ethical principles and guidelines for the protection of human research subjects.

Overcoming that justifiable and deeply embedded distrust is imperative to developing cancer treatments that can benefit Black patients, Gomez said.

"Physicians need to be more intentional in their efforts to gain the trust of Black patients so they may be better represented in clinical trials. Unfortunately, due to a host of issues such as systemic

racism and fewer access points into the healthcare system, we are seeing that Black patients tend to experience poor outcomes with certain cancers. This reality should raise a lot of alarms, because if we're trying to develop new treatments and the patients who need them the most aren't part of the clinical trials testing them, then we're missing a big group of important people."

Gomez said the findings might guide the development of training programs for researchers and physicians to help with recruitment efforts. "I think it would be well-received if physicians were trained to address these issues and perhaps incorporate these discussions into their protocols," she said.

In light of the weight given to religious and spiritual beliefs, she said it may also be important to include family and community members in discussions about the potential benefit and importance of participating in clinical trials. "Sometimes, patients seek out guidance to help them make that choice, alongside their family and other community members, and it becomes a shared decision-making process."

Gomez also said more studies like this one are needed to further explore the factors that may impede participation in clinical research for underrepresented groups. "It's crucial for us to improve the recruitment of Black patients into cancer clinical trials," she said. "But to do that, we have to understand the values and priorities of patients in this underserved population."

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