

African-American breast cancer survivors report inadequate information, options, support services

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African-American breast cancer survivors were satisfied with their cancer treatment, but most were never offered clinical trials opportunities or support services during or after their treatment, according to a study by a UC Davis Comprehensive Cancer Center researcher and her community partner, Rev. Tammie Dynse.

The study, "The Unmet Needs of [African-American Women](#) with [Breast Cancer](#)," involved interviews with 137 African-American women who survived breast cancer. Researchers sought to assess patients' clinical experiences, concerns and needs, asking participants questions about their treatment, access to information, support services and clinical trials, insurance and employment status, general health and lingering effects of [cancer treatment](#).

"Anyone who takes care of people with cancer should be aware of these concerns," said Marlene M. von Friederichs-Fitzwater, director of the UC Davis Comprehensive Cancer Center's Outreach Research and Education Program, principal investigator and lead author of the study, which was published online in *Advances in [Breast Cancer Research](#)* in April. "We know that one powerful factor in cancer outcomes is the extent to which patients obtain information and participate in their treatment decision-making."

African American women have the highest incidence of breast cancer of

any population group in the United States, and the highest [mortality rates](#), according to the National Cancer Institute. The death rate -- 33 per 100,000 -- is more than twice that of Asian-American women and Hispanic women.

But while many studies have documented African American disparities in breast cancer screening, detection, mortality and disease staging, few have looked at the experiences from a patient's post-treatment and survivorship perspective.

For the study, von Friederichs-Fitzwater telephoned African-American women throughout the Sacramento region known to have been treated for breast cancer. The women were identified through support groups and advocacy organizations, survivorship events and other agencies.

A majority (90 percent) of participants reported that they were satisfied with their treatment, but nearly one-fourth of them were not satisfied with the information they received about breast cancer and treatment options from their doctors.

For example, more than 80 percent of respondents would have liked to have received information about complementary medicine options but did not, and 60 percent reported that they sought treatment information on their own. Seventy-eight percent of interviewees said their doctors did not talk to them about clinical trials, but the same percentage said they would have enrolled, if eligible.

Additionally, nearly half of the women (43 percent) said their doctor or other health-care provider did not provide information about support services, but 62 percent said they wanted such services.

Of the minority of women who did access support programs, about one-fourth of them said they were not at all satisfied. One respondent said

she felt out of place at a support group meeting where she was the only African-American woman, and never returned after her first visit.

The study also underscored the fact that many African-American women diagnosed with breast cancer perceive discrimination in the delivery of their care. Concerns included perceptions that information or certain types of treatment were being withheld because of their race or socioeconomic circumstances.

Study co-author Denyse, president and founder of Carrie's Touch, a Sacramento-area nonprofit community organization for African-American women with breast and other cancers, said the findings confirmed many of the concerns that she had heard from individuals in the community.

"The experiences that these women encounter have a lot to do with a lack of trust of the medical professional community," said Denyse, herself a breast cancer survivor. "Our culture as a whole is very silent about breast cancer. When you find out a woman in the African-American community has had cancer, it's usually at her funeral."

Von Friederichs-Fitzwater said such perceptions -- whether based in reality or not -- can affect a patient's satisfaction and overall outcome. "This study points to the need to develop more patient-centered care that is culturally sensitive and to deliver comprehensive care that addresses the physical, mental, psychosocial and spiritual needs of patients," she said.

For example, von Friederichs-Fitzwater said African-American women could benefit greatly from a peer navigator program, in which specially trained [breast cancer survivors](#) would work one-on-one with newly diagnosed women, guiding them through the earliest, most difficult phases of diagnosis and treatment.

"If you don't have someone continually educating and supporting you and reminding you of the symptoms that can come along with chemotherapy and radiation, you will think you are dying, and then stop your treatment," added Denyse. "I hope this research is a stepping stone to a more in-depth study so that we can really learn some of the challenges African-American women are facing in an effort to save their lives."

Provided by Queen's University Belfast

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