

A new study explores concerns of African American breast cancer survivors

September 1 2016

Although there is some overlap, past research has shown that the challenges faced by African American breast cancer survivors differ somewhat from Caucasian women. But the studies that demonstrated difference were not designed to explore those challenges in depth. Now new research from Thomas Jefferson University helps identify problems that are important to African American women - a first step in creating programs that better serve the needs of the community, and which could help reduce cancer disparities and improve health outcomes.

"We know that 21 percent of African American [women](#) with [breast cancer](#) don't survive five years past their diagnosis, compared to only eight percent of Caucasian women. We wanted to explore whether the problems they experience after their first round of treatment might contribute to that disparity," says lead author Andrea Barsevick, Ph.D., R.N., a Professor in Medical Oncology and researcher at the Sidney Kimmel Cancer Center at Thomas Jefferson University. The study was published in the journal *Supportive Care in Cancer*.

In order to understand the experience of African American breast [cancer survivors](#), the researchers conducted eight [focus groups](#) with 60 survivors to learn what was most important to them. One of the ideas that came up in every focus group was the problem of medical mistrust. Women expressed concern that the information they received was inferior to Caucasians leaving them less prepared to deal with survivor challenges after treatment completion.

Findings from the focus groups were used to refine a survey of survivor problems to be distributed to African American survivors. A survey of 31 survivor concerns that had been validated previously was modified to include 20 new items based on the focus group discussions. Questions about medical mistrust were also added to the survey based on concerns raised in the focus groups. The survey was mailed to over a thousand African American cancer survivors, of which 297 completed surveys were returned (a response rate comparable to other studies).

Respondents rated problems like, "Feeling less feminine," or "fatigue, loss of strength," or "being treated as different from others," as "not a problem, somewhat of a problem, or a severe problem."

The researchers found that survivor problems reported in this survey could be grouped into four categories of concern: emotional, physical, resource, and sexual problems. Previous research using this survey identified physical, emotional, and economic concerns in a mixed group of cancer survivors (mixed race, gender, and cancer diagnosis).

In addition, the importance of these groups of problems varied between survey participants. For example, younger women reported more concerns overall than older women, women who had two or more chronic conditions in addition to cancer also reported a higher number of survivor problems. And women with higher levels of [medical mistrust](#) also had more survivor problems.

Does this suggest that survivor problems are being caused by mistrust or that younger women are at greater risk for problems than older women? "Not necessarily" says co-author Amy Leader, Dr.P.H., M.P.H. an assistant professor of Medical Oncology and research at the Sidney Kimmel Cancer Center who collaborated on this research. "The associations aren't causal, but they do show us how much diversity there is within the African American women as a group, and that it will be important to craft different approaches to address the needs of different

parts of the community. For example, different types of educational resources may be needed by younger versus older survivors. And for all of them, educational materials and resources should be culturally tailored to African American survivors."

"Combating cancer disparities in the African American community will take a multi-faceted approach," says co-author Patricia K. Bradley, Ph.D., R.N., F.A.A.N., associate professor in the College of Nursing at Villanova University. "This research is the first step toward bridging the gap in care after initial [cancer](#) treatment is completed."

"African American survivors have taught us what's important to them," says Dr. Barsevick. She and her colleagues are now working with a panel of local advisors to create a tailored survivorship care plan that includes resources and coping methods addressing the concerns that are most important to African American women.

More information: Andrea M. Barsevick et al. Post-treatment problems of African American breast cancer survivors, *Supportive Care in Cancer* (2016). [DOI: 10.1007/s00520-016-3359-z](https://doi.org/10.1007/s00520-016-3359-z)

Provided by Thomas Jefferson University

Citation: A new study explores concerns of African American breast cancer survivors (2016, September 1) retrieved 26 April 2024 from <https://medicalxpress.com/news/2016-09-explores-african-american-breast-cancer.html>

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