

30: African American Women's Perspectives on Donating Healthy Breast Tissue for Research: Implications for Recruitment

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African American women die of breast cancer at a higher rate than any other racial group, and they are more likely to develop triple-negative breast cancer, a type harder to treat than others. Yet they also seem to be reluctant to donate breast tissue to the Komen Tissue Bank, an ongoing clinical trial that collects healthy breast tissue from women of all racial groups. Researchers all over the world use these samples as controls as they test new ways to prevent, detect and treat breast cancer. If their samples are from only one demographic, their new tools may not work as well in other demographics.

Methods:

Researchers designed a study to gather African American women's perspectives about donating tissue as a way to participate in research. They designed an online survey, which they sent to African American women who had donated tissue to the Komen Tissue Bank in the past. The survey asked about the importance of research in general and about the donors' impressions of the donation process specifically, among other questions.

Findings:

Seventy-one women responded to the survey, and some of their impressions were similar to women who identified themselves as other races. They talked about their emotions (fear, pride) during the procedure as well as reflected on the importance of being involved in research. Some also talked about their donation as a way to honor friends or family affected by breast cancer.

But some of their remarks were unique. They addressed why African American women may be reluctant to donate, including the Tuskegee Airmen and Henrietta Lacks cases, where African Americans were exploited in secret and unethical ways to promote research.

Others said they became advocates, encouraging others in their communities to donate and explaining the importance of donating to those who felt distrustful of clinical trials. They also commented that, aware of the disproportionate effects of breast cancer in their communities, they felt the importance of being a participant in the research.

Why this study is important:

The Komen Tissue Bank aims to use the survey information to better communicate with the African American community, to better explain why their contributions are so important. African American women's samples account for about 16 percent of the bank, but the bank wants to increase the sample size to about 25 percent to support research into breast cancer issues that are uniquely tied to the female African American population. Research using their normal tissue could result in information that leads to better screening and treatment.