

Poster 28: Decision-making regarding ovarian cancer risk-reduction among women of color who carry a BRCA mutation

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Topic: Genetics

Objectives

Racial disparities persist in uptake of genetic testing and risk-reducing bilateral salpingo-oophorectomy (rrBSO) among women who carry a BRCA mutation. To better understand provision of equitable healthcare related to genetic risk, this qualitative study explores decision-making regarding ovarian cancer risk among Hispanic White, Mexican, Native American, and Black identified women, as well as experiences of discrimination in health care, in a minority-majority state where much of the population is rural and/or lives in multi-generational settings.

Methods

A demographic questionnaire and semi-structured qualitative interviews with 18 participants self identified as women of color ages 18-55 years, with confirmed pathogenic germline BRCA mutation, regardless of rrBSO status. Interviews were digitally audio-recorded, transcribed, and coded for themes.

Results

Participant decision-making was heavily influenced by family networks, including personal experiences with family members with cancer, and desire to pursue risk-reducing surgery in order to avoid burdening family members with caregiving responsibilities. Additionally, participants felt information provided was sufficient but internalized risk differently, influenced by multiple factors including perceived bodily awareness. Fertility and childbearing considerations were not predominant themes. While some participants felt welcomed in the health care setting, multiple participants discussed history of research exploitation within their communities contributing to medical mistrust and skepticism of genetic testing as well as removal of bodily organs. Several participants also discussed feeling comfortable and cared for when a member of their medical team shared a component of their identity.

Conclusions

Intergenerational experiences with cancer influenced how participants understood their ovarian cancer risk as well as how they made decisions regarding uptake of both genetic testing and rrBSO. These findings offer new insight into our patients' counseling needs, suggesting that by better understanding patients lived experiences navigating cancer within their families, we may better tailor counseling both for patients and increase opportunity for family engagement.

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