Second Opinions and the Treatment Gradient
Experienced by African American Breast Cancer Patients: An Exploratory Study
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The excess burden of breast cancer mortality experienced by African American women is well documented, and a growing body of research points to differences in quality of treatment as a major determinant of this disparity. This inequity takes many forms including treatment delays, inappropriate non-guideline-concordant treatment, and underuse of treatment. The reasons these occur among African American breast cancer patients are multi-faceted. First, this population is disproportionately low income and more likely to receive care in low-resource settings where there are many barriers to guideline-concordant care. One study has shown that cancer outcomes for Medicaid patients are only slightly better than for the uninsured. In addition, the population is disproportionately represented among those with low health literacy and thus experiences reduced ability to comprehend the standard of care for their condition, and to advocate on their own behalf. Overt and implicit racial discrimination have also been documented. It has also been shown that patients who participate in cancer clinical trials have better outcomes compared with non-participants, regardless of study arm. That African Americans are under-represented in such trials limits the generation of evidence that would improve the efficacy and safety of their cancer treatment and it is another missed opportunity for high quality care. Finally, patients who obtain care in low-resource settings rarely receive genetic counseling and testing for hereditary breast and ovarian cancer (HBOC), even though they may be at very high risk. Recent research shows that African American women can carry deleterious mutations in the absence of an overt family history.

A small proportion of African American patients find their way to academic cancer centers where the likelihood of state of the science care is greatest. The second opinion is one mechanism that can connect a diverse array of patients with the best available knowledge. The overall goal of the proposed exploratory research is to extend the reach of elite cancer research and treatment institutions to those at highest risk of death from breast cancer through second opinions that influence patients’ prospects for receipt of the most appropriate treatment, that enable their participation in clinical research, and that offer them genetic counseling for hereditary breast cancer. Our specific aims are:

1. Through outreach to clinicians, churches, and other community organizations, identify low-income, primarily African American patients newly diagnosed with breast cancer and who would like an academic cancer center second opinion.
2. Deliver second opinions to 20 low-income women in-person, by phone, or via video conference. Assess these patients for eligibility for clinical trial participation and for genetic counseling, and offer these services as appropriate. (Consultations and genetic counseling will be provided at no charge; trial participation will depend on insurance status).
3. Assess the immediate and longer term impact of the encounter by i) audio-taping the consultation for analysis of effectiveness of the communication (patient comprehension, satisfaction, cancer distress, decisional conflict, perceived stress, and patient centeredness); and ii) following patients through the treatment decision process to document their experience and perceptions regarding communication with their clinicians, the treatment they receive, and their choices regarding genetic counseling and clinical trial participation.

These aims will be achieved through two phases of research. First, using a community-based participatory approach in low income regions of the SF Bay Area, conduct formative research with primary care clinicians and patients, and community organization leaders and members to develop effective strategies and messages for outreach to identify newly diagnosed African American women with breast cancer and encourage their participation. Methods will include development and implementation of a second opinion protocol that addresses all aspects of the process including financial access (grant funds will offset costs as needed) and video conference access (e.g., Skype, preferred over phone for patients who cannot attend in person - may be provided by a research associate for the purpose of the study). Audio record each consultation and interview patients within 48 hours. A research associate will maintain communication with each patient in the course of her treatment decisions, taking detailed field notes and/or audio recording conversations. Tapes will be transcribed and coded along with field notes to identify themes that reflect the impact of second opinions, the potential of this approach to influence treatment outcomes, and challenges that must be addressed in the scaling up of this intervention. A primary outcome will be development of a proposal to conduct a randomized controlled trial to demonstrate the effectiveness of the model that emerges from this exploratory research.