Susan G. Komen for the Cure
Research Grants – Fiscal Year 2012

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Translating Cancer Genetics for the Safety Net Setting

Investigator(s): Galen Joseph, Ph.D.

University of California, San Francisco, CA

Awarded: $898,347.60

Grant Mechanism: Investigator Initiated Research

Public Abstract:

Breast cancer caused by the BRCA gene mutations is rare, but these gene mutations significantly increase the risk for both breast and ovarian cancer. Fortunately, research has shown that genetic counseling, BRCA testing and associated screening, treatment and preventive measures can reduce the chance of getting cancer and deaths from cancer, and can improve quality of life. As a result, genetic counseling and testing has become the standard of care for individuals at risk of hereditary breast and ovarian cancer. However, studies show that while the prevalence of BRCA mutations is similar across ethnic groups (except Ashkenazi Jews), fewer than 13% of all women who receive BRCA testing are of non-European ancestry even though people of color, who are disproportionately low-income, make up 35% of the US population. As genetics and genomics become mainstream medicine, it is important to increase access to these medical advances, but we also need to ensure that underserved women (including people of color, low income and/or low literacy) are able to benefit from genetic risk services once they gain access. Gaps in effective communication (when a message reaches the intended audience and where the meaning is mutually understood) are widely recognized as a major contributor to health disparities. Yet, little research has examined the role of health literacy and cross-cultural communication in cancer genetic services. The overall goal of the proposed study is to elucidate the strengths and limitations of current genetic counseling communication practices with underserved patients and to develop communication strategies that foster effective genetic counseling across culture and literacy. Given the limited research on this topic to date, we propose in-depth formative research study that will allow us to: 1) describe current practices in hereditary breast cancer GC communication with low-income English-, Spanish- and Cantonese-speaking patients; 2) identify dimensions of hereditary breast cancer GC communication that vary with patient culture, language, and health literacy levels; and 3) develop genetic counseling communication strategies, and pilot-test these with genetic counselors from four public hospitals that serve diverse patient populations. The contribution of the proposed research will be to document current practices of genetic counseling communication with underserved patients from both the patient and counselors' perspectives, and to examine the extent to which the communication is effective. This contribution is significant because effective communication can reduce health disparities and facilitate informed decision-making.