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Genetic Testing for Breast Cancer

Understanding the Decision Making Process among Latinas

The Latino/Hispanic population is the largest minority in the U.S. and the highest concentration of Latinos is along the U.S.-Mexico Border. A partnership between The University of Texas-Pan American and the Cancer Center at The University of Texas Health Science Center at San Antonio has been formed to address the specific needs of this population in cancer research and education. This four-year project is being funded through a P20 grant from the National Cancer Institute. The projects being conducted will not only develop translational research in basic science but also address cancer related health disparities in the Hispanic border population. One of the pilot projects funded under this new initiative is directed toward understanding the attitudes and decision making processes in genetic testing for increased breast cancer risk.

Differences in awareness and beliefs about genetic testing for cancer risk across demographic and socioeconomic groups may reflect health literacy heterogeneity. The apparently lower level of genetic testing awareness by Latinos compared to all other major ethnic/racial groups (2005 National Health Interview Survey data shows that 19 percent of Latinos, 32 percent of African Americans, and 48 percent of non-Hispanic whites have heard of genetic testing – Pagan, Su, and Li, 2008) may be indicative of a relatively lower level of health literacy and could be

related to underutilization of preventive care, such as breast cancer screening.

This project will use qualitative techniques to assess decision-making among Latinas regarding: 1) knowledge, attitudes, and behaviors related to breast cancer genetic testing; 2) behavioral intentions to undergo genetic testing; 3) relationship between proportional (numeric) understanding of the risk and attitudes towards genetic testing; and 4) perceptions of self- and collective efficacy to face the challenges posed by having a genetic predisposition to breast cancer and its relationship with intentions to undergo testing. Participatory techniques will be used to develop and adjust research instruments, assuring appropriate community input and inclusion of all aspects that may be relevant to the community.

Investigators will conduct 16 focus groups to evaluate current knowledge and behavior, understanding of numeric risk proportionality, as well as attitudes and outcome and self- and collective efficacy expectations related to genetic risk and genetic testing. Key aspects to be studied include: 1) Latinas' understanding of the balance between genetic, environmental, and behavioral determinants of disease and genetic risk variability; 2) relationship between their capacity to understand numerical concepts and basic statistics (numeracy) and their comprehension of breast cancer



genetic risk; 3) their expectations about the potential consequences of genetic risk and genetic testing; 4) potential action motivators for testing, counseling, risk prevention, reduction, and treatment; 5) their perceived self- and collective efficacy to use genetic information to gain control of their own health and avoid stigmatization; and 6) policy and ethical issues about safeguarding information about their genetic risks.

Using the extensive information collected, this project will develop and pre-test a survey instrument to assess factors associated with breast cancer genetic testing, and prepare and submit proposals for larger-scale assessments and interventions in Latino cancer genetics and testing readiness. Researchers at The University of Texas Health Science Center at San Antonio, who have ample experience in qualitative research, will lead the study with the help of training researchers at The University of Texas-Pan American, who will actively participate and become proficient in the use of qualitative techniques.

The project will take place in Hidalgo County, located in South Texas' Lower Rio Grande Valley. In 2006, Hidalgo County had a population of nearly 701,000 – about 359,000 women (51 percent) and 342,000 men (49 percent). The median age was 27.1 years, and 36 percent of the population was under age 18 while nine percent was age 65 and older. Almost 90 percent of the total county population is of Latino origin, most of them Mexican (95 percent). Almost 37 percent of the population earns less than the poverty level, and yearly median family income is only \$30,255.

Individual subjects will gain increased knowledge and awareness regarding breast cancer genetic risk assessment, prevention and reduction among Latinas. Since a clear understanding of Latinas knowledge, attitudes and behaviors regarding breast cancer risk assessment and genetic testing is urgently needed for the development of culturally appropriate interventions, this project will meet a critical research need in this population. A study of this kind can increase scientific understanding of how at-risk individuals can be exposed to effective cancer prevention messages.

IPHP Research Brief 08-10 is based on excerpts/summary from a P20 subproject proposal to the National Cancer Institute (Genetic Testing for Breast Cancer: Understanding the Decision Making Process among Latinas, by Amelie Ramirez and Jose A. Pagán).