Willingness to Participate in a Breast Cancer Registry

Audrey Kesselring and Susan Pinney

Dept. of Environmental Health

Introduction: Breast cancer is the second leading cause of cancer deaths among women in the US, claiming 39,800 lives per year. The pattern of breast cancer occurrence differs in African-Americans and Caucasians. Although the incidence of breast cancer is less for African-Americans than for Caucasians, mortality rates are higher.   These rate differences in combination with the reality that African-American women are less likely to join research studies creates a serious predicament. Because a breast cancer registry is a valuable source of potential research participants, it is important that the data in the registry itself accurately reflect the distribution of the case population. **Rational:** The rationale for this study was to identify factors or beliefs that predict willingness to provide data to a breast cancer registry and to examine the differences between Caucasian and African-American women.   **Methods:** Breast cancer patients were recruited primarily from the practices of Drs. Beth Shaughessy and Elyse Lower in the Barrett Cancer Center. Neither physician referred those just learning of their diagnosis, those in psychological distress or those currently undergoing intense therapy. The purpose of the study and the consent forms was explained and followed by a 20-item structured interview.   Additional data were abstracted from the medical record.   Upon the conclusion of the interview, participants were given the registration packet for the Breast Cancer Registry of Greater Cincinnati. **Results:** Of the 97 subjects, 22 were African-American (22.7%). Responses to interview items indicated that those whose physicians encouraged them were more likely to enroll (43.2% vs. 25.4%) while time required or importance of confidentiality of the data did not affect enrollment rate. In logistic regression analyses, having had radiation therapy was the strongest predictor of joining the registry (OR 4.8, 95% confidence interval [CI] 1.7, 13.3), followed by an inverse relationship with importance of knowing someone else who has enrolled (OR 0.3, 95% CI 0.1, 1.0). Speaking to one's sister about breast cancer was predictive in ethnic groups other than African-Americans (OR 1.5), but not predictive in African-Americans. Other predictive factors of joining the registry include a less severe stage of breast cancer, having more than a high school education, having a living spouse, having had a lumpectomy and having an opinion that medical research is valuable. **Conclusions & significance:** The findings of the first study of factors affecting willingness to enroll in a Breast Cancer Registry suggest that factors that are predictive of other health seeking behaviors, such as educational level, earlier stage at diagnosis, and support from family members, are also important in the choice to enroll. Those who are comfortable sharing their health status with family members also may be more comfortable with providing their information to a registry. Treatment for women with early stage breast cancer usually consists of radiation therapy and a lumpectomy, which may explain the relationships seen. A larger sample size is necessary to explore whether race/ethnicity is an independent significant predictor, or whether it is an effect modifier of other factors. These findings, and findings of future studies, will be important in planning educational and recruitment strategies for cancer registries.