

Using a Community-based Participatory Research Approach to Collect Hopi Breast Cancer Survivors' Stories [Abstract]

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INTRODUCTION AND OBJECTIVES: Breast cancer is the most frequent cancer endured by women on the Hopi Indian Reservation in northern Arizona. Women diagnosed with breast cancer and their family caregivers need knowledge of how other native women living on the reservation have successfully survived. Focus groups were used to explore local perceptions of breast cancer and breast cancer caregiving. Insights gained were incorporated into digital stories on a DVD designed for the Hopi Women's Health Program (HWHP) as an educational and navigational tool for those receiving a mammogram, those newly diagnosed with breast cancer, their caregivers, and community members at large attending community health events.

METHODS: Three separate focus groups representing three different sets of participants were conducted: Hopi female breast cancer survivors, caregivers of Hopi breast cancer survivors, and HWHP staff and community health workers (CHW).

RESULTS: Based on three focus group outcomes, conceptual topics were identified and included in the stories created. Story topics were: HWHP information, breast cancer support systems, surviving breast cancer, treatment side effects, and family support.

DISCUSSION: The strengths of the project included the development of a strong collaboration with the HWHP; the realization that focus groups are not an appropriate method for gathering personal information, particularly in a small community setting; the integration of local perspective in the creation of a health education tool, specifically the DVD of digital stories; and the successful application of a community based participatory research (CBPR) approach in a Native community. Digital stories created from this project have been used at local community events to educate about breast cancer and caregiving within the Hopi reservation. The primary limitation of the project was the small number of focus group participants.

Key Words: American Indian, breast cancer, rural health, health education, women's health, focus groups, community-based participatory research, personal narratives

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