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Breast Cancer Education for Navajo Women: a Pilot Study Evaluating a Culturally Relevant Video

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Abstract

This pilot study evaluated a culturally specific video designed to teach Navajo women about breast cancer treatment options. Fourteen Navajo women diagnosed with breast cancer and 26 healthcare providers participated in a mixed-method evaluation that documented their perceptions immediately and 6 months after viewing the video. After initial viewing, women reported reduced anxiety about treatment and interest in support groups. Six months later, women said the video prompted them to seek more information from printed sources and their provider. Younger Navajo women who were 44 to 51 years old were more likely to attend support groups than women who were 55–67 years. Providers corroborated the positive effects of the video. The providers believed the video encouraged patients to seek information about breast cancer and to ask questions about treatment plans and side effects. A culturally relevant video for Navajo women can be an effective teaching tool and can enhance patient–provider communication.

Keywords

Breast cancer; Navajo; Culturally relevant video; American Indian

In the 1990s, the incidence of breast cancer among American Indian women did not change and remained lower than that reported nationally for US women of all races [1]. However, during this same decade, American Indian women suffered the lowest 5-year breast cancer survival rate of all racial and ethnic groups in the United States [2]. Wilson et al. [3] reported that older American Indian women experience a delay from diagnosis of cancer to treatment that is two times greater than that reported for non-Hispanic White women. Delays contribute to poor outcomes and ultimately to greater mortality. Reasons for the delay have been attributed

to funding and staffing shortfalls within the available system of care, e.g., Indian Health Service or other rural health facilities [3]. For American Indian people, these epidemiological trends are of grave concern as women are considered the backbone of American Indian societies, and their health affects the health of families and future generations. While working in American Indian communities, Lantz [4] and Giuliano et al. [5] identified lack of cancer knowledge, limited access to screening services, and linguistic differences between patients and providers as factors influencing low breast cancer screening rates and treatment disparities.

Two studies conducted in the southwest region of US in the late 1990s document American Indian women's perceptions of breast cancer screening services. In an evaluation of a mammography program in Shiprock N.M., Steinhart and Daniels [6] reported that Navajo women thought mammography was inconvenient, uncomfortable, and unsafe because of their concern with radiation exposure. From their household survey of rates and predictors of southwest American Indian women's participation in breast cancer screening service, Giuliano et al. [5] concluded that education is key to early detection and increasing survival rates among American Indian women.

Cancer screening and treatment disparities in American Indian and Alaskan Native women have been linked to a lack of culturally and linguistically relevant cancer education [2,7]. Kelly-Powell [8] and Valdez et al. [9] demonstrated that previous experience or familiarity with various treatment options and screening procedures and talking with others who have undergone the same treatment positively influenced decision making and health information seeking behaviors, helping patients anticipate their own adaptation to treatment and recovery. Mcvea et al. [10] and Kelly-Powell [8] pointed out that patient education and self-efficacy may be particularly important for breast cancer patients who feel socially and economically disempowered due to income and racial inequities and thus, are "less prepared to engage in a rational deliberative decision making process". These investigators suggest that patient-provider dynamics may favor physician control over decision making and support the idea that culturally and contextually relevant education and communication tools have the potential to teach underserved populations the importance of early breast cancer detection and treatment.

The purpose of this pilot study, conducted by investigators of the Native American Cancer Research Partnership, was to document the perceptions and impact generated by a 12-min culturally specific educational video entitled, "Breast Cancer: It Can Be Healed" on the target audience, Navajo women diagnosed with breast cancer, and providers serving Navajo patients. The video is narrated in the Navajo language with English subtitles, provides information on breast cancer treatment options, and was produced by a Navajo breast cancer survivor and her oncology nurse [11].

One Navajo health educator who regularly translates for patients took the lead on translation. The video was back-translated by well known Navajo health educators fluent in the Navajo language before pretesting it. The draft version of the video was then shown to 100 viewers, and 97 provided feedback [11].

This pilot study is unique in that it offers a predominantly qualitative analysis of open-ended questionnaires administered to Navajo breast cancer patients and health care providers immediately after viewing the video and 6 months later. The questionnaires gauged the perceived value in facilitating the selection of treatment options. The objectives of the pilot study were to: (1) evaluate the educational video's impact on treatment-related knowledge, attitudes, and beliefs of Navajo women with breast cancer and (2) assess health care providers' perceived value of the video's information to Navajo women diagnosed with breast cancer.

Material and Methods

Patient Assessment

The investigative team developed a 16-item questionnaire administered immediately to patients after the video. The topics included knowledge of breast cancer treatment options and perceived helpfulness or value of the video in explaining specific information. A 6-month follow-up interview was conducted with each patient by the same interviewers.

Two health technicians trained in qualitative data collection served independently as recruiters and interviewers, explaining the purpose of the project and extent of involvement, securing informed consent, and completing the interviews. Inclusion criteria for recruitment into the patient component of the evaluation were Navajo female ≥ 18 years of age with a recent diagnosis of breast cancer from March through December 2005. Interviews were administered verbally in English and were completed in 25–45 min. Although the Navajo women participants self-identified themselves as bilingual, the participants preferred that the English language be used during their interviews. Using English during the interviews and the video narrated in Navajo language with English subtitles in this pilot study allowed the participants to receive information in a linguistically comfortable format and for investigators to understand women participants' responses "in their words."

Provider Assessment

This provider questionnaire had four demographic questions documenting provider gender, professional degree, specialty area, job title and years of practice, and seven open-ended questions soliciting comments on the provider's perceived accuracy, adequacy, and value of the video. At 6 months, that questionnaire queried providers about their use and perceived impact of the video. Due to the difficulty of scheduling interview sessions, all provider questionnaires were self-administered. Inclusion criteria for the provider component of the video evaluation were health care providers practicing within an Indian Health Service (IHS) hospital or off-reservation medical centers serving Navajo patients from March through October 2005. All protocols and questionnaires were reviewed and approved by institutional review boards of the Navajo Nation, Northern Arizona University, and San Juan Regional Medical Center.

Analysis

Patients' responses to the closed-ended questions in the initial question were summarized using Excel. A multi-investigator-consensus method of qualitative analysis previously described by Teufel-Shone et al. [12] was used to identify patterns and themes in patients' and providers' opened-ended responses to both the initial and follow-up questionnaires.

Results

Patient Demographic

The mean age for the 14 patients was 54 years (SD 7.2 years), and the range was 44 to 67 years. Forty-two percent of patients had been diagnosed with breast cancer within the past month; 33% had had a diagnosis within the last 2 months, and 17% had had a diagnosis within the last 3 months.

Patient Cancer Knowledge, Attitudes, and Beliefs

In the first interview, most patients answered the five knowledge questions correctly and responded positively to the four attitudinal questions.

Of those who did respond, a majority believed that the video would help them communicate with their provider, explained that support groups were an important part of recovery, and believed that watching a Navajo woman with breast cancer in the video would help them act on the information given. All of those who responded stated that the video in the Navajo language helped them to understand their treatment choices. Half ($n=7$) indicated they would recommend the video to Navajo women diagnosed with breast cancer. The other half did not respond.

The second interview questionnaire asked about patients' attitudes and beliefs. In general, patients credited the video with helping them to make decisions about treatment options and to talk with their health care provider about their treatments. Although most (77%) had not attended a support group to assist with recovery, 50% of the younger patients (age 44–51 years) did report having attended one compared with 0% of the older patients (age 55–65 years). A majority of the patients (85%) did not use traditional Navajo medicine to help in their recovery. Yet, most patients said the video empowered them to consult with someone, generally a family member, for treatment decisions. In this second interview, all patients who responded indicated they would recommend the video to Navajo women with breast cancer. Most (86%) reported listening to the Navajo dialogue and reading the English subtitles indicating that this educational method is appropriate to this bilingual setting that involves Navajo-speaking patients and English-speaking health care providers.

Patients' Reaction to the Video

Table 1 provides the emergent themes derived from the 14 patient interviews conducted immediately after viewing the video and 6 months later. The sixth-month follow-up questionnaire did not ask patients to recall their overall impression of the video but focused on perceived value to health behavior change.

In the initial interview, patients reported that the instructional strength of the video was the visual images and that the graphics allowed them to better understand and envision the treatment processes. Patients described a connection with the Native actors, stating that they "could relate" to the Native cancer patient and to the behaviors of the Native family members. In an analysis of the patients' initial responses, no clear theme relating to the role or value of the Navajo language was evident.

In the initial interview, patients linked the health behavior value of the video to reducing anxiety and promoting action. Patients reported that the behaviors of the Navajo actors in the video encouraged them to make a treatment choice and enhanced their interest in gaining more information about side effects, their personal treatment options based on their diagnosis, and support groups.

Six months after viewing the video and for the 13 patients who completed treatment, respondents recalled that knowledge was gained from the video through the graphics and Navajo language. This knowledge prompted them to select and adhere to a treatment regiment, to seek additional information about their condition, and to ask their provider questions. Although patients expressed an interest in cancer support groups in the initial interviews, no patient reported involvement in such a group in the interview following the sixth month.

Provider Demographic

Twenty-six (26) providers participated in the video evaluation project. A majority of the providers (22) worked for IHS on the Navajo reservation and were non-Native. A majority of the providers were females; 58% were MDs.

Provider Video Evaluation

For the first interview, a majority of the providers were in agreement (i.e., 96% to 100%) that the video provided medically accurate information; the amount of information was adequate; the depictions were realistic for surgical options, chemotherapy treatment, radiation treatment, and the graphics in the depiction of radiation treatment were realistic.

The second interview revealed that in the 6-month follow-up time period, 15 providers had not treated any Navajo women with breast cancer, but the five providers who had treated Navajo women were able to complete all of the follow-up questions.

Most believed the video helped their patients discuss and make decisions about their treatment plans for breast cancer, discuss treatment plans, and encouraged their patients to seek more information about breast cancer. A majority of the providers (94%) would recommend the video to Navajo women with breast cancer.

Providers' Response to the Video

Table 2 provides the emergent themes derived from the questionnaires completed by the 26 providers immediately upon viewing the video and 6 months later. In general, providers' overall impression of the video was positive, commenting that similar videos were needed for Native patients about survivorship, side effects, treatment of other cancers, and perhaps other health conditions. They reported that the video provided good basic information and that graphics of treatment procedures were clear.

With regard to the video's value to oncology care, providers initially predicted that the video could serve as a good tool for encouraging provider–patient communication and patient acceptance of and preparation for treatment. Providers thought the Navajo actors and language would enhance the appeal and relevancy to the patients. Six months after viewing the video, providers perceived the video as having encouraged patients to ask questions, to be proactive about their treatment, and to seek more cancer treatment information.

Discussion

This study evaluated patients' and providers' perceptions of an informational video produced specifically for Navajo women with breast cancer. Several important findings emerged from this mixed-method study. First, immediately after viewing the video, both patients and providers spoke positively about the video, praising the factual information. Patients also stressed how much they could “relate” to the Navajo actors. They stated that it sparked an interest in gaining more information about treatment options and reduced anxiety related to the treatment process. The providers corroborated this idea that the use of Navajo patients and their families in the video promoted patient acceptance of the information and that the video was a good tool for opening provider–patient communication. The visual modeling in this video resulted in positive responses by the patients who expressed an interest in obtaining additional information about treatment and the side effects of various treatment modalities. Likewise, the providers felt that the video was a good tool to prepare patients for breast cancer treatment.

Another theme that emerged at the initial interview was the inconsistent responses to the role of the Navajo language in the video. A majority of the patients agreed the video helped them understand their treatment choices because it was presented in the Navajo language. However, of those who responded, only one patient reported listening solely to the Navajo language dialogue in the video while most reportedly reading the English subtitles and listening to the Navajo dialogue. The preference of listening to Navajo dialogue and reading the English subtitles is not surprising because of the historical educational experience of many Navajo

people. The Navajo language is a descriptive Athabascan language that conveys relationships and descriptions of things that provide a mental picture to the listener. Navajo communication had some culture-specific facial expressions, hand gestures, and posturing. Thus, Navajos have a diversity of linguistic patterns with monolingual speakers and bilingual speakers, readers, and writers having a wide range of proficiency. This video accommodated various speakers, English- or non-English-speaking patients and providers.

The follow-up data also revealed some important patterns. Patients were more likely to mention the value of the Navajo language in understanding the video in the follow-up interview. In addition, these interviews revealed that most women reported that the video prompted them to seek additional information with the assistance of family members. Patients also stated that the video prompted them to talk to their providers about their treatment (which was corroborated by providers) and to discuss their treatment actions with other people. Our findings are supported by similar studies which have found an increase in knowledge regarding the importance of seeking mammography screening after involvement with an intervention [13–15].

Despite an initial interest, most patients did not attend a support group to assist with recovery. Prior to 1990, there was no documented cancer education and survivor support programs in American Indian communities [16]. During the time of this study, the IHS hospital where the video evaluation was being conducted began its first breast cancer support group. The attendance was low when compared with the breast cancer support group in a nearby reservation border town. American Indian cancer support groups are steadily growing; however, there are few resources available to them [16]. Some women “perceive support groups as depressing, morbid, dwelling on illness” and “discussions consisting of deep, meaningful and exhausting conversations”. Expressive social support which includes companionship, moral support, encouragement, advice, and friendship may help American Indian women to participate [17]. Although the patients in the first interview believed that the participation in a support group may be an important part of recovery, the second interview revealed that only three of the patients attended a support group. Younger Navajo women were more likely to attend a support group than older women. Navajo people are reluctant to share personal information about cancer in their community. The traditional teachings taught to young Navajos are to not share important personal information as the information may be used against them. In addition, in close community networks and clanship, news and personal information can easily spread. Cultural beliefs may make it difficult for Navajo women to be a part of a Western-model support group, since verbal discussion of cancer and other diseases with people who are not related may be considered in direct violation of cultural norms and beliefs. Specifically, Navajo cultural views tend to discourage open verbal discussion about negative health topics because it is believed that talking and thinking about these topics in first-person rather than third-person, may bring disease or illness upon the person speaking [18]. The Navajo authors corroborate this experience with their relatives when discussing their breast cancer video project. The relatives immediately cautioned against “talking” about this sensitive topic in public and not to discuss it at all as negative complications or risks may result from this discussion. As a result, there may be a reluctance to participate in breast cancer support groups, especially among older women. Information and referrals should be provided to the patient and her family members so they can independently seek information and referral to a personal adjustment counselor to deal with breast cancer diagnosis, coping skills, medical treatment, and rehabilitation.

There are some limitations to this pilot study which must be addressed. First, the sample size was very small, due to the small numbers of Navajo women diagnosed with breast cancer in this region of the Navajo Nation during the study period. The results suggest the promise of culture-specific educational materials but cannot be used to make a generalized statement about

the entire population of Navajo women receiving treatment for breast cancer nor to American Indian/Alaska Native women representing other tribal communities. Second, because the study team wanted to minimize respondent burden, the interview was kept short and was not comprehensive. Third, the study design was not ideal; there was no true pretest prior to patients watching the video nor was there a comparison group.

Despite these limitations, this pilot study provides some extremely valuable information about a locally tailored educational video for Navajo women, and the qualitative and quantitative findings suggest that this video, which utilized visual modeling, appeared to have had a positive impact on both health care providers and patients. Overall, these findings suggest that a culturally relevant video for Navajo women can be an effective teaching tool and may enhance patient-provider communication regarding breast cancer survivor's treatment options, which in turn, could lead to improved treatment outcomes for Navajo women. These types of locally based, culturally relevant approaches are necessary to reduce cancer disparities in American Indian and Alaska Native women.

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To request the video, "Breast Cancer: It Can Be Healed", please send an e-mail message to Ms. Fran Robinson at vrobinson@sjrmc.net.

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Table 1Emergent themes from patient interviews ($n=14$)

Topic	Initial interview	6-month follow-up
Overall impression of the video	<ul style="list-style-type: none"> • Good instructional graphics • “Could relate” or connect to Native actors • “Could relate” to family support demonstrated by actors • Inconsistent response to role of Navajo language 	<ul style="list-style-type: none"> • Not queried
Relationship to health behavior	<ul style="list-style-type: none"> • Reduced anxiety related to treatment selection • Sparked willingness in “making a treatment choice” • Sparked interest in gaining more information, e.g., details on treatment processes and treatment side effects • Sparked interest in attending cancer support group 	<ul style="list-style-type: none"> • Enhanced knowledge through the use of instructional graphics and Navajo language • Provided information of treatment options which supported willingness to select and complete treatment • Promoted action and interest in more information • Cancer support groups were not utilized • Prompted search for additional information, in some cases with help from family members • Enhanced communication with providers on a number of topics

Table 2Emergent themes from health care providers questionnaires ($n=26$)

Topic	Initial responses	Six-month follow-up response
Overall impression of the video (accuracy and adequacy)	<ul style="list-style-type: none"> • Good basic information • In general, graphics of treatment procedures were clear • Specific criticism of the accuracy of the depiction of anti-estrogen therapy • Video of actual operational procedures would have enhanced realism • No consensus on appropriateness of the educational level • Need similar videos for Native patients sharing survivor stories and addressing screening and treatment of other types of cancer • Need more information on side effects of treatment modalities 	<ul style="list-style-type: none"> • Not queried
Value to oncology care	<ul style="list-style-type: none"> • Good tool for opening provider–patient communication • Use of Navajo patients and families promotes patient acceptance of information • Good tool for preparing patients for breast cancer treatment 	<ul style="list-style-type: none"> • Encouraged patient to ask questions, e.g., about treatment plans and side effects • Encouraged patients to be involved in their treatment plan • Encouraged patients to seek more information about breast cancer