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# Using a Community-Based Participatory Research Approach to Collect Hopi Breast Cancer Survivors' Stories

*Felina M. Cordova, Lori Joshweseoma, Nicolette I. Teufel-Shone, and Kathryn Coe*

## INTRODUCTION

### *The Hopi Reservation and the Hopi Women's Health Program*

The Hopi Tribe's reservation is located in northern Arizona, spreading over four thousand square miles (fig. 1).<sup>1</sup> The Hopi live in twelve villages located on three separate mesas known as First, Second, and Third Mesas. Most of the villages are located between five to thirty minutes of one another. The nearest city off-reservation is Flagstaff, which is a one-and-a-half to two-hour drive for most Hopi reservation residents. According to the Hopi Women's Health Program (HWHP), the Hopi Tribe has 12,442 enrolled members, with 5,143 of those members living off the reservation. Approximately one thousand non-Hopis live on tribal lands; they work on the reservation and/or are married into the tribe.<sup>2</sup> The HWHP is the primary source of cancer information for the Hopi. The HWHP, in collaboration with Indian Health Service (IHS), provides education, information, and

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FIGURE 1. The boundary of the Hopi reservation and its villages. The Hopi Women’s Health Program is located in the village of Kykotsmovi. Source: the Hopi tribe. Used with permission.

screening for both breast and cervical cancer through mammograms, tests for the human papillomavirus (Pap smears), and case management for female cancer patients. HWHP was created in 1996 as part of the CDC-funded Native Initiative with funds provided by the Centers for Disease Prevention and Control’s (CDC) National Breast and Cervical Cancer Early Detection Program (NBBCEDP).<sup>3</sup> This initiative provides funds to screen American Indian/Alaska Native (AI/AN) women for breast and cervical cancer. AI/AN women, however, make up only 4 percent of the total of all the NBBCEDP’s screenings.<sup>4</sup>

HWHP has eight staff members and since 1996 has been collaborating with Mobile Onsite Mammography Inc. (MOM) to bring breast cancer screening mammography services to the reservation. Together with MOM, HWHP has provided

breast-screening services to 2,436 women since program initiation. This figure includes a total of 7,414 mammograms, as well as re-screenings for 371 women who needed a follow-up examination after abnormal results. Of those 371 women, 41 confirmed cases of breast cancer have been diagnosed since 1996.

The number of women who have died of breast cancer since initiation of this program is unknown. HWHP does not collect this data and often women leave the local IHS service area for treatment and may pass away during this time outside of the area. According to the CDC and HWHP, most women screened on the Hopi reservation are between fifty and sixty-four years of age (38.4%). Women between forty and forty-nine years of age receive the next highest percentage of mammograms (35.4%).<sup>55</sup> Prior to the inception of the program, 55 percent of women fifty years and older reported they had never received a mammogram at any point during their lives and according to the HWHP, 47 percent of women on Hopi have not received a mammogram as of 2013.<sup>6</sup>

### **The Hopi Reservation and Breast Cancer Research**

A substantial amount of published research is available that provides general information about breast cancer screening and etiology; much of this information is biological and research-based.<sup>7</sup> Unfortunately, the majority of research has not involved AI/AN women and evidence indicates that AI/AN tribes are poorly represented in research efforts.<sup>8</sup> Most information regarding breast cancer in AI/ANs provides data such as mammogram screening rates and recommended strategies to increase screening rates.<sup>9</sup> Little information exists on how AI/AN patients are able to successfully navigate breast cancer diagnosis and the treatment process. The literature on AI/AN survivors does not examine perceptions or factors that increase survival or improve quality of life during treatment and recovery, but focuses on psychological and physical problems that AI cancer survivors report experiencing.<sup>10</sup>

The 1993 Healthy Hopi Women Survey documented sociodemographic characteristics of a random household sample of participants' cultural behaviors (such as attending traditional ceremonies, speaking the Hopi language, and using traditional healing), as well as knowledge of risk factors and screenings (such as mammograms and breast exams), and respondents' breast screening history.<sup>11</sup> Outcomes revealed that a low percentage of women had a mammogram and clinical exam and only half the participants knew about mammograms.<sup>12</sup> These results brought to light the need for increased breast-screening services and education.<sup>13</sup> An additional study with Hopi women on the reservation using focus groups documented that for promoting cancer prevention, members felt traditionalism—specifically Hopi ceremonies and language—would be most important and culturally appropriate.<sup>14</sup>

A review of the literature reveals a serious gap in an understanding of Hopi breast cancer survivorship, including effects of breast cancer on caregivers. To adequately address the needs of cancer survivors, more information is needed on support systems that Hopi women use and/or need, such as family and financial support; experiences during the treatment process from diagnosis to remission; type of and rationale for treatment choices; and side effects. Information is also needed to document experiences

of family caregivers of Hopi women with breast cancer. Current research on caregivers is limited and focuses primarily on non-Natives. Existing studies report the negative aspects of caregiving, such as the economic and psychological impacts, but without also reporting positive aspects of caregiving.<sup>15</sup>

### *Digital Stories of Breast Cancer Treatment*

Storytelling has been used for tens of thousands of years as an important part of Native cultures,<sup>16</sup> serving not only as entertainment, but also as an important vehicle for transmitting knowledge and culture.<sup>17</sup> Since the 1990s nursing research has investigated storytelling—but by itself, without the use of modern media technology to capture stories verbally and enhance them visually—and storytelling’s use in health education continues currently.<sup>18</sup> The process of digital storytelling, which allows participants to personally share their experiences in creating stories, involves recording participants speaking about pre-identified topics, taking pictures of objects that are culturally and personally important to participants, and then combining voice recordings and images to create short stories, which can be compiled onto a DVD.<sup>19</sup> Using easily accessed software such as Microsoft Movie Maker, the process generally yields two- to three-minute stories.

The Yavapai-Apache Tribal Nation of northern Arizona uses digital storytelling as a language preservation tool and has advocated for increased training in producing digital stories. At the Yavapai-Apache digital storytelling festivals, those who are new to speaking Yavapai and Apache are able to watch and hear digital stories in Native languages.<sup>20</sup> The HWHP have also been involved in producing digital stories, creating two digital stories in 2009 that showcased their organization to the community. Using digital stories to convey messages about cancer treatment is acceptable to the Hopi Tribe, given this medium’s similarity to traditional storytelling, which provides messages “emphasizing the particular values of health and wellness.”<sup>21</sup>

## METHODS

### *Approval Process*

This project was funded by the Inter-Tribal Council of Arizona as a community-based participatory research (CBPR) project between the HWHP and the first author of this commentary, Felina Cordova. This project conducted focus groups with three cohorts: breast cancer survivors; caregivers and HWHP staff-administrative assistants, administrative professionals (HWHP director) and case managers; and community health workers. Further, members of all three cohorts together created digital stories that could share their experiences with newly diagnosed Hopi breast cancer patients and their caregivers. To obtain tribal support the project proposal was first submitted to the Hopi Health Advisory Committee, the Hopi Tribal Council, and the University of Arizona’s Institutional Board Review. As a CBPR project, co-principal investigators Cordova and Lori Joshweseoma presented the proposal to the Hopi Health Advisory Committee. Approval was granted by all entities within four months after submission. As a CBPR project, HWHP staff participated in the question and probe development

for focus groups and focus group training, and assisted in conducting focus groups, digital-story training, and creation of digital stories and data analysis. Third author Nicolette I. Teufel-Shone provided the focus group training; she is familiar with qualitative data collection and has collaborated previously with the Hopi Tribe.

### *Focus Groups*

Local perspectives were collected using focus groups. To ensure community awareness of the project and to recruit for participation, the project was detailed in an insert in the *Hopi-Tutuveni*, the community newspaper. The insert contained general information on the project and research personnel and identified the project staff, listing local contact information. HWHP case managers assisted in recruiting breast cancer survivors and family caregivers by identifying potential participants, discussing the project, and providing a flyer specific to their focus group eligibility.

Three separate focus groups were planned for each different cohort: cohort 1, Hopi female breast cancer survivors of both pre- and post-menopausal females over the age of eighteen; cohort 2, Hopi female breast cancer family caregivers male and female over the age of eighteen; and cohort 3, HWHP staff and community health workers. Each of the three separate focus groups sought to recruit five to seven participants.

Development of focus group questions and probes was guided by two objectives: (1) to collect personal stories that would provide insight into surviving cancer; and (2) to enhance education on breast cancer survival on the Hopi reservation. The first draft of questions was developed by Cordova and sent to HWHP staff for discussion and comments. This collaborative process of question and probe development required two months of revisions and yielded a set of culturally appropriate and informative questions and probes used in the focus groups. All focus groups were conducted by Cordova at the HWHP's conference room. Each focus group session lasted approximately one hour.

During the introduction to focus group participants, the director of the HWHP identified the tribal affiliation of each focus group facilitator. Two HWHP staff members who were Hopi tribal members and served as the note-takers were also introduced. A disclosure form was distributed and read aloud. Participants were asked if they had questions; five to fifteen minutes were allocated at the start of each group to ensure that participants understood the intent of the project and process of the focus groups. To protect the identity of participants, voices were not recorded; only notes were taken. There was neither spoken nor written use of names during this process and participants were not given pseudonyms. Participants in the breast-cancer-survivor group and family-caregiver group were given a short anonymous questionnaire to document the following information only: age at diagnosis of the breast cancer survivor; years breast cancer-free; type of breast cancer treatment received; and relation to survivor (for caregivers only). Both groups were given the opportunity to fill out a separate questionnaire asking about interest in taking part in a digital story. For participants answering "yes," the form had a blank space to provide their name and phone number. All participants (excluding HWHP staff) were given a twenty-five-dollar Wal-Mart gift card for time and participation.

## *Focus Group Data Analysis*

Focus groups' handwritten notes were converted to typed notes and any identifiers were removed. Focus groups were conducted in English; although participants were notified that should they prefer to speak in Hopi, the note-takers were fluent Hopi-speakers, none of the participants chose to speak in Hopi. Qualitative data was analyzed collaboratively by Cordova and HWHP staff at the HWHP's conference room at Kykotsmovi, Arizona, and was initiated by creating a matrix to organize responses consisting of questions, probes, and responses.<sup>22</sup> As a means to identify themes, notes from the focus groups were reviewed and a summary chart was created of responses for each question.<sup>23</sup> Topics were grouped by similar or identical responses. Using a CBPR approach, special consideration was given to topics HWHP staff identified as beneficial to the women they served and the effectiveness of their program.<sup>24</sup>

## *Digital Story Recruitment and Development*

Participants for digital stories were recruited using their indication of interest on the questionnaire completed after the focus groups. A letter was created by Cordova and sent to the HWHP director for editing and comments. After consensus on the letter's content, invitation letters were printed on HWHP's official stationery and sent or hand-delivered by HWHP staff to those who indicated willingness to participate. The letter explained participation activities and gave the date and time of the session for creating digital stories. The letter listed the following activities: participants could pre-write a paragraph or statement to read and be audiorecorded; either they or someone they designated could read their paragraph; if participants did not want to write anything but still wanted to participate, they were offered the option of having written responses to the focus group questions incorporated into a story; and they could provide pictures of themselves, people important to their recovery, or objects, such as pottery, drawings, and quilted blankets. HWHP case managers followed up with those who indicated an interest in participating. Digital-story training was provided to all members of the research team. Before any recordings or pictures were collected, participants provided written informed consent to have their stories distributed for educational purposes. Audiorecordings were collected from participants; some spoke freely and one spoke from a created script. Pictures were taken of participants and their selected personal items. All participants were given a twenty-five dollar Wal-Mart gift card for their time and participation. Information was organized by topic and placed in a logical progression with the pictures, audiorecordings, text, and visuals. The digital stories were compiled on a DVD, which was titled *Breast Cancer Digital Stories: Survivors and Families*.

## RESULTS

### *Focus Group Results: Participation, Diagnosis, Treatment, and Side Effects*

Data from the short questionnaire was examined. At the request of the Hopi Tribe, participant numbers are not being reported: on the closely knit Hopi reservation, participants would be identifiable by age at diagnosis and number of years cancer-free.

All survivor and caregiver participants were over the age of fifty years old and survivors were in remission for at least one year. All females attended the Hopi breast-cancer-survivor focus group, while a mixed group of male and female participants attended the Hopi breast-cancer-survivor family/caregiver focus group. HWHP staff members, administrative staff and case managers, and a community health worker (CHW) attended the third focus group. Diagnosis and the associated sentiments were similar for breast cancer survivors. In the breast-cancer-survivor focus group, the majority of the women reported hesitancy to disclose to their family when they received their breast cancer diagnosis because they “don’t want to burden them with it.” A participant relayed that she was fearful of creating a burden by stating that when telling a family member of her diagnosis, she said “I’m sorry, I’m sorry to put you through this.” In addition, the majority of the women related that they would tell their family caregivers that they were going to be “all right” or “not to worry” after being diagnosed. For treatment, all women chose a mastectomy, while their adjuvant therapies varied with the various combinations being reported: chemotherapy and radiation, chemotherapy and biological therapy, or radiation and mastectomy alone. These routes of treatment were chosen after talking to their families and doctors, who provided all options but encouraged specific courses of treatment. The opinion of family members was reported as being highly important to all of the participants; a participant stated that she chose a mastectomy because her family member “talked me into getting it removed.” When asked of knowledge of cancer treatments prior to diagnosis, less than half of the participants indicated that they had no prior knowledge and had to learn about treatments after diagnosis; case managers were consulted at the HWHP and all were given booklets by the HWHP that addressed treatment. All participants reported positive perceptions of health care providers and stated “they all treat you well.”

The side effects reported included nausea, often on smelling specific foods; arm pain (lymphedema) for those who had a mastectomy; general fatigue; weight loss and hair loss; and feeling like the “ability to heal” had been negatively affected. All participants stated that side effects from the treatments were the most negative aspect of cancer treatment. Despite side effects, the participants in both the survivor and caregiver focus groups reported knowing the importance of completing treatment.

One survivor stated, “Your children kick in but you don’t want to tell them you need help.” All caregiver-focus-group participants reported that they did not consider being a caregiver to be a burden and they were “glad that they could help.” Caregivers had varying levels of treatment knowledge prior to their family member’s diagnosis, with less than half of the caregivers having knowledge of chemotherapy and radiation. All caregivers indicated positive interactions with the doctors and medical staff. Caregivers also echoed the sentiments of breast cancer survivors in terms of the challenge of the side effects. One caregiver participant stated families of a newly diagnosed breast cancer patient should know that because the side effects of fatigue and nausea are particularly elevated after the first treatment, the first chemotherapy treatment might be the worst for the patient. One caregiver reported the importance of maintaining treatment despite the side effects and stated that their family member with breast cancer knew if radiation treatment were not continued she would “go down fast.”



The CHW and HWHP staff expressed sentiments similar to those of the survivors and caregivers in regard to treatment. Additionally, they recognized that as an expression of denial, patients could sometimes express anger towards their doctors at diagnosis. HWHP case managers and the CHW reported that patients would feel remorse after expressing anger, and that patients would say “I got upset with my doctor’ and they would blame themselves.” HWHP offers cancer education during home visits and mammograms, but HWHP staff reported that the majority of treatment explanations are the oncologist’s responsibility. HWHP case managers and the CHW reported making home visits to follow up with patients. At these visits, treatments are discussed in locally appropriate ways, such as reducing medical jargon and using Hopi language when appropriate. Case managers also helped patients navigate their health concerns. They encouraged patients to keep a log provided by HWHP with questions for their doctors and to take this log to appointments to ask the doctor themselves. If patients were apprehensive about speaking during the appointment, they were advised to give the log to the doctor at each appointment. Participants in the CHW and HWHP staff focus group also indicated that they encourage patients to take family to medical appointments, preferably those providing direct care, so that their caregivers would know the progression of treatment.

### *Focus Group Results: Support Systems*

Support for cancer patients was found to be of high importance to Hopi women. One of the survivors related the need for emotional support for cancer patients on the reservation by stating, “Everyone needs someone and there is a lot of cancer with Native Americans.” The major form of emotional support survivors received was from their primary and extended family members. Less than half of the women also turned to local non-Native churches for emotional support. The majority of participants worked with HWHP for educational and supportive interactions, occurring through HWHP monthly cancer survivor support groups as well as through regular contact with HWHP staff, mostly case managers during home visits. Of the monthly support groups at HWHP, five participants on average attended each session, with an average of three being breast cancer patients or survivors. A participant described the program and its staff as “lifting that weight off your shoulders. They listen.”

Caregivers felt they supported their family member with cancer by providing transportation to and from appointments and “just being there for them.” One caregiver stated that the patient he was supporting wanted to stop treatment because of the side effects and that through “encouragement she was able to handle it.” One of the family caregivers also stated that an extra way she helped care for her family member was by taking the patient to town so she could have a “personal day.” A family caregiver also mentioned how support groups at HWHP had helped their family member: “Support groups really help. Cancer is really hard to deal with, she (the breast cancer survivor) knows you can be in remission for so long and cancer can come back.” Support systems described by CHW and HWHP staff were the same as those mentioned by survivors.

## *Treatment Strategies*

To assist with travel expenses such as the meals, gas, and lodging needed to receive treatment services in Flagstaff, the majority of the survivors utilized the Hopi Cancer Assistance Fund provided by fundraisers and donations collected through the HWHP. The majority of the survivors also reported they did not find the two-hour drive from the Hopi reservation to Flagstaff for treatment to be a burden and one stated that she enjoyed the chance “to get out.” With a longer course of treatment, the majority of survivors stayed at the Taylor House, or a motel or hotel if the Taylor House was full. The Taylor House was built in 2001 by Flagstaff Medical Center to provide patients and their family members with a place to stay while undergoing treatment or in need of emergency care. Survivors described informal support groups at the Taylor House where they learned about what to expect with side effects from both staff and other patients.

## *Drawing Story Topics from Data and Disseminating the Digital Stories*

Drawing from all three groups, the pertinent main topics identified to share in digital format were: (1) HWHP information; (2) Hopi female breast cancer survivors' stories of experiences during the diagnosis and treatment; (3) support systems; and (4) Hopi family caregiver stories. At the time the digital stories were created, fewer than half of the Hopi female breast cancer survivors, fewer than half of the family caregivers, and one-half of the HWHP staff members took part.

Digital stories have been used by the HWHP as a component of education at their community events, such as their mother/daughter tea luncheon, and also during mammography screening by MOM. Participants have shared their digital stories and taken questions during in-person talk events coordinated by HWHP. The digital stories have opened up the opportunity of asking cancer-related questions in the community, and also have been particularly beneficial to the participants. According to the HWHP director, the medium has allowed participants to “share their experience of cancer openly, so I believe the DVD opened up this opportunity.” The digital story DVD was also introduced and shared with the Hopi Tribal Council.

## DISCUSSION

### *Study Relevance, Challenges, and Limitations*

This project is the first to look at Hopi cancer survivor and caregiver perceptions of the treatment process, with their digital stories sharing the experience of AI breast cancer survivors and caregivers. Despite less participation than anticipated, the focus groups yielded some previously undocumented findings specific to the Hopi. Inconvenience associated with treatment was not described as challenging. Most survivors and caregivers did not find the four-hour round trip to and from Flagstaff for treatments to be burdensome; in fact, two survivors reported that they found it nice to get out of their home for these trips. Additional insight was provided on family communication. One woman reported she delayed telling her family of her cancer diagnosis because she did not want to become a burden. The finding has been echoed in other studies

of non-Native populations.<sup>25</sup> Low participation in both survivor and family caregiver focus groups was a limitation of this project. Although the lead university investigator was a tribal member, no doubt this reflects a general distrust of research and concern about exploitation. The research violation by Arizona State University while it was working with the Havasupai Tribe of north-central Arizona intensified these sentiments in Arizona, and a lawsuit resulted against the Arizona Board of Regents, which oversees the three state universities—including the parent institute of this research, the University of Arizona.<sup>26</sup> Some in the Hopi community are aware of Arizona State's research violation; a HWHP staff member stated, "I think after this episode, Hopi has been more cautious about research." Unfortunately, universities are often viewed as "elitist and as not being committed to the welfare of minority communities."<sup>27</sup> This lack of commitment to improving Havasupai welfare was echoed by the director of the HWHP, who stated that "One of the main things that we always hear from our (local) people is that they feel they are always being researched and there is never anything in return for it. They never know what happens to the information."

Another limitation was the data-collection methodology selected, specifically the use of focus groups. Limited participation in this small community setting also suggests that focus groups may not be the appropriate method to collect personally sensitive information. Focus groups in small communities do not allow for true anonymity between participants, and if a facilitator comes from outside of a small community, this may also decrease participants' willingness to offer personal experiences and information. Confidentiality in small communities should be protected, as participants in these communities may worry about other community members finding out what they have said in focus groups. Anonymity on voice recordings is of concern if confidentiality is to be maintained in small communities, and thus preference for focus groups not to be audiotaped may help increase participant perceptions of anonymity. The setting of a focus group in a small community is also of concern because participants may view the setting as being associated with prior events that have taken place in the same location. Time should be taken between events that take place here in order to separate them, such as cancer support groups and other health-related events, research-related events, and Hopi case-manager meetings with clients.<sup>28</sup>

The above finding of privacy being a concern was supported by HWHP staff. The director of HWHP relayed that "people on Hopi are private, still learning about cancer and don't want others to know they have cancer."<sup>29</sup> The focus group location was probably not related to the low turnout, as Hopi females expressed comfort with and a preference for health-related services given at the HWHP.<sup>30</sup> One-to-one interviews may have allowed participants to share more openly. An additional limitation of the focus group methodology was the enthusiasm of one survivor to speak more than other participants and the hesitation of the other survivors to speak. This outcome further supports interviews as a more appropriate means of data collection for such a personal topic. This study also does not capture the experience of male caregivers on Hopi. There was low male caregiver participation. According to the HWHP director, males tend to internalize and not share information. Future research should seek to specifically recruit this population and to determine if their caregiver experience differs from females.

The inability to maintain anonymity in this tight-knit community was certainly a deterrent to women's interest in participating in the digital story-making. Given the small size and the unique cultural, social, and rural context of the Hopi community, results of this project may also not be generalizable to all American Indians. However, the results do provide insight into barriers and strengths in cancer survivorship.

### *Project Strengths and Implications*

The primary strength lies in the tribe-university collaboration in a CBPR project. The research process relied on the experience of university and tribal investigators. HWHP staff and the lead investigator collaborated in each step of the project. The value of this collaboration was particularly noted in designing questions and analyzing focus-group data. Staff was trained in conducting focus groups and analyzing data alongside the primary university investigator, creating a shared learning experience and building capacity of all project personnel.<sup>31</sup> A CBPR approach is essential when outside researchers, even if the researcher is a tribal member, are working on tribal lands.<sup>32</sup> A CBPR approach is beneficial, as outside researchers gain more insight into the culture and can understand practices that might influence the project participation and acceptability.<sup>33</sup> Information gathered in this project will add to the sparse information about the diagnosis and treatment experiences of American Indian and, specifically Hopi, breast cancer survivors and caregivers. The digital stories are used by HWHP as part of education at community gatherings. The stories have also been shared when the MOM unit conducts mammograms at HWHP, and they contribute to Hopi women's and family caregivers' knowledge of what to expect with the treatment process. Receiving a diagnosis of breast cancer can be isolating and the intent of the stories is to show newly diagnosed women that they are not alone and that support resources and systems are available. This support, whether emotional, financial, or educational, might make the treatment process more bearable. This message is particularly important for cases in which the survivors delayed telling family members about the diagnosis, but once they did so, they realized they had emotional support. For family members, the family caregiver stories might increase their knowledge of how to respond and support their family member.

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