GIVING VOICE TO THE OCCANEECHI PEOPLE: AN EXPLORATION OF THE SOCIAL DETERMINANTS OF HEALTH WITHIN AN AMERICAN INDIAN COMMUNITY

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To my ancestors:

I hear your voices
I feel your presence
I know your pain
I acknowledge your existence
I know you are with me
Ever present
You give me strength when I think I have nothing left to give
I will give your struggle a voice
I will make your sacrifices known
I will tell the world our story
Your lives will be validated
Your cries will be heard
Your existence will not have been in vain
I am learning the lessons, walking the path
Stepping in your footsteps
I am heeding your call
I will revive our songs, our language, our ceremonies, our dances
This will be passed on for future generations to share
  We will survive
  We did survive
  I do this,
    I carry this bundle
to honor you.

- Written by Vivette Jeffries-Logan, Occaneechi poet
Abstract

Purpose

The purpose of this paper is to give voice through photographs and words to the Occaneechi people and explore the social determinants of health within an American Indian community. The Photovoice process enables people to record and reflect their community's strengths and concerns, to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs, and to reach policy makers through collective action.1

Methods

These data were originally collected for a class project at the University of North Carolina School of Public Health using the qualitative method of Photovoice to explore the social determinants of health among the Occaneechi people. The community gatekeeper identified and recruited community members. Five community researchers took photographs that reflected their lives as Occaneechi people. Photographs served as triggers for three photo­discussions that were recorded and transcribed. University researchers conducted a time­limited qualitative data analysis. Eleven codes, or key ideas, emerged from the transcripts. Two researchers independently coded each transcript and met to resolve differences. University researchers pulled representative quotations from the transcripts for each code and shared these results with the community researchers to check for accuracy and to identify themes. Community researchers self-selected the photographs to be displayed to the public and brainstormed for a model to represent the themes. For this study, the author used ATLAS.ti v5.2, a qualitative data analysis (QDA) software program to organize and further analyze the data. The author reviewed all transcripts for consistency and queried quotations for each of the
eleven codes. Community researchers reviewed the enriched selection of quotations and associated photographs for contextual accuracy and created a model to display the themes.

Results

Eleven codes emerged from the transcripts, which are listed in alphabetical order: ancestors, ascribed identity, encroachment, identity, invisibility, our future, our story, racism, regaining our power, spirituality, and Yesah ("the people" in the Tutelo-Saponi language). Community researchers drew the codes in one circle to demonstrate the interconnectedness of the codes and the equal importance of each code. The "Circle of Themes" resembles the medicine wheel, a symbol of American Indian spirituality.

Conclusion

The Photovoice method invoked an open dialog among the university and community researchers. A sense of cultural safety, or the ability to discuss culturally sensitive topics without judgment, fostered a co-learning environment, which led to a reciprocal transfer of knowledge and power between the research partners. This was demonstrated by the community researchers' decision to utilize the systematically derived codes in conjunction with their worldview, resulting in the Circle of Themes. This research has built trust between the university and community researchers and led to a motion by the Occaneechi Tribal Council to create a formal academic-tribal partnership. The Circle of Themes provides tribal specific insight into the native worldview, which defines health as a balance between physical, mental, emotional, and spiritual aspects of one's being and one's community. In addition, the Circle of Themes will inform health-related interventions with the Occaneechi community and provide a framework to work with other indigenous peoples who share a similar worldview.
Introduction

American Indians and other indigenous people have been subjected to centuries of encroachment upon their land, identity, spirituality, and way of life. Western researchers have attempted to intervene but often disregard the culture of native peoples.\(^4\) In practically all realms of life, the Western, linear paradigm eclipses the indigenous, circular model.\(^5\) This persistent racism adversely affects the physical and mental health of fourth world indigenous peoples,\(^6,\ 7\) where the fourth world refers to circumstances in which “a minority, indigenous population exists in a nation wherein institutionalized power and privilege are held by a colonizing, subordinating majority.”\(^4\)

In the United States, American Indians have been subjected to centuries of oppression by the white majority population.\(^8\) The federal government committed several overt acts of genocide, including the distribution of small pox-laden blankets in the late 1700’s, forced removal of American Indians to reservations without proper provisions in the 1800’s, and non-consensual sterilization of American Indian women by the Indian Health Service in the 1970’s.\(^4\) In the late 1880’s, the federal government shifted its aim towards assimilation of American Indians into mainstream society, which resulted in acts of cultural genocide.\(^8\) The Dawes Act of 1887 called for the redistribution of tribal lands to individual allotments by blood quantum (a phenotypic guess of one’s degree of Indian ancestry); from 1870-1929 American Indian children were required by law to attend boarding schools where tribal languages and customs were banned.\(^4,\ 8-11\) Currently, the most pervasive form of colonization is the right of the federal and state governments to determine the legal right of American Indians to their own tribal identity through the recognition process.\(^12\)

Perhaps as a consequence of colonization, American Indians and Alaskan Natives (AI/ANs) experience health disparities when compared to the white majority population.\(^13\) AI/ANs are twice as likely to have diabetes as are Whites.\(^13\) AI/ANs have an infant death rate almost double that as for Whites;\(^13\) AI/ANs also have disproportionately high death rates from
unintentional injuries and suicide. Cultural barriers, geographic isolation, and low income frequently prevent AI/ANs from seeking health care, which perpetuates these health disparities.

American Indians in North Carolina

North Carolina has the largest American Indian (AI) population east of the Mississippi River. According to the 2000 U.S. Census, 131,736 residents of North Carolina self-identified as American Indian alone or in combination with another race. The state has eight recognized tribes: the Eastern Band of Cherokee, Coharie, Haliwa-Saponi, Lumbee, Meherrin, Occaneechi Band of the Saponi Nation, Sappony, and Waccamaw-Sioux Nation. The Occaneechi Band of the Saponi Nation (Occaneechi) is the smallest (847 members) and most recently state recognized tribe (2002). American Indians in North Carolina experience substantial social and health inequalities in comparison to whites. In 2005, the NC Office of Minority Health (OMH) reported that about 21% of American Indian families live below the poverty level as compared to 8% of white families, and the unemployment rate of American Indians is two to three times that of whites. American Indians are more than twice as likely as whites to die of diabetes, HIV disease, motor vehicle accidents, and homicide. However, most collected data is not tribe-specific, and these data may not represent the smaller tribes, such as the Occaneechi.

History of the Occaneechi Band of the Saponi Nation

The Occaneechi descend from the Siouan people who migrated in prehistoric times from Ohio to the piedmont of North Carolina and Virginia, where they led an agricultural way of life. In the 1600’s, the Occaneechi occupied the largest of three islands (Occaneechi Island) on the Roanoke River near Clarksville, Virginia, with their relatives (the Saponi, Eno, and Tutelo) living on the other two islands. From this strategic location, the Occaneechi controlled the trade
along the Great Trading Path, or Occaneechi Trading Path, that connected northern tribes and the future Virginia settlers to the Cherokee and Catawba in the Southeast. Nathaniel Bacon grew envious of the wealth of the Occaneechi and of their relationship with Governor Berkley of Virginia and, in 1676, led a successful attack on the Occaneechi.

Following Bacon's Rebellion, many of the Occaneechi survivors settled along the Eno River in present day Orange County. In 1701, the English explorer, John Lawson, visited a small Occaneechi town in present day Hillsborough, which was excavated from 1983 to 1986 by UNC archaeologists. Occaneechi tribal members utilized the information gained from the excavation to build a replica village on nearby land in the early 1990's. This village became a popular historical site for the town of Hillsborough and was maintained by tribal members until the spring of 2007.

In the mid 1700's, the Occaneechi relocated to present day Alamance County, which became known as the "Little Texas" community. Most people in Little Texas owned and farmed their own land; tobacco was the major cash crop. Social life revolved around primarily Indian churches (e.g. Jeffries Cross Church and Martin's Chapel Baptist Church) and schools (e.g. Martin School). Up until the 1940's, Little Texas was inhabited mostly by related families. With the shift away from agricultural life, some people moved to Hillsborough and surrounding areas, and others sold portions of their land to outsiders. Martin School was consolidated into Pleasant Grove Union School and still plays a key role in this community along with the churches.

Throughout the era of segregation and Jim Crow, local authorities attempted to place the Occaneechi people into a biracial system. Many Occaneechi, especially those with darker skin color, were classified as "colored" or "negro" on their birth certificates and other official documents, were not allowed to enter white churches and schools, and were restricted to the "colored" section of theatres and other public places.
In 1984, the Occaneechi people formally organized as the Eno-Occaneechi Indian Association with the goal of researching and preserving their Indian heritage. The Association sought to correct misclassifications on birth certificates by changing the race from “colored” or “negro” to Indian. Also, the Association began to hold an annual Pow Wow (an American Indian celebration and homecoming) at the replica village site and applied for and received federal grants to research their heritage and revive their language (Tutelo-Saponi).

The Tribal Council changed the name to the Occaneechi Band of the Saponi Nation in 1995 to more accurately document their lineage. A long battle for state recognition ensued, wherein the North Carolina Commission on Indian Affairs (NCCIA) denied recognition on several occasions. Following many appeals, the Occaneechi received recognition through a court order on February 4, 2002.

Currently, the 847 living Occaneechi tribal members primarily reside in Orange and Alamance counties where they continue to rekindle the traditional ways and language. In 2002, the Occaneechi purchased 25 acres of their ancestral land in the Pleasant Grove Township of Alamance County with plans of constructing a 1701 replica village, ceremonial ground, orchard, tribal museum, nature trail, and community meeting area. The development of this land will advance the economic status of the tribe as well as provide an opportunity to share its history with the general public. In June of 2007, the Occaneechi-Saponi Annual Spring Pow Wow was held at the new tribal grounds and featured native dancing and the dedication of the Occaneechi replica village site and land.

The Occaneechi will need to overcome centuries of colonization, racism, and oppression to accomplish their goals of self-sufficiency and cultural identity. Tribal members carry the weight of the past struggles of their ancestors in addition to their own and those of future generations. Many seek out platforms to tell the story of their people and fight to reclaim their tribe’s identity as indigenous people or “Yesah,” which means “the people” in the Tutelo-Saponi language.
Purpose

The purpose of this paper is to give voice through photographs and words to the Occaneechi people and explore the social determinants of health within an American Indian community. The Photovoice process enables people to record and reflect their community's strengths and concerns, to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs, and to reach policy makers through collective action.¹
Literature Review

In this section, background information will be provided on three topics: 1) social determinants of health, 2) community-based participatory research, and 3) Photovoice. The author conducted a literature search in PubMed to relate this information to American Indian populations using the search terms: American Indian, Native American, indigenous, Indian, native. The search terms for each topic were: 1) social determinants of health, social determinants, health determinants, racism, discrimination, stress, psychosocial stress, colonization, social exclusion; 2) CBPR; 3) Photovoice, photonovella. The author selected articles based on relevance to the topic and cultural acceptance in the American Indian community; preference was given to systematic reviews and works authored or co-authored by indigenous researchers. Articles and books were also found by reviewing the references of the selected articles, by recommendations from experts in the field, and from the author's personal library. This is not meant to be a complete systematic review of the literature but provides an overview of the work occurring in American Indian communities and other indigenous populations.

Social Determinants of Health

For many years, public health researchers have been aware of the connection between an individual's health and his/her social and physical environment.\textsuperscript{23, 24} According to the socio-ecological model, health behavior change is not the sole responsibility of the individual but also of society.\textsuperscript{24} Healthy People 2010 declares that a better understanding of the social determinants of health, at the individual and community level, is key to improving quality of life and eliminating health disparities in the United States.\textsuperscript{25} The main social determinants of health, as determined by the World Health Organization (WHO), include race, education, socioeconomic status, stress, early life experiences, social exclusion, working conditions, unemployment, social support, addiction, food quality, and transportation.\textsuperscript{26} Furthermore,
racism may exist at three levels: institutionalized (systematic structures that cause preference towards one racial group), personally-mediated (consciously or unconsciously expressed by the dominant party towards the minority party), and internalized (feelings of hatred or disrespect towards one's own racial group). Institutionalized racism is postulated to have the most deleterious health effects on minority groups. Social Determinants of Health in American Indian Communities

Racism and psychosocial stress, in particular, have been found to have ill effects upon health in American Indian and other indigenous populations. Paradies reviewed 138 studies and found a positive association between self-reported racism and ill health for racially oppressed groups after adjusting for potential confounders. This effect was stronger for poor outcomes in mental health than for physical health. Some studies were limited by a non-experimental design, non-validated exposure instruments, and/or an unclear definition of racism. In addition, studies did not thoroughly examine the interaction between the three levels of racism.

Stress negatively affects the health of American Indians and other indigenous populations. A systematic review of over 50 studies found that psychosocial stress was associated with a range of chronic diseases and mental health disorders among fourth world indigenous peoples and African-Americans. While stress may originate from events that affect one personally, social environmental stress may affect a larger body of people over a longer period of time. Daniel et. al. propose that the stress experienced by indigenous populations "reflects inequalities and imbalance in society, linking lived experience to health status." Some indigenous researchers argue that colonization in its historical and ongoing forms should be considered a social determinant of health. Historical grief from the past massacre of one's people may be carried on for several generations, predisposing American Indians to anxiety and other mental disorders. Walters and Simoni examined the ill health
effects of colonization on American Indian women through a stress-producing mechanism, and Moffitt\textsuperscript{30} noted the present-day discrimination and marginalization of aboriginal women within the Canadian health care system and attributed this to the lingering effects of colonization.

Present day indigenous researchers seek to redefine the study of their people by decolonizing the perceived meaning of the results and the research process itself.\textsuperscript{33} Decolonization occurs by discarding the notion that one culture is superior to another culture and developing a mutual respect for all cultures and ways of thought.\textsuperscript{4, 33} Through the indigenist perspective, native cultures receive recognition for their contributions to humanity and provide their own solutions to their health problems.\textsuperscript{4, 33, 34} For instance, Walters and Simoni\textsuperscript{4} propose a an indigenist model for the stress, coping, and health outcomes of American Indian women wherein stress from traumatic events (e.g. discrimination, historical trauma, traumatic life events, and physical or sexual abuse) is mediated by cultural buffers (e.g. spiritual coping, identity attitudes, enculturation, and traditional health practices).\textsuperscript{4}

Cultural buffers may mitigate the effects of stress by decreasing stressors or enhancing coping skills.\textsuperscript{4} Spiritual coping is associated with psychological, social, and physical adjustment to stressful life events as well as with physical and mental health outcomes even after control for the effects of non-spiritual coping methods and global religious measures.\textsuperscript{4} Positive identity attitudes, or “the extent to which one internalizes or externalizes attitudes toward oneself and one’s group, and enculturation, or “the process by which individuals learn about and identify with their minority culture,” may enhance self-esteem and promote positive coping skills.\textsuperscript{35} p. 523 Furthermore, traditional health practices (e.g. herbal teas, sweat lodges, etc.) alleviate the burden of stress on indigenous peoples.\textsuperscript{4}

Interventions that take into account the indigenist stress coping model, or the unique way that American Indians deal with their stress and the stress of their ancestors, may be more effective than those that ignore the past and present cultural components.\textsuperscript{4} An approach that conveys humility and respect for the beliefs, customs, and sovereignty of indigenous peoples is
necessary to gain an indigenist perspective on health concerns. Community-based participatory research has been proposed as a crucial method to achieve this goal.

The Role and Principles of Community-Based Participatory Research

The community-based participatory research (CBPR) method guides the development of a mutually respectful partnership between the "outsiders" and the "insiders," by involving the community in all stages of the research process. CBPR is founded in feminist theory, critical social theory, and action research. In 1970, the Brazilian educator Paulo Freire wrote the Pedagogy of the Oppressed and proposed a revolutionary style of education that replaced the traditional teacher-student relationship with an equal partnership among learners. From frequent interaction with one another, the co-learners (formerly teacher and student) would construct a new viewpoint, raise collective consciousness, and act for social change. Accordingly, CBPR dispels the traditional role of researcher and subject and creates a co-learning environment.

To ensure scientific rigor, Israel, et. al. established eight principles of community-based participatory research. These include:

(1) recognizing community as a socially constructed unit of identity; (2) building on strengths, resources, and relationships within the community to address the community's health concerns; (3) making possible collaborative partnerships in all phases of the research; (4) integrating knowledge and action for mutual benefit of all partners; (5) encouraging a co-learning and empowering process that addresses social inequalities and reciprocally transfers knowledge, skills, and power; (6) incorporating a cyclical and ongoing process; (7) addressing health from both positive and ecological perspectives; and (8) disseminating findings and knowledge gained to all partners in understandable and culturally appropriate language.

These principles serve only as guidelines; community input and ownership are essential to the CBPR process.

Since participation is the key component to community-based participatory research, an objective measure of citizen participation was sought by researchers. Arnstein proposed an eight rung ladder of citizen participation. At rungs one and two (manipulation and therapy,
respectively), the citizen is a non-participant. As the citizen moves up the ladder to rungs three, four, and five (informing, consultation, and placation, respectively), he or she reaches differing degrees of tokenism. At the top of the ladder at rungs six, seven, and eight (partnership, delegated power, and citizen control, respectively), the citizen gains varying degrees of power.

Community-based Participatory Research in American Indian Communities

American Indians are hesitant to take part in traditional research, where traditional refers to the lack of involvement of the participants in the study, design, and/or implementation of health promotion interventions. Burhansstipanov conducted focus groups to determine why American Indians were opposed to research; reasons included "study results not shared with the Native Community; researchers get promotions and Native Communities get poorer; and fear that studies designed are actually designed to harm (or kill) Native Americans." Due to limited research participation by American Indians, some researchers have adapted the community-based participatory research principles to circular cultures and successfully utilized them to form partnerships between academia and American Indian communities. This section will review seven articles on CBPR in Indian country that were identified on a PubMed search on CBPR and Native Americans or American Indians. Key results include the necessity, not just the preference, for citizen participation in the research process as well as flexibility in timeliness, outcomes, and expectations.

Although each American Indian nation has its own history and culture, many nations share common elements, such as learning patterns. Davis et al. identified common indigenous learning modes from the literature:

(1) learning through observation and practice, (2) learning from storytelling, (3) learning metaphorically, (4) holistic learning, (5) learning by trial and error, (6) learning through play, (7) learning cooperatively, and (8) learning through reflection.
The researchers, then, incorporated these learning modes, particularly storytelling, into an obesity prevention program that targeted elementary school-aged American Indian children. During the three year feasibility phase, researchers surveyed and observed American Indian teachers and students; the pilot program was found to be culturally appropriate in this community.

Over a ten year time period, researchers from the University of Washington partnered with two Pacific Northwest Indian tribes to carry out cancer prevention projects and found community based participatory research to be culturally appropriate and consistent with the cultural values of these tribes. In addition, the need for consistent funding from the developmental stages through the intervention and evaluation stages was noted as a way to build trust and maintain relationships with the tribal communities. This financial problem was partially solved by using students throughout the CBPR projects, which reduced costs and built a larger community and university network.

Burhansstipanov, Christopher, and Schumacher noted lessons learned from conducting community-based participatory research in "Indian Country." The experiences were drawn from the partnerships formed between Native American Cancer Research, an American Indian-run, non-profit organization, foundations, and federal agencies as well as a CBPR project carried out by the American Cancer Society in partnership with the Apsaalooke community (more commonly known as the Crow Nation). Lessons learned included:

1. Invest time into the development of a partnership and subsequent project,
2. Distribute the budget fairly among the partners,
3. Work with leaders who have decision-making powers from each organization,
4. Provide salaries to tribal partners and project staff,
5. Create and maintain communication among all partners,
6. Share data related to the project,
7. Adjust evaluation procedures to be culturally sensitive and respectful,
8. Follow the tribal and researchers' protocols for disseminating and publishing the findings.

The following recommendations were given to facilitate CBPR in American Indian communities: be respectful and honest, spend time with communities, partner with tribal colleges, and involve communities in all research stages.
Evaluation of CBPR projects requires culturally sensitive methods as well as community input. Holkup et al.\textsuperscript{47} conducted the Caring for Native American Elders study using CBPR principles and introduced the concept of "community voice" as an evaluation component for interventions involving American Indian communities. Community voice referred to the involvement of "the Native research team member...in all phases of research project, including problem identification, intervention development, research design particularly as related to cultural sensitivity, data collection, data analysis, and dissemination of results" that is documented within the minutes of all meetings.\textsuperscript{47} Thus, the "voice" of at least one representative of the indigenous study population was heard and recorded at all sessions.\textsuperscript{47} This culturally sensitive terminology reflects the expressed need of many American Indian communities to be given a "voice" in their struggle.\textsuperscript{9,22}

In 1999, West Virginia University and UNC-CH partnered with the North Carolina Commission on Indian Affairs and American Indian communities to successfully develop a smoking cessation program for American Indian teens, entitled American Indian Not On Tobacco (AI N-O-T).\textsuperscript{40} The community was involved in all phases of the research process, which was reflected in the name adopted by the Community Advisory Board: Many Voices, One Message: Stop Tobacco Addiction.\textsuperscript{40} Horn and colleagues determined that applying the CBPR principles in American Indian communities resulted in the production of a culturally competent program, which was useful for the researchers and communities.\textsuperscript{40}

In 2003 and 2004, the AI N-O-T program was piloted in North Carolina with a quasi-experimental design; 74 American Indian youths aged 14 to 19 years received a brief 15-minute intervention or were enrolled in the AI N-O-T program. Using intention-to-treat analyses, male teens in the program were more likely to quit than those who received the brief intervention (17.5\% vs 10\%, respectively), whereas no females quit in either group.\textsuperscript{48} A larger scale intervention is needed to determine the effectiveness of the AI N-O-T program.\textsuperscript{48}
Most federally recognized and some larger state recognized American Indian tribes have institutional review boards that must approve proposed studies prior to the commencement of research. An element of community participation is preferred, and often required, for researchers to approach American Indian communities with research proposals. Noe et al. surveyed 1066 American Indian students at tribal colleges/universities about their reasons for participating or not participating in research by showing them several abstracts of study proposals. Factors that significantly increased the odds of participation included the location of the study at a tribal college/university, community involvement in study development, the presence of an American Indian principal investigator, and the pertinence of the study to the community. The possibility of discrimination against one's people, physical harm, and lack of confidentiality decreased the odds of participation. Thus, researchers must establish trust to gain access to the community.

The Photovoice Method

Photovoice is a qualitative research method developed by Caroline Wang at the University of Michigan School of Public Health, that "operationalizes participatory research by allowing the assessment and problem-solving to be in the hands of the community." The three main goals of Photovoice are: "to enable people to record and reflect their community's strengths and concerns, to promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs, and to reach policy makers." These goals are explained in more detail below.

First, community researchers choose a photo-assignment, or theme, and then take photographs for that represent that theme. These photographs serve as triggers for more in-depth discussions among community researchers. Second, university researchers facilitate this process by helping the community researchers identify problems and form solutions often through the SHOWED technique. The acronym SHOWED stands for: See, Happening, Our,
Why, Empower, and Do. This technique generates a critical thinking dialogue among the co-learners and moves the discussion beyond concrete thought and personal reflection to analysis and action on a societal level. Table One gives examples of questions for each component of the SHOWED process. Finally, the Photovoice method generates a critical consciousness about social issues among vulnerable populations. The researchers, then, work with these populations as advocates for social change through collective action.

<table>
<thead>
<tr>
<th>SHOWED</th>
<th>Question Posed</th>
<th>Type of Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>See</td>
<td>What do we see in the photograph?</td>
<td>Concrete</td>
</tr>
<tr>
<td>Happening</td>
<td>What is happening in the photograph?</td>
<td>Concrete</td>
</tr>
<tr>
<td>Our</td>
<td>How do these issues related to our lives?</td>
<td>Personalizing</td>
</tr>
<tr>
<td>Why</td>
<td>Why have these issues arisen?</td>
<td>Analytic</td>
</tr>
<tr>
<td>Empower</td>
<td>How can we become empowered?</td>
<td>Problem-posing</td>
</tr>
<tr>
<td>Do</td>
<td>What can we do about these issues?</td>
<td>Problem-solving</td>
</tr>
</tbody>
</table>

Table 1. SHOWED Technique. Adapted from Wallerstein.

Photovoice in American Indian Communities and other Fourth World Peoples

The Photovoice method could play a large role in eliminating health disparities among American Indians and other fourth world peoples, including African-Americans. Photovoice projects with African-Americans in rural North Carolina and aboriginal peoples in northern Canada have been conducted and documented in peer-reviewed journals. Although no studies of Photovoice in American Indian communities were found in the author’s PubMed search of peer-reviewed literature, a single report was identified in an internet search that demonstrated the successful adaptation and implementation of the Photovoice method in an AI community.
African-Americans, similar to other fourth world peoples, suffer from a history of colonization in the previous form of enslavement and through ongoing racism and discrimination. Thus, successful interventions with the African-American community may guide research in American Indian communities. Lopez conducted a unique study of the quality of life (QOL) needs among rural African-American breast cancer survivors from eastern North Carolina by combining the methods of Photovoice and grounded theory. Behaviors that enhance QOL (support-seeking, adjustment to survivor role, comfort with the future, and becoming a role model) were driven by three social forces (racism, stigmas regarding cancer, and African-American cultural expectations). Survivors relied upon spiritual faith and developed ways to maintain social standing to address these issues. At the conclusion of the study, the women held a community forum to present their photographs and results to influential university researchers, which led to the formation of a collaborative partnership and two taskforces; one taskforce was charged with the responsibility of educating religious leaders about breast cancer and the other with developing peer support networks. Thus, the Photovoice method was empowering within a highly spiritual and collectivist culture.

Moffitt utilized the Photovoice method to explore the reasons behind the negative perinatal outcomes of Tlicho (Dogrib) women, members of an indigenous, nomadic community in the northernmost parts of Canada. These women travel far distances for perinatal care that is often paternalistic and dismissive of their cultural values. Photovoice prompted a dialogue among the women and allowed them to voice their concerns through images and stories. These findings were presented at the 2005 Bridging the Distance Canadian Rural and Northern Health Research Conference. The health beliefs and health promotion practices of these women are to be incorporated into a training curriculum for Canadian nurses and other health workers. Although the Tlicho community is more remote than most American Indian communities, both are colonized peoples utilizing a health care system that often does not accommodate cultural beliefs outside the mainstream.
The Indigenous People Task Force in Minnesota adapted the community-based participatory research principles that underlie the Photovoice method to better reflect the circular belief system of American Indian communities by incorporating a Medicine Wheel-based philosophical approach. The Medicine Wheel is a symbol of native spirituality found in many AI cultures and represents the seven directions: north, south, east, west, up (sky or heavens), down (earth), and center (inner self or where you currently stand). In this study, a circle was divided into four equal compartments that represented learning, listening, reflecting, and sharing; each research component and participant was given equal significance and respect.

A Community Research Team (CRT) of American Indian women from several different tribes as well as Indian and non-Indian researchers chose the Photovoice method to explore the reasons behind smoking behaviors of pregnant women. Five community researchers participated in the Photovoice project. The Photovoice process uncovered “Family” and “Indian Country” to be “key spheres of influence” that made tobacco cessation difficult for American Indian women. In addition, the “Changing Culture,” or the transition to everyday use of tobacco in the form of cigarettes as a result of federal prohibition of tobacco in ceremonies for over 80 years, has created mixed messages about the appropriateness of tobacco usage. The results were disseminated to the community via a calendar that utilized photographs and quotes from the photo-discussion sessions. Limitations of the study included the focus on a specific health issue (prenatal smoking) rather than on a larger social problem and a limited ability to assess the effects of the calendar on behavior change within the American Indian communities. However, the utilization of an indigenous learning model, or medicine-wheel based philosophy, for conducting Photovoice was a unique contribution to the field.
Methods

Background

In the spring of 2007, five graduate students worked together on a class project for Health Education Health Behavior 710, Community Capacity, Competence, and Power: Community-Based Participatory Research and Photovoice at UNC-Chapel Hill School of Public Health. The goal was to utilize the CBPR principles and Photovoice method to establish a relationship with and advocate for a vulnerable population. Because one university researcher had pre-existing ties with the Occaneechi community, the university researchers decided to further explore and illustrate the life experiences of the Occaneechi to uncover what social determinants might strengthen or diminish their health and access to care.

Recruitment

A respected elder in the Occaneechi community (the "gatekeeper") was approached and agreed to participate in a Photovoice project. The elder, then, recruited four other Occaneechi tribal members. Five community researchers met as a group for a total of six meetings, which included an informational meeting, a Photovoice training session, three photo-discussion group sessions, and a final organizational meeting. A time-limited qualitative data analysis was conducted prior to a community researcher-led classroom presentation of the project’s findings.

Informational Meeting

At the initial meeting, university researchers discussed the informed consent process with the five community researchers to ensure that each community researcher understood the purpose of the project, what it entailed, and that they could terminate their involvement at any time during the project activities if they wished.
Training Session

At the next meeting, the community researchers turned in their consent forms and learned about the Photovoice process. Tips were given on how to use a camera. The group established ground rules, which were followed throughout the process. In addition, university researchers offered the community researchers the opportunity to define the research aim, and the community researchers phrased the aim to be "telling our story." At the end of the session, community researchers brainstormed and selected the first photo-assignment of "going home."

Photo-discussion sessions

The five Occaneecchi tribal members participated in three photo-discussion group sessions. Each session lasted approximately three hours and was recorded and transcribed. For each photo-discussion session, the five participants took photographs of people and objects that represented their lives as Occaneecchi people and centered on the pre-determined themes for each session ("going home" or ancestors, spirituality, and "Who am I? Who I am"). One university researcher facilitated each photo-discussion session through the SHOWED technique.

Final Meeting

In preparation for the final meeting, university researchers and one community researcher performed a time-limited qualitative data analysis of the original transcripts. The transcripts were divided into three sections. Two researchers independently coded each transcript section and met to resolve differences. Quotations were selected from the text to illustrate the codes and presented to the community researchers at the final meeting. From this material, the community researchers proposed writing the code words in two inter-locking circles to represent the emerging themes, but the process was not completed. In addition, the
community researchers chose to design the classroom presentation in a non-linear, non-Western format with visual aides in the form of posters. The community researchers selected photographs in three tiers of importance to be included in the presentation. Two university researchers designed a poster for each tier of photographs, obtained approval from two of the community researchers, and printed the posters in color ink.

Classroom Presentation

The five community researchers and another minor, who had been featured in one of the photographs and informally attended all of the Photovoice sessions, co-presented with the university researchers for the HBHE 710 class. Three posters served as visual cues to the community presenters. The community researchers and students sat down in a circle; community researchers invited the students to engage in a conversation with them rather than listen to a didactic lecture.

Institutional Review Board and Consent Procedures

The author of this paper applied for approval from the UNC-CH Institutional Review Board to utilize the data collected from the classroom project to conduct a thorough secondary data analysis in order to give voice to the Occaneechi in the scientific community as well as explore social determinants of health within an American Indian community. After obtaining approval from the Occaneechi Tribal Council Executive Board, the UNC-CH IRB approved the application by expedited review in June of 2007.

The author approached the community researchers to gain consent to go forward with the study. Community researchers ranged in age from 9 to 67 years old; there were three males (two adults and one minor) and two females (both adults). All adults gave consent to have the previously collected data utilized in this study. The minor gave assent, and the minor’s guardian gave consent for the minor to participate in the study. One additional Occaneechi
minor was featured in some of the photographs selected for display. The minor gave assent and the minor's guardian gave consent for the minor's photograph to be used in the study. This study offered no direct benefit to the participants.

**Qualitative Data Analysis**

The qualitative data from the Photovoice project was analyzed using ATLAS.ti v5.2, a commonly used data reduction and data retrieval software for qualitative data. All transcripts were reviewed for coding consistency. After the data was codified in ATLAS.ti v5.2, all quotations associated with one or more of the eleven codes were extracted. By viewing the data in a holistic manner, codes became more clearly interconnected and themes emerged in a circular manner that could be perceived by a non-indigenous researcher. The codes and associated quotations and photographs were presented to the four adult community researchers, who critiqued the findings. An Occaneechi artist constructed a circular model with the codes written along the perimeter of the circle to represent the interconnectedness of the codes and the balance of all aspects of health. Community researchers entitled this model the Circle of Themes. Community researchers and members of the Occaneechi Tribal Council reviewed and approved the Circle of Themes as being representative of their worldview.
Results

The eleven codes that were selected from the transcripts are listed in alphabetical order in Table 2. By reviewing the below photographs and quotations from the photo-discussion sessions organized by code, one can see the interconnectedness between the codes. This is also illustrated by the Circle of Themes, wherein the codes were placed at random along the perimeter of the circle (Fig. 1). Community researchers chose fourteen photographs that most powerfully illustrated their story; these photographs are displayed in the paper near the code that they most closely reflect. However, each photograph could be matched with every code. Community researchers reviewed and approved the lay-out of all photographs and quotations.

<table>
<thead>
<tr>
<th>Ancestors</th>
<th>Our Story</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listening to them</td>
<td>Telling it</td>
</tr>
<tr>
<td>Taking guidance and strength from them and their struggle</td>
<td>Struggles and strengths of our people</td>
</tr>
<tr>
<td><strong>Ascribed Identity</strong></td>
<td><strong>Racism</strong></td>
</tr>
<tr>
<td>How others identify us</td>
<td>Discrimination</td>
</tr>
<tr>
<td>Encroachment</td>
<td>Skin color</td>
</tr>
<tr>
<td>Past and present</td>
<td>Regaining Our Power</td>
</tr>
<tr>
<td>Disrespect</td>
<td>vs. powerlessness</td>
</tr>
<tr>
<td><strong>Identity</strong></td>
<td>vs. colonization</td>
</tr>
<tr>
<td>Belonging</td>
<td>Spirituality</td>
</tr>
<tr>
<td>Modeling the traditional way</td>
<td>vs. religion</td>
</tr>
<tr>
<td>Invisible</td>
<td>Of Yesah</td>
</tr>
<tr>
<td>How we experience others’ treatment of us</td>
<td>Connection to nature</td>
</tr>
<tr>
<td><strong>Our Future</strong></td>
<td><strong>Yesah</strong></td>
</tr>
<tr>
<td>Children</td>
<td>Roots</td>
</tr>
<tr>
<td>Carry on tradition</td>
<td>Family</td>
</tr>
<tr>
<td>Reviving tradition/language/ceremonies</td>
<td>Our people</td>
</tr>
</tbody>
</table>

Table 2. List of Codes. Codes are in bold. Description and dimensions covered by each code are in regular font.
Fig. 1. Circle of Themes. Drawing by Sharn Jeffries, Occaneechi artist.
Ancestors

The Occaneechi people honor their ancestors by listening to them and taking guidance and strength from them and their struggle. A community researcher was advised by an elder to “listen to the Old Ones and they will sing to you from the trees.” A community researcher described the struggle of the living members of the tribe as being interwoven into the struggles of past and future tribal members:

The struggle that we are goin’ through now, it is always...tied to the ancestors. The ancestors are always with us. They struggle for their ancestors and they struggle for their ancestors, time immemorial....there’s no linear form of time....it’s a different worldview.....when I say our struggle, I’m talking about our struggle...there is no beginning and there is no end. So, they’re still here struggling right along with me just as I was there...in the future struggling with them....this is to honor, not just my ancestors, but seven generations into the future. I do this for all my people...it’s collective....we do this to honor them, but they’re always here and we have always been with them.”

Fig. 2. Eno River. Photograph by a community researcher.
Community researchers expressed a strong connection to the land of their ancestors. During the construction of Kerr Lake in the late 1940’s, Occaneechi Island was inundated and remains this way today. Figure Four shows an aerial view of the Island in early 1940’s.

"For indigenous people, it is important to have a connection to the land...your ancestors walked on but this [Occaneechi Island] is under water and...I can't put my feet on it so this is why I keep this, 'cause this is as close as I can get." Quote by a community researcher. Photograph by an unidentified photographer.
The new tribal grounds in Alamance County (Fig. 5) provide the Occaneechi with an opportunity to be closer to their ancestors.

Fig. 5. Ancestral Land. "The spirits of my ancestors are always with me." Photograph and quote by a community researcher.

Ascribed Identity

Community researchers spoke of having an identity ascribed upon them by Europeans and their descendants. "So often, in this country you're not...considered an Indian unless you've got on buckskin, beads, and feathers." Many members of the Occaneechi tribe are bi- or tri-racial, which makes outward appearance an even poorer predictor of American Indian heritage. The process of gaining recognition frustrated and disempowered the community researchers. One community researcher said, "I ask a group of people, 'Let me see your card. Do you have a card?' 'No, we don't have a card.' Well, I have to have a card to prove that I am an Indian."

The identity of the Occaneechi people often is masked by the way others view them. Even the term American Indian does not accurately reflect the ancestry of these tribal members.

When somebody says, 'you're an American Indian?' I say, 'No, I'm not an American. My people were here before the Europeans came. And the word America came from a European name Americus Vespucius...I'm Yesah. I'm Yesah.' Occaneechi was
probably a European name slapped on us, too.

Indeed, European colonizers would often ask one native tribe for the name of a neighboring tribe, resulting in misidentification of native peoples. For example, Occaneechi means “people of esteemed high water” in the Choctaw language, but the tribal members historically referred to themselves as “Yesah,” which means “the people” in Tutelo-Saponi language. Community researchers identified as Yesah or indigenous rather than American Indian or Native American.

Encroachment

Encroachment was addressed throughout the photo-discussions. This includes past and present encroachment, or disrespect, of the Occaneechi people. As shown above, the historic Occaneechi Island was flooded in the late 1940’s to create a recreational lake. In regards to the newly purchased tribal grounds, a community researcher emphasized, “We had to buy our own land.” Furthermore, the Occaneechi decided to move the replica village located along the Eno River to their new land, in part, because of disagreements with Hillsborough town officials over construction projects, lack of funding, and uninvestigated acts of vandalism.

Fig. 5. Old Village Site with construction along Stillhouse Creek. “I wanted the village to stay here [Hillsborough] because...it’s about half a mile from the original village. But when they did what they did here, with no money in there - the town or the county never put a
dime in this village....So when I look at this right here, that's encroachment...And they still taking from us...still taking." Photograph and quote by a community researcher.

Encroachment also manifests itself as theft of identity and culture. For instance, the matriarchal system was disrupted with the arrival of the Europeans. "Women were running the tribe when men's first came. The men refused to listen to the women and that's how...male natives in the east became...empowered because they (the women) asked them (the male natives) to talk to the...Europeans." One participant recounted a present day example of encroachment upon the Indian way of life:

I was dancing at a pow wow one time and this lady was standing on the outside...She said, 'you know I'm just so fascinated with the Indians...if I had my opportunity, I would just love to be an Indian...it's so wonderful being an Indian.' I said, 'yes mam, you know. It's so wonderful...I've been spat on...I've had people throw rocks at me...I've been called nigger. I've been called everything, pagan...I've been discriminated against going into restaurants because of the color of my skin...I've been denied sitting in the front of a bus because of the color of my skin...I've been put in the back of the line at the drivers license thing because of color of my skin...And walking in the grocery stores and people sneering at me because my hair's curly...being an Indian is the greatest thing in the world. I just wish you could have been an Indian.'

Identity

The notion of identity versus ascribed identity became apparent during the photo-discussion sessions; community researchers selected the theme of "Who am I? Who I am." A community researcher stated, "I'm Episcopalian...by choice and I'm a southerner because some idiot drew a line, but I'm Indian by the grace of God." Participants found strength in embracing their American Indian heritage. A community researcher showed a photograph of an elder taken shortly after the tribe received recognition and said, "my dad never wore anything native and at this pow wow in Hillsborough, that's my dad with his Occanechee cap on and his Occanechee shirt sitting down at the pow wow and he was proud...to wear that." Another participant said, "I'm a veteran...since my eyes are open up, the American flag now it doesn't mean nothing to me. My flag is...our eagle staff....that's my flag."
Community researchers identified their culture as being collectivistic rather than individualistic. A community researcher explained, "When... Native people speak of '1,' I do mean '1.' but I mean 'I' in the tribal sense, because it's about empowerment... if I become empowered... my entire community becomes empowered. So, it's not 'me,' in the individualistic Western cosmology." One way that the community becomes empowered is by relearning and modeling the traditional ways through cultural workshops (Fig. 6).

![Cultural Workshop at the Occoneechi Tribal Grounds. Photograph by a community researcher.](image)

**Invisibility**

On many occasions, community researchers expressed a feeling of invisibility. A community researcher read aloud the words on a t-shirt, "This was my home. Now I am the guest," and commented, "and now we are below guest. I got that [in the] 80s. We are not even thought of that much lately anymore I feel like." In reference to the problems that occurred at the old village site in Hillsborough, a community researcher said, "I do feel invisible because they don't treat the landmarks for the Revolutionary war and Colonial period like this at all. And it's just complete and utter disrespect for the people Indigenous to this land."
Community researchers felt that their people were unrepresented and ignored in American politics. A community researcher stated:

When those in power say America...they don’t talk about me. And that’s evident when George Bush stood up and said we were goin’ into war with Iraq...to liberate the people whose skin color does not look like ours...when he said that, he struck down everybody in this country who did not look like him. So, this is a man who is supposedly the elected leader of our country sayin’ that we’re goin’ to liberate a group of people whose skin color does not look like ours, and where in the hell does that leave me? I am not an American citizen, I am Yesah...We live in a system that you don’t really have a choice. If you want to make a better life for yourself at that time, you could go into the service...But then you’re goin’ over there to fight for a country that doesn’t even respect you as a human bein’. And that causes me great pain. So, this patriotism, that yes, we all stick together, and we’re goin’ out to bring democracy to the other people, to these uncivilized people, when it doesn’t even work over here...you haven’t even admitted what they have done to several groups of people.

However, this feeling of non-existence or invisibility in history may be utilized as a catalyst for change. A community researcher, who had recently traveled to Ohio to visit the ancestral land of the Siouan people, stated:

History says we didn’t, we don’t exist. And so I was...in a sense, a tree with no roots...and I had no foundation. So, I gained strength when I found my foundation, when I put my feet firmly on the foundation of my people...I found my voice. I found my strength. And anger does brew up, but the way that I deal with my anger is to speak and to tell our story. To tell the story of my people.

Our Future

Although the Occaneechi people have experienced much hardship, a sense of optimism prevails over their future. This is reflected in the community researchers’ choice to display photographs of the new tribal grounds and other positive signs of spiritual, community, and economic development. Currently, the Occaneechi are working towards reviving traditions, ceremonies, and the language. One community researcher stated, “If the Occaneechi people do get their language back, they will carry on the language and they will know their past and their future.” Another community researcher serves as a fire carrier, meaning this person has “the responsibility of carrying the story of my people and passing it on.” Furthermore, the new land offers many economic opportunities for the tribe.
Fig. 7. Occaneechi Tribal Grounds. "This [the land] is the future of the Occaneechi people." Photograph and quote by a community researcher.

The children play an integral role in carrying on tradition. One community researcher showed a photograph of children praying over the drum and said, "I see this as bein' our future, because, right now, these are the only two Occaneechi children that... know...[how] to do this. And other children pay attention to children and so, they will be leaders...I just see this as the future of our original and old culture comin' alive."

Fig. 8. Occaneechi Child at the Tribal Grounds. "Without the young people you cannot go forward." Photograph and quote by a community researcher.
Our Story

Consistent with the oral tradition of native peoples, community researchers desired to tell "our story." This means sharing the struggles and strengths of their people with others. In particular, the struggle for recognition of their rich past and appreciation for their culture still has not ended. A community researcher stated:

We are not a post-colonial people. We are still a colonized people...what we have just talked about is nothing but illustrations of our continuation to say that that we’re still here, we’re still fighting for recognition. Even though we have recognition on paper, people do not recognize us as Yesah, as indigenous people. So it’s colonization, and it is a fight for recognition. We are still fighting for recognition, to say that we have always been here. Everything we have described is colonization and we are still fighting for recognition.

However, the future of the Occoneechee people entails a restoration of the power of their people, as stated by a community researcher:

It’s an illustration of the prophecy that we’re a people of the seventh fire and the seventh fire is a time of...reclamation. When...you’re walkin’ on your path and everything that was taken from you is at your feet. It will be restored, because the sixth fire was a time of great suffering and great pain. And our people survived through that and now we’re a people of the seventh fire and...everything that was taken from us will be restored to us and we are actually walking on that path now and it’s coming to fruition.

Fig. 9. The Palisade at the Occoneechee Tribal Grounds. "We actually controlled the trail between Virginia to Georgia...we were powerful." Photograph and quote by community researchers.
Racism

Community researchers spoke of the impact of racism on their lives. Most experienced discrimination on the basis of their skin color. A veteran stated, "We (Indian people) fought for this flag...then we come back and can't go into an establishment because of the color of our skin...I was just a colored boy." "Colored" was the term used, then, because most Indian people were "too dark to be white....too light to be black."

Community researchers noted racism at all three levels: internalized, personally-mediated, and institutionalized. A community researcher expressed internalized feelings of self-doubt, "I feel indecisive and I feel blinded by so many things and crippled by the other things about racism." Another community researcher discussed acts of personally mediated racism, "They [Hillsborough town officials] are treating us like black sheep, like Indians, like we don't matter still." Finally, community researchers felt that the American political system was founded on racist principles that continue to maintain the status quo. A community researcher stated:

When the declaration of independence was drafted we were mentioned and...called savages...So America doesn’t see me as an American citizen and I am not American...[the American flag] was constructed over land that was stolen from my people...and then the wealth of this country was built on the backs of another people’s stolen from their land. So I have issues with that, and I have issues with America, the new world, and all of this because I’m like if you’re going to tell it, tell the entire truth, tell the dirty and the ugliness that went on with what your forefathers did...they didn’t say all men were created equal. Yeah, all white European men were created equal.

Regaining Our Power

Community researchers mentioned the subject of empowerment on many occasions. This was defined as "regaining our power" and was examined in terms of the contrast with powerlessness and colonization. Over the last decade, the Occaneechi community has grown stronger by gaining state recognition and beginning an economic development initiative. One community researcher no longer feels "limited" and said, "I feel like we are powerful beyond belief, beyond measurement." Some derive their power from telling the story of their people. One community researcher said, "As I told one man...it is not H-I-S-S-T-O-R-Y. It is OURstory,
and that's what we are telling...and that where our power comes.” Even the youngest community researcher utilized story telling to dispel myths about American history by explaining to his classmates that “one day...the settlers just sat on there and said that was their land, but the [Indians] said that was Creator's and Mother Earth's land...it actually everybody's land.”

![Image](image_url)

Fig. 10. Building the Village and Palisade on the Occaneechi Tribal Grounds. “We have people who are working on that village site right now who are faithful every Sunday, every Wednesdays...So it’s like a few come in and see that ‘oh wait a minute, they ain’t worshiping the devil’ and...it’s part of the oral tradition....even if it's brick by brick or straw by straw, we are coming together.” Quote and photograph by a community researcher.

**Spirituality**

Spirituality is intertwined into all aspects of the traditional Occaneechi life. Community researchers emphasized the connection of spirituality with nature as demonstrated in Figures 11-13. All adult community researchers emphasized the difference between spirituality and religion; they preferred to give thanks to the Creator in private prayers rather than attending organized church services.
Fig. 11. A Spiritual Tree. "In our worldview...[the] tree is as much a part of me as I am a part of that tree. Because that tree is part of our circle. We don't see ourselves apart from nature. We don't see ourselves as superior or inferior to nature. We are a part so...if we destroy that tree we are, in essence, destroying ourselves. So, that tree is as much a part of me as it was my people...because that tree survived, that means that we survived." Photograph and quote by a community researcher.
Fig. 12. Hawk in Flight. "With the hawk coming back...it's like the Creator and the ancestors are really watching over us. So this is...really, really powerful." Photograph and quote by a community researcher.

Fig. 13. Prayer. "Each morning and each night...I have my prayer...facing the four directions." Photograph and quote by a community researcher.
Community researchers repeatedly identified themselves as Yesah, or "the people" in the Tutelo-Saponi language. Yesah describes the heritage of the Occaneechi people, which is a traditionally "circular" culture where community takes precedence over individual gain. Spirituality is intimately related to the struggle and survival of Yesah.

![Old Village Site. Photograph by a community researcher.]

The following excerpt from a photo-discussion transcript demonstrates the interconnectedness of all of these codes:

A: What does it mean to be a descendent of one of the nation's original atrocities; To live with the legacy of your peoples' trauma; To watch its impact on the health and welfare of your people; To leave home and study in the isolation of mainstream culture; To be the only you somewhere, sometimes, in lonely classrooms; To experience the invisibility of your history; To have your story interpreted by everyone else; To carry the pain and power of your people's story inside you; To celebrate your people's survival in spite of the odds; To dance in silent defiance-a dance of celebration, and triumph, Knowing full well you weren't supposed to be here.

R: WHAT DO YOU DO ABOUT THIS?
A: Speak. And tell our story. That's what I have been given. This is what I do. Because history says we don't exist, and I'm fighting history every day.

B: Nanka yaht yamooneiah watjitse.
A: Stay tall, sing, dance.
Discussion

Photovoice offered a unique opportunity to give voice with words and images to the social and health concerns of the Occaneechi people. Community researchers represented three generations of Occaneechi people, which created an intergenerational dialogue. Photographs triggered powerful discussions about the past, present, and future way of life of the Occaneechi people. From these discussions, eleven interconnected codes emerged and were displayed in the Circle of Themes by the insistence of the Occaneechi community researchers.

This section will discuss the cultural significance of the Circle of Themes as well as explore social determinants of health, Photovoice, and application of CBPR principles in an American Indian Community. In addition, the author will address limitations of the study, share personal reflections, and discuss implications of this research.

Fig. 1. Circle of Themes. Drawing by Sharn Jeffries, Occaneechi artist.
Circle of Themes

The Occaneechi people share a worldview that encompasses all the ancestors and seven generations into the future; the circle represents this worldview by indicating no start or end point. The survival of the circle is vital to the preservation of their culture. Thus, the community researchers chose to display the qualitative data results as a Circle of Themes rather than in thematic sentences. The Circle of Themes is powerful because of the multigenerational input and the ability to capture the past, present, and future of the Occaneechi people. Furthermore, the Circle of Themes incorporates features of the Medicine Wheel, an important symbol of native spirituality.

The Circle of Themes displays the systematically derived codes and themes in a manner that respects indigenous forms of expression. Scott et. al. utilized a Medicine Wheel-based philosophy to generate photo-discussions with an American Indian community by dividing a circle into four equal compartments that represented learning, listening, reflecting, and sharing; however, no parallel was drawn between the resulting themes and this philosophy. Burhansstipanov et. al. presented their findings in a diagram that contained the Medicine Wheel, which appeared to be for aesthetic purposes only. In contrast, the Circle of Themes incorporates indigenous cultural values and beliefs into the analytic phase of qualitative research.

Social Determinants of Health in an American Indian Community

The Circle of Themes represents the interconnectedness of several factors (ancestors, ascribed identity, encroachment, identity, invisibility, our future, our story, racism, regaining our power, spirituality, and Yesah) within the Occaneechi community. These factors may be considered their tribal social determinants of health. Community researchers emphasized that each factor is equally important in telling their story.
Overall, the Circle of Themes fits well into Walters and Simoni's Indigenist Model of Trauma, Coping, and Health Outcomes for American Indian Women while also accounting for the unique experiences of the Occaneechi people. In the Indigenist Model, traumatic events (e.g. discrimination, historical trauma, traumatic life events, and physical or sexual abuse) are mediated by cultural buffers (e.g. spiritual coping, identity attitudes, enculturation, and traditional health practices). Within the Circle of Themes, discrimination, historical trauma, spiritual coping, identity attitudes, and enculturation are explored in greater depth but traumatic life events, physical or sexual abuse, and traditional health practices were not mentioned.

Racism, which has been demonstrated to be an important social determinant of health among fourth world peoples, appears in the Circle of Themes. Community researchers placed a strong emphasis on discrimination based on skin color as well as the lack of acknowledgement of their presence by others, which were coded as racism and invisible, respectively. Racism manifested itself at all three levels: institutionalized (e.g. government systems that maintain the status quo), personally-mediated (e.g. being treated like "black sheep" by the Hillsborough officials), and internalized (e.g. feeling blinded and indecisive by racism). Although the code invisible may be interpreted as an act of omission at the personally mediated level of racism, it may also be a unique characteristic of American Indians in the Southeast who do not fit into a biracial society. Similarly, urban American Indians, who do not fit into mainstream society, have reported the feeling of invisibility. This research supports racism as a social determinant of health and suggests examining the Southeastern American Indian experience of being invisible in addition to or in concert with racism.

Colonization, including historical trauma and discrimination, is considered by some to be a determinant of health for indigenous peoples. The Circle of Themes indirectly addresses the detrimental effects of colonization upon the Occaneechi people through the codes encroachment and ascribed identity. Encroachment refers to past and present effects of colonization (e.g. dispossession of ancestral lands, disempowerment of women in a traditionally
matriarchal society, banning native spiritual practices, inundation of Occaneechi Island for the construction of Kerr Lake, requiring a card to be declared Indian, etc.) and an overall disrespect for American Indian culture. Ascribed identity, or how others identify American Indians in a stereotypical fashion, often results in cultural appropriation, which is a form of encroachment upon their identity as an indigenous people (e.g. non-natives building sweat lodges, romanticization of Indian culture, etc.). Furthermore, these findings recognize colonization as its own social determinant of health.$^{30}$

Within the Occaneechi community, spirituality, identity, and collectivism (or enculturation) may be protective to their health and well-being, similar to the Indigenist Model.$^4$ However, traditional health practices were not explored in-depth and do not appear in the Circle of Themes. Community researchers viewed spirituality to be closely intertwined with all aspects of life. In particular, they spoke of spirituality in relation to Yesah ("the people" in Tutelo-Saponi), nature, and religion; spirituality represented a connection to their people and land whereas organized religion symbolized European encroachment upon their spiritual beliefs and traditions. One community researcher, who practiced traditional spirituality, also chose to be Episcopalian. Similarly, many Occaneechi people practice Christianity in addition to or in place of traditional spirituality. Research is needed to determine whether spiritual coping through traditional practices is an important cultural buffer within the Occaneechi community as found in several other American Indian and Canadian First Nations.$^4,66$

In addition, community researchers not only listened to and took guidance from Creator but also from their ancestors, which was a separate and equal part of the Circle of Themes. The honoring of one's ancestors is typically viewed as a part of traditional spirituality.$^{66}$ It may be important to consider ancestors in their own context because historical connections may have negative or positive effects upon indigenous people.$^4,32,66$ While the community researchers carried the burden of their ancestors' struggles, this historical grief or trauma was accompanied by guidance or lessons learned from their ancestors.
According to the community researchers, identity entailed a feeling of belonging and modeling the traditional way. Community researchers strongly internalized a feeling of pride for their people and actively worked to externalize negative attitudes toward themselves and their people. Their identity attitudes were fairly positive and, perhaps, indicative of a cultural buffer to stress. Furthermore, through the Occaneechi Homeland Preservation Project, community researchers noted that many tribal members are coming together, which has strengthened community identity.

Collectivism, which characterizes many indigenous cultures, historically connects the Occaneechi people to one another and currently drives the revitalization of their culture. Community researchers emphasized the importance of “our story,” Yesah (our people), “our future,” and “regaining our power.” This entailed telling their story, sharing the struggles and strengths of their people, teaching the children, reviving and carrying on traditions, language, and ceremonies, and overcoming powerlessness and colonization. Empowerment through enculturation may eventually overcome the centuries of oppression by the White majority culture and improve health outcomes in the community.

Photovoice in an American Indian Community

University and community researchers have aimed to fulfill the three main goals of Photovoice in a culturally sensitive manner. First, the community's strengths and concerns have been recorded and reflected upon by the community researchers. Throughout the data collection and analysis process, the ground rules that were determined by the community researchers were upheld (i.e. if one person did not want something to be shared outside of the group, his/her request was honored without justification). Permission was obtained by the Occaneechi Executive Council to document these findings in this Masters paper, and
Community researchers worked closely with the author to ensure an accurate interpretation of their photographs and words.

Second, several small group discussions have been held to promote critical dialogue and knowledge about personal and community issues, including a presentation to a public health class in April of 2007, a medical student seminar in November of 2007, and at the monthly Occaneechi Tribal Council meeting in November of 2007. All of these sessions were co-led by university and community researchers and organized in a circular format. In March of 2008, community researchers will present to a large group at the New Directions in American Indian Research Conference on UNC-CH campus. Future endeavors to generate discussions about the photographs include display of photographs in the Occaneechi Cultural Center as well as submitting a manuscript for publication in a peer-reviewed journal and an abstract to speak at the 2008 American Public Health Association Annual Conference.

Third, university and community researchers are forming a plan to engage policymakers. Key federal and state legislators will be invited to the New Directions in American Indian Research Conference. A community forum in Hillsborough and/or Mebane, NC, would serve as an opportunity to gather citizens and local politicians to discuss the unique challenges faced by the Occaneechi people. Furthermore, both community and university researchers are searching for funding to gather tribal-specific epidemiological data, which can then be used to design an intervention that takes the Circle of Themes into consideration.

Adherence to CBPR Principles in an American Indian Community

Community involvement is absolutely critical to conducting meaningful research with the Occaneechi people as has been noted in much of Indian Country. Community researchers were included in all phases of the research process, including the selection of topics for photo-assignments, approval of transcripts for accuracy, approval of codes identified by university researchers, coding of the transcripts, determination of themes, and presentation.
format. By adhering to the CBPR principles, university and community researchers established a trusting and mutually respectful partnership.\textsuperscript{41}

Most importantly, university researchers promoted a co-learning environment and empowering process that addressed social inequalities and reciprocally transferred knowledge, skills, and power.\textsuperscript{1,41} This CBPR principle was challenged during the Photovoice process, but the conflict was successfully resolved. When the university researchers approached the community researchers with coded transcripts and sought to determine three major themes from the data, the community researchers refused to allow their story to be deconstructed in a linear manner. Instead, community researchers proposed a Circle of Themes to give equal importance to each of the eleven codes and to reflect their worldview. This collective paradigm displayed the qualitative results from an indigenist perspective\textsuperscript{4} but also acknowledged and validated the codes that the university researchers had identified in the transcripts. Thus, the university and community researchers learned from one another and constructed a new viewpoint.

**Limitations**

This study has several limitations. First, a convenience sample identified by the community gatekeeper was used, which may or may not have represented the community as a whole. Second, the sample was small; only five community researchers took part in the Photovoice process. To counter these two limitations, the results were presented to and approved by the Occaneechi Tribal Council. Community buy-in was also demonstrated by the drawing of the Circle of Themes by an Occaneechi artist, who had not participated in the project. Third, university researchers had no previous experience with Photovoice and had to make adjustments throughout the process. This, too, could be considered a strength because the process was iterative and the university researchers were more likely to assume a role of co-learner rather than instructor. Finally, medical problems were not directly discussed. This is
contradictory to the Western medical model that emphasizes diagnosis and treatment of illness. Instead, community researchers addressed the importance of balance in one's life and explored social and health concerns of their people in a larger context.

Reflections as a CBPR Researcher

This study not only demonstrates the importance of including community researchers in all stages of the research process but also the benefit of approaching the community with cultural humility, or a respect for a culture different from one's own. The university research team was composed of one African-American woman, one African-American man, one White man, and two White women. Each had varying degrees of contact with American Indian populations, from very little to almost total immersion from marital ties, but all expressed interest in learning more about the cultural values and practices of the tribe. This cultural humility decolonized the research process by eliminating a hierarchical relationship between White mainstream culture and indigenous ways of life and led to the enthusiastic participation of the five Occaneechi community researchers.

In a culturally safe environment, peoples from different backgrounds will be able to hold an open discussion on emotionally charged topics, such as racism, discrimination, and colonization. The dynamic between the university and community researchers enabled people to speak frankly, allowed people to ask questions, and helped people grow in their understanding of these issues. In particular, the author gained a deeper appreciation for the detrimental effects of racism and oppression and how these experiences shaped people's lives.

The author felt compelled to intervene as a White female to combat racism at all three levels: institutionalized, personally-mediated, and internalized. Currently, the author works to address racial and ethnic health disparities as a co-instructor in a seminar for medical students, member of community-based participatory research teams, and in other roles in her professional and personal life. She has learned that her primary role is in exposing the White
majority to these concepts by holding conversations on race, racism, and discrimination and helping the White majority to move beyond guilt for their White privilege and into collective action. She has adopted the style of co-learner rather than teacher or lecturer. Furthermore, this experience has made the author a better physician and person.

Several nursing and medical schools now recommend a “cultural immersion” experience as part of their curriculum. These are often one or two week trips to remote places to conduct a health needs assessment or provide medical services. This study, however, suggests that interacting locally with peoples of a different culture, building relationships slowly over time, and beginning without a set agenda may achieve a deeper and longer-lasting effect than the short-term health service experience. Over several months, university researchers learned about the Occaneechi culture by participating in ceremonies, the annual Occaneechi-Saponi Pow Wow, and the Occaneechi Homeland Preservation Project. University and community researchers maintain close friendships and professional relationships. Through this cultural immersion experience, the author feels connected to the Occaneechi people and personally invested in the welfare of their community as well as aware of the need to explore the unique social determinants of health in other peoples and communities prior to conducting research.

Implications

On November 8, 2007, the results of the Photovoice project were presented at the monthly Occaneechi Tribal Council meeting to verify that the information was representative of the viewpoints and experiences of the Occaneechi people and propose the establishment a formal academic-tribal partnership. The Tribal Council embraced the Circle of Themes and passed a motion to pursue publication of the research, form a health committee, and pursue an academic-tribal partnership. Currently, university and community researchers are searching for grants that will fund data collection on health and social conditions in the Occaneechi
community. Tentative plans also include the design and implementation of an intervention to reduce tobacco addiction and substance abuse within the Occaneechi community.

The Circle of Themes is being shared with other indigenous scholars to see if this model would be applicable to other American Indian nations. Future research may include validating the Circle of Themes concept as well as utilizing a tribe-specific Circle of Themes to design culturally appropriate interventions in other American Indian communities. Most importantly, community researchers will give voice to their struggles at the New Directions in American Indian Research Conference in the spring of 2008. Additional opportunities to reach policymakers, public health officials, and the general public are being pursued.
Conclusion

The Photovoice method invoked an open dialog among the university and community researchers. A sense of cultural safety, or the ability to discuss culturally sensitive topics without judgment, fostered a co-learning environment, which led to a reciprocal transfer of knowledge and power between the research partners. This was demonstrated by the community researchers' decision to utilize the systematically derived codes in conjunction with their worldview, resulting in the Circle of Themes. This research has built trust between the university and community researchers and led to a motion by the Occaneechi Tribal Council to create a formal academic-tribal partnership. The Circle of Themes provides tribal specific insight into the native worldview, which defines health as a balance between physical, mental, emotional, and spiritual aspects of one's being and one's community. In addition, the Circle of Themes will inform health-related interventions with the Occaneechi community and provide a framework to work with other indigenous peoples who share a similar worldview.
MAHK JCHI

MAHK JCHI TAHM BUOOI YAHMPI GIDI
(OUR HEARTS OUR BIO)
MAHK JCHI TAUM BUOOI KAN SPWEWA EBI
(OUR MINDS OUR GOOD)

REFRAIN

MAHMPI WAH HOKA YEE NONK
(SPIRIT OF THE OLD ONES)
TACHOND TANI KIYEE TIYEE
(HAVE STRENGTH)
GEE WE-ME ETIYEE
(GIVE US STRENGTH)
NANKA YAHT YAMOONIEAH WATJITSE
(STAY TALL, SING, DANCE)

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References


36. Lowery J. *The North Carolina Department of Health and Human Services’ Secretary And Commission of Indian Affairs’ Joint Task Force on Indian Health Recommendations for Improving American Indian Health In North Carolina*: NC Department of Health and Human Services and Commission of Indian Affairs; Mar 14 2005.


