Native Pathways to Health: A Culturally Grounded and Asset-based CBPR Project Exploring the Health of North Carolina's American Indian Communities

Megan B. Irby, Parissa J. Ballard, Tony Locklear, Vivette Jeffries-Logan, Teryn Brewington, Randi Byrd, Charlene Hunt, Sarah Langdon, Ronny Bell

Among the eight tribes within North Carolina, American Indian communities experience disparate rates of poverty, low education, chronic disease, low access to health care, and low quality of life. Addressing inequities and knowledge gaps will require novel and culturally appropriate approaches designed in partnership with AI communities, and should be underscored by the cultural assets those communities possess.

Introduction

In the time since first European contact five centuries ago, American Indian (AI) communities have faced health disparities brought about by a traumatic history of oppression, marginalization, and the inequitable distribution of resources. The eight Tribes in North Carolina (Eastern Band Cherokee, Lumbee, Meherrin, Haliwa-Saponi, Coharie, Wacammaw-Siouan, Occaneechi Band of the Saponi Nation, and Sappony) and four Urban Indian Organizations (UIOs; Cumberland County Association of Indian People, Guilford Native American Association, Metrolina Native American Association, and Triangle Native American Association) include over 130,032 individuals who self-identify as AI [1]. Though collectively they account for less than 2% of the North Carolina population, the tribal communities carry a disproportionate burden of poverty, low formal education, some chronic diseases, limited access to health care, and low quality of life compared to North Carolina's other racial/ethnic groups. At the same time, North Carolina's tribal communities have many assets that lend themselves to addressing health disparities based on their rich cultures, customs, history, and community traditions.

More than one-quarter (25.5%) of the AI population in North Carolina lives at or below the federal poverty level and fewer than 18% have health insurance [2]. Compared to other racial and ethnic groups, AI communities in North Carolina are disproportionately more likely to die from unintentional opioid overdose, adolescent suicide, homicide, Alzheimer's disease, chronic liver disease, motor vehicle accidents, cancer, or diabetes [2]. North Carolina tribal communities also experience significantly more environmental disparities compared to other groups, including poor infrastructure, contaminated food and water sources, and hazardous exposures, all of which are exacerbated by poverty, rural location, historical marginalization, and less collective power to participate in and inform policy and regulatory decision-making [2].

Despite a wealth of ongoing research, national surveys and more proximal state- and county-level health assessments provide only limited information—primarily in aggregate—with very little data to characterize needs and priorities unique to each of the North Carolina tribes. Many previous health assessment methodologies also were considered by tribal members to be culturally mismatched and stereotypically misrepresentative of health and life within North Carolina's Native communities. Culturally appropriate and tribe-led data collection techniques are needed to better understand what drives the health of unique tribal communities and what is needed to overcome disparity.

Akin to challenges faced by minoritized populations across the United States, AI communities are underrepresented in research and often overlooked in state and federal funding decisions, policy making processes, and establishing of health care priorities. In-depth and comprehensive data obtained at the most proximal levels are needed to identify tribal health concerns and optimize intervention strategies in alignment with the cultural identities and values of AI communities. Implementation of such projects should be fundamentally rooted in collaborative partnerships with AI community members and tribal leaders. Of the few successful examples of research partnerships between individual

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Address correspondence to Dr. Megan Bennett Irby, Wake Forest School of Medicine, Medical Center Blvd, Winston-Salem, NC 27105 (mirby@wakehealth.edu).

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tribal communities and academic researchers, it is clear that community-engaged research approaches are essential as they are more likely to facilitate trust-building, equitable collaboration, and sustainable partnerships to produce research that is meaningful to both tribal and academic communities [3]. Such approaches are well suited to increasing representation of AI communities in research as they draw on the assets of communities and are designed with the acknowledgment of, and desire to reduce, health disparities.

Native Pathways to Health (NPTH) is a novel, community-engaged project designed to enhance understanding of North Carolina AI health needs, priorities, assets, and concerns by empowering and elevating the voices of tribal communities through sacred forms of communication and community-driven data collection projects. Importantly, NPTH builds upon relationships and research carried out through the Sacred Hoop of Native Health and Wellbeing (SSHAW) project conducted by the University of North Carolina's American Indian Center (UNC AIC). To explore diversity of thought and perspective within tribal communities, NPTH also focuses on the intersection of cultural and developmental considerations across the lifespan by

using intentional engagement strategies inclusive of both AI adults and AI youth. Although still underway, the NPTH project intends to bridge limitations in current knowledge by providing accurate documentation of the health priorities and concerns of North Carolina AI populations as well as assets they possess for directing and facilitating meaningful changes within each tribal community and UIO.

Native Pathways to Health

NPTH builds upon existing community-academic partnerships with AI communities in North Carolina and seeks to leverage community strengths to better understand and address tribal health priorities. Support for this work includes collaborations with the UNC AIC and Wake Forest School of Medicine's (WFSM) Office of Cancer Health Equity and Maya Angelou Center for Health Equity. Here we describe methods and preliminary findings from the first two years of NPTH with a focus on our Tribal Health Ambassador model, derived from the core principles of community-based participatory research (CBPR), and the role of storytelling as a means of communicating about Native health.

Consistent with recommendations and approaches described in the "North Carolina American Indian Report on Conducting CBPR in American Indian Communities" [4],

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authentic engagement with tribal leaders and community members, followed by formation of the NPTH Tribal Health Ambassador model, were and are fundamental components of NPTH. This CBPR approach adds to the growing body of literature on CBPR with American Indian tribal communities. Based on the establishment of equitable partnerships between community members and academic researchers, CBPR maximizes fairness, supports bidirectional transfer and cocreation of knowledge, builds community capacity, enhances validity of research products, and facilitates real-world translation of research into practical community settings [5-10]. Beyond the core principles of CBPR, NPTH seeks to be not only tribally based but tribally driven. The direction and the ultimate products of the research are determined by community members and tribal leadership [11-21]. This tribally driven model better supports and honors the sovereignty of each AI community and the active power of their tribal governments.

Aligned with these principles, NPTH has two key objectives: 1) to develop a clear understanding of the health needs, priorities, and assets of each of North Carolina's tribal communities and 2) to do so through a process designed to build tribal capacity to promote health in each community. The data collected during this work are being used to engage, educate, and empower each tribal community to create sustainable community health action plans. To meet our objectives, Year 1 was guided by the following aims:

Aim 1: Relationship Building

Establish relationships, reaffirm trust, and garner tribal leadership support. Consult tribal leaders and Tribal Health Ambassadors (THAs) to guide cultural aspects and ensure study objectives align with the goals of the AI communities.

Aim 2: Data Collection

Collect data from the communities via culturally appropriate techniques and tribally driven projects.

Aim 3: Analysis and Dissemination

Reconvene with tribal leaders and THAs to review findings from aims 1 and 2 to: create data dissemination plans to present findings to each community, plan next steps for

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addressing expressed health concerns unique to each tribal community, and discuss strategies to address health concerns identified in the research.

Data from NPTH will be of value to each tribal community and to public health researchers, as they will provide an understanding of specific health needs and concerns of communities and examine the biological, behavioral, social, and environmental determinants of health issues unique to each tribal community. The partnerships and data resulting from this work will inform subsequent NPTH projects featuring interventions and interactions with additional research partners. Over time, we hope this work will assist in overcoming historical underinvestment in North Carolina AI communities while also enhancing community capacity to influence local public health (e.g., policy makers, state and federal agencies, medical and health corporations).

Methods

Tribal Health Ambassadors and Research Training Retreats

NPTH was designed to include members of all North Carolina AI tribes and UIOs. In the initial year of the project, the NPTH academic research team (which includes faculty, staff, and well-respected members of North Carolina AI tribes from UNC-Chapel Hill and WFSM) partnered with adults and youth from North Carolina tribes and UIOs to form a THA Program. THAs were recruited to participate as paid research staff with assistance from tribal leaders who advertised THA positions within their specific communities. THAs included at least one adult and one youth from each tribe and UIO (N = 24), all of whom were invited to participate in a two-day research retreat featuring interactive lectures, group discussions, and an overview of the research processes (e.g., ethics, partnerships with AI communities, research methods). All research procedures were approved by the Wake Forest Baptist Health IRB.

During the research training retreat, adult and youth THAs engaged in discussions regarding how to best collect information about health from their tribal communities. Following the SSHAW model set forth by the UNC AIC, NPTH adult THAs all chose Talking Circles (a sacred approach for engaging in discussion) as an efficient, culturally appropriate, and engaging way to better understand health within each of the tribal communities. In addition to

Talking Circles, youth THAs also chose a variety of other data collection methods, including surveys, interviews, and filmed documentaries. Adult and youth THAs were assisted by trusted Talking Circle facilitators (Jeffries-Logan and Locklear) and the academic research team to carry out the design and implementation of their research methods. Youth THAs were encouraged to partner with adult THAs in their community as well as other community members who could prove helpful in meeting their research goals.

THAs collaborated with the academic research team to assess health in their communities: adult THAs led Talking Circles and youth THAs designed projects following a Youth Participatory Action Research (YPAR) approach. Findings informed development of community surveys to document health needs, priorities, and assets; revealed unrecognized areas of concern; and will inform development of tribally led action plans in future steps.

Talking Circles with adult community participants. Talking Circles are a culturally appropriate and traditional way of fostering honest and intergenerational dialogue in Native communities. Facilitated by previously trained and well-respected individuals from North Carolina's tribal communities (Jeffries-Logan and Locklear), between two and four Talking Circles were held within each North Carolina AI tribal community and UIO. Adult THAs served as liaisons between the community, tribal leadership, and the research team, and worked with Talking Circle facilitators (Jeffries-Logan and Locklear) to assist in planning, recruiting for, and facilitating Talking Circles. Talking Circles were designed to: 1) elicit perceptions of health and health needs; 2) develop an understanding of each tribal community's unique priorities; 3) learn each tribal community's unique resources, strengths, and sources of resilience with potential to influence health; and 4) understand how each tribal community perceives environmental health risks (e.g., climate issues and the Atlantic Coast oil pipeline) and various other social determinants of health. Though information shared during Talking Circles traditionally is considered sacred and does not "leave the circle," all THAs, Talking Circle facilitators, and community participants agreed that themes from the Talking Circles could be shared with the research team and more broadly in community reports, academic presentations, and publications. No personal health information was obtained and verbatim information shared by unique participants was kept confidential.

Youth THA Community Research Projects

Youth THAs (YTHAs) designed projects based on their perceptions about how best to reach and gain insights from youth in their own communities. After initial training on the research process, YTHAs were supported by research partners through various methods of communication to further develop methods for their research projects, which included surveys, interviews, filmed documentaries, and Talking Circles. At least three of the YTHAs implemented more than one method in order to reach different age ranges of youth. YTHAs identified several common themes as health assets, such as the importance of tribal communities themselves and the strength of community ties/kinship and a desire for more inter-tribal and intergenerational knowledge-sharing about cultural practices and traditions (e.g., beading and traditional medicine). Common challenges to health included: mental illness, exposure to substance misuse, lack of physical activity, and lack of healthy food choices. YTHAs summarized their findings in various forms, such as reports, videos, and PowerPoint presentations, and presented their findings at a YTHA retreat. An important outcome of the YTHA engagement in NPTH was capacity-building; there now is a cadre of North Carolina AI youth who have articulated the desire to continue this work and find new and innovative ways to improve all aspects of health for AI communities.

Discussion

The Native Pathways to Health project has potential to yield a great deal of information about the health needs, priorities, and assets of AI tribal communities in North Carolina. Information gleaned from adult and youth THA projects directed an in-depth qualitative analysis of health issues specific to each tribal community. These data were compiled into community reports specific to each tribal community and presented for review such that THAs and tribal leaders reviewed, edited, and confirmed information pertinent to their respective tribal communities. These data facilitated development of a NPTH project report describing information unique to each community as well as similarities across communities. In partnership with THAs and tribal leadership, data from the THA projects also informed development of a single health survey that will provide quantitative data to more broadly assess tribal community health, including information regarding the COVID-19 pandemic that emerged during the course of this work. Surveys currently are being distributed to tribal members via mail and email, with an expectation that data collection will culminate by December 2021. Surveys will be analyzed to provide community-level data.

Once complete, evaluation of the NPTH project will focus on documenting both qualitative and quantitative data to inform sustainable health improvement community action plans. One subsequent project already underway focuses on better understanding attitudes about tobacco and cigarette smoking among North Carolina AI communities—an important common theme that emerged across multiple NPTH Talking Circles that may require implementation of unique interventions specific to individual tribal communities.

Engagement of YTHAs added an innovative component to traditional CBPR-based projects and provided additional opportunities for Native youth to be involved in their own communities [3]. Though relatively rare, youth-focused CBPR is a form of research in which youth are trained to identify and analyze problems relevant to their lives [22], and

has potential to enhance project goals, empower youth, and increase access to the youth population [23-26]. Given that data documenting health issues in AI communities are particularly lacking as pertains to younger demographics, inclusion of YTHAs was critical for NPTH as youths themselves are best positioned to recruit from their peers to provide valuable insights about health issues facing younger generations. At the same time, YTHAs had the unique opportunity to engage in meaningful work that contributed to their communities, obtain research and leadership skills, grow their social and professional networks, and gain mentoring from working with adult THAs and NPTH project staff with whom they interacted during the project.

As a result of historical and ongoing abuses committed against Native and Indigenous peoples, it is imperative that research entities approach data collection through methods that are free of exploitation, appropriation, and misrepresentation of their cultures, and supportive of their sovereignty [27, 28]. In an attempt to carry forward these ideals, the NPTH project was uniquely designed to follow a tribally driven, strengths-based, and community-partnered approach that supports sustainable health. All research processes were led or informed by tribal community members as equal partners in the research process, and were designed to support data sovereignty such that each tribal community or UIO retains ownership over the data collected in their respective communities. NCMJ

Megan B. Irby, PhD assistant professor, Department of Psychiatry and Behavioral Medicine, Wake Forest School of Medicine, Winston-Salem, North Carolina.
Parissa J. Ballard, PhD assistant professor, Department of Family and Community Medicine, Wake Forest School of Medicine, Winston-Salem, North Carolina.
Tony Locklear, MS doctoral student, University of North Carolina at Greensboro, Greensboro, North Carolina.
Vivette Jeffries-Logan, MS equity, leadership, and organizational development consultant, Biwa Consulting; cultural educator and ambassador; citizen of the Occaneechi Band of the Saponi Nation, Burlington, North Carolina.
Teryn Brewington, BS project manager, American Indian Center, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.
Randi Byrd, MPH project manager, American Indian Center, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina.
Charlene Hunt, BS project manager, Office of Cancer Health Equity, Comprehensive Cancer Center, Wake Forest School of Medicine, Winston-Salem, North Carolina.
Sarah Langdon, MPH program manager, Maya Angelou Center for Health Equity, Wake Forest School of Medicine, Winston-Salem, North Carolina.
Ronny Bell, PhD professor, Office of Cancer Health Equity, Comprehensive Cancer Center, Wake Forest School of Medicine, Winston-Salem, North Carolina.

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