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Community Based Participatory Research (CBPR): A Dynamic Process of Health care, Provider Perceptions and American Indian Patients' Resilience

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Abstract

American Indians are disproportionately affected by factors that lead to health disparities, however many Native people demonstrate resilience when faced with health risks. Study objectives were to use a resilience framework to identify wellness strategies among American Indian people and to assess health care provider perceptions of American Indian wellness. Participants included 39 American Indian adults who self-reported resilient change and 22 health care providers who served American Indian patients. Thematic categories across American Indian and health care provider data were identified: 1) relationships inform resilience; 2) prejudice stymies resilience; and 3) place shapes resilience. Results indicated the salience of relationships in demonstrating resilience. Identified challenges and supporters of resilience are discussed.

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Keywords

American Indians; resilience; social determinants of health; community-based participatory research

Health disparities are produced through a complex interplay of processes embedded in social and physical ecologies resulting from systematic inequalities in social insitutions.[1–3] However, many American Indians have demonstrated the ability to live healthy lives despite conditions of inequality. The objectives of this research were to use a resilience framework and a community-engaged approach to identify wellness strategies among American Indians and assess health care provider perceptions of American Indian wellness in the U.S. southwest.

The concept of resilience emerged from investigations of how natural ecosystems withstand, respond to, and recover from disturbance.[4] Resilience among human beings may be characterized by the capacity to balance positive and negative emotions, engage in flexible problem solving, and take a reflective stance while maintaining overall fitness and safety.[5] Invocations of the term resilience in health research and interventions point to efforts on the part of individuals and communities to compensate for the adverse health impacts resulting from unjust structural conditions.[6–7] Michael Ungar[8] defines resilience as "a set of behaviors over time that reflect interactions between individuals and their environments, in particular the opportunities for personal growth that are available and accessible"[p.3] and points to the importance of environmental, contextual, temporal, and political economic factors in examinations of resilience. The comparison of people to natural environments is highly problematic, and the assumption that everyone can be resilient is also destructive. Our use of resilience is intended instead to develop ways of initiating education for health care providers on what people do that works.

American Indians have long experienced poorer health status and lower life expectancy when compared with other groups in the United States;[9] however, American Indians have also demonstrated remarkable resilience considering historical and contemporary challenges to wellbeing[10–12] and have worked to exercise greater control over tribal health care delivery in response to 1970s federal self-determination legislation.[13,14] Scholars have attributed the persistence of health disparities among American Indians to historical and contemporary social, political, and economic forces including termination, forced relocation and assimilation, and rapid socioeconomic change.[15–18] Less attention has been paid to how American Indians leverage existing supports or create conditions to navigate their lives towards greater wellness.[19] Population-level assessments often fail to project a nuanced picture of how American Indians experience patterns of unequal social conditions through embodied experiences of health. In addition, gaps in data surrounding American Indian health care impede accurate assessment of and interventions for health disparities.[20] More explorations of health resilience among American Indians are needed to elucidate the diversity of ways individuals and communities achieve and maintain good health despite narratives and statistics that demonstrate that American Indians, as an ethnic group, face significant health disparities and dismal social and economic conditions.[21]

American Indian concepts of resilience reflect culturally embedded values that simultaneously draw from traditional and contemporary forms of knowledge and strategies to successfully navigate social, political, and economic structures.[22–24] The literature indicates that these strategies include educational attainment, strong sense of self, participation in familial and community support, and the integration of traditional beliefs and practices in everyday life.[10–12,25] A framework of resilience recognizes population-level historical and present challenges as well as individual and community ability to navigate external factors to achieve healthy change. The application of the concept of resilience to research with Indigenous peoples has been critiqued. Dian Million[26] writes of the colonial practices that become embedded in a framework of victimhood that conceptually re-inscribes practices that it claims to dismantle. Moreover, positioning resilience within health research may contribute to a medicalization of individual and community experience related to inequity, and its framing in terms of therapeutic approaches to it. The goals and approaches of this study reposition resilience not as a therapeutic model but instead as a way to draw attention to an area that is often unrecognized by health care providers to broaden views rather than limiting them.

The direction and focus of this study drew on previous work with local communities suggesting a large gap in health care provider understanding of American Indian culture and beliefs.[27–28] Researchers and community collaborators developed a “resiliency approach” in that study objectives were targeted towards the identification and documentation of positive strategies that American Indian people use to become and stay well. The current research is a part of a local wellness coalition called the Center for American Indian Resilience (CAIR) that defines resilience as: “The ability to move forward like a willow with renewed energy, with a positive outlook with attainable goals to achieve one’s dream, and overcome negative life experiences from current and past political and historical events, with the goal to reduce health disparities among American Indians.” (personal communication, Center for American Indian Resilience—Priscilla Sanderson)

With the recognition that people know what works to become well, this research sought to: 1) document American Indian patients’ resilience by identifying their wellness strategies in the context of health care provider perceptions of American Indian wellness; and 2) inform and improve health care approaches that recognize and align with the behaviors and understandings of American Indians. Researchers used a community- engaged research approach to explore wellness strategies among American Indians living in Arizona that incorporates knowledgeable community members as co-researchers.

Methods

Setting.

Researchers conducted this community-engaged study with American Indian adults living off reservation in Flagstaff, Arizona and surrounding areas between 2012 and 2015. Flagstaff is a mid-sized city located in northern Arizona, with proximity to the Hopi Tribe and the Navajo Nation, and is a major employment center drawing people from the surrounding areas to work.

Approach and research team.

The plan and implementation for the project utilized the principles of community-based participatory research (CPBR)[29–32] and Rapid Assessment, Response and Evaluation (RARE)[33–35] for data collection and analysis. The study began by drawing on prior community-engaged research that resulted in findings indicating a lack of knowledge among local health care providers about the lives of their patients, and a need to challenge suggestions that non-providers did not know how to be healthy. Project leads drew on this research to develop a proposal that reflected stated community needs and then used RARE to delve into the project focus. A mixed methods approach, RARE combines systematic ethnographic data collection and analysis with complementary research methods, such as surveys or observation.[33–35] It utilizes pre-existing data sets, involves local community members, incorporates methodological training for field researchers, and includes oversight from academic and other professional researchers with RARE expertise.[35]

The plan included recruitment, interviewing, hiring, and training of community researchers.[36] In this study, community researchers are defined as persons from the local community who work as non-academic co-researchers alongside university researchers.[36] A university-affiliated medical anthropologist and public health scholar hired four community researchers with different tribal affiliations. The research team included a medical anthropologist, public health scholar, community researchers, undergraduate and graduate anthropology and health sciences students, a librarian with experience in conducting qualitative research, and a project coordinator. Team members included people with diverse ethnicities, including different tribal affiliations. Team members participated in an intensive training session covering research development and design, ethics, project management, and multiple research methods. University researchers led the training sessions with a focus on group involvement and shared decision-making. Community researchers learned how different methods could be used to develop a dataset and then chose the most appropriate methods they thought would answer their questions. The team also worked together to modify and develop new methods during the training sessions, resulting in the creation of a Wellness Mapping Toolkit.[37] Analysis of all data was iterative and happened in a group session. This provided training in analysis and an in-depth, interactive platform for community-engaged research and practice.

Recruitment.

Team members identified and used a purposive sampling strategy[38–39] to outline study eligibility of two groups of research participants. Community researchers decided to use social networks and local resources to recruit participants for the study through word-of mouth and research fliers. Recruitment was only one of many tasks the researchers used throughout the project. For the first group, study eligibility included being an American Indian, aged 18 and older, living in and around Flagstaff who during recruitment screening self-reported making lifestyle and/or changes in biomarkers with the intent to become healthier. These changes included lifestyle modifications such as starting an exercise regimen or nutrition plan and improvements in clinical indicators such as body mass index (BMI), glycosylated hemoglobin (HbA1c), and/or blood pressure. The research team relied on the reports of potential participants and did not confirm eligibility through other sources,

such as medical record review. The second group included health care providers, of multiple ethnicities working in a health care setting providing care for American Indian patients. The requirements were that people were employed in a local health care entity, held the appropriate credentialing, and served American Indian patients.

Data collection.

Project leads and community researchers collaboratively designed interview questions to obtain information on knowledge, attitudes, beliefs, and behaviors related to wellness strategies as demonstrated through lifestyle change. Specific interview domains included wellness, motivation/inspiration, setbacks/overcoming struggle, community support and social networks, and cultural support/spirituality. The team designed interview questions for health care providers to elicit perceptions of their ability to communicate health information effectively to American Indian patients and their understandings of the challenges and successes of American Indian people they serve. Team member-defined areas of inquiry in provider interviews included medical training, everyday clinical experience, personal health, wellness, needs of American Indian patients, and healthy lifestyle change.

Project leads and community researchers conducted semi-structured interviews in English with American Indian adults and health care providers who met the eligibility criteria. While community researchers had the capacity to conduct interviews in tribal languages, the team did not encounter this need and all data collection activities were conducted in English. Interviews ranged from one hour to two and half hours and were audio recorded.

For the wellness mapping[37] activity, researchers asked the adult American Indian participants to draw stressors and supports involving “wellness” on each side of a blank piece of paper using colored pencils. After these participants completed the activity the researcher conducted brief interviews to provide the participant an opportunity to elaborate upon illustration details as an opening for information that might not appear in interview data.[37] American Indian participants could choose to complete an interview only and forgo the Wellness Mapping activity.[37] Health care providers did not complete the Wellness Mapping activity due to time constraints. Most providers participated in interviews in between shifts and on lunch breaks. In future research the team would like to conduct mapping with health care providers and additional non-provider participants.

Once interviews and Wellness Mapping[37] activities were complete, researchers conducted a mini-focus group with two American Indian men to complement study results. Given that the majority of American Indian participants in the interviews were women, research team members deemed it necessary to include additional perspectives from American Indian men. Facilitators provided topics and asked the participants to elaborate on each topic in relation to health and wellness. Topics included food, space/ place, health care providers, family, friends, and how to achieve wellness. Following the discussion, researchers asked participants to write words related to health and wellness on paper and to reflect on these words by writing other words or drawing images that came to mind.

Graduate student team members transcribed interview and mini-focus group audio recordings and Wellness Mapping[37] drawings were scanned and stored electronically for

subsequent data analysis. This study was approved by the Intuitional Review Boards of Northern Arizona University, Navajo Nation, Hopi Tribe, Northern Arizona Health care, and Phoenix Area Indian Health Service. All participants provided written consent.

Community-engaged data analysis.

Research team members analyzed all data using an inductive strategy that incorporated the principles of CBPR,[29–32] RARE[33–35] and applied thematic analysis.[40] Throughout data collection, community and university researchers participated in analysis meetings to discuss interview summaries, field- notes, and memos that pointed to connections that the researcher made between data and emergent themes.[38,40] Each meeting allowed all team members to interpret the data while it was being collected and to reflect on themes. This brought to bear the community researchers' insider perspectives together with the medical anthropologist's and public health scholar's outsider perspectives to identify areas where the team needed clarification or further inquiry. At the conclusion of fieldwork, the team created a preliminary code list of themes that were revised and checked through the discussion and group reconciliation.

University researchers used the preliminary code list to guide analysis of interviews, the mini-focus group, and Wellness Maps[37] in line with team-identified areas of inquiry using the software program ATLAS.ti.[41] First, three coders individually applied the preliminary codes to data and recorded reflective notes. Next, coders met as pairs to discuss patterns and recurrences in possible themes to refine the code list. Alongside investigators, the coders engaged in the cross-comparison of findings across data sources to identify similarities and dissimilarities; a refined coding schema was developed. Coders then applied the final coding schema to the data, and instances of coding discordance were resolved through group discussion. Through constant comparative analysis, researchers identified redundancies in the data and determined that data saturation[42] was achieved.

Results

Participants.

Thirty-nine American Indian adults (8 men, 31 women) who self-identified as "resilient" and reported achievement of healthy lifestyle change participated in this study (hereafter referred to as "resilient participants"). Of the 39, six participated in Wellness Mapping activities in addition to interviews, and two of the male participants took part in the mini-focus group only. Fourteen, or almost 36%, resilient participants, self-reported a change in a clinical measure such as HbA1c, BMI, or blood pressure. Others told detailed stories about either gradual or sudden critical reasons for changes in health behaviors.

Twenty-two health care professionals (7 men, 15 women), including medical doctors, doctors of osteopathic medicine, nurse practitioners, nutritionists, physical therapists, and diabetes educators who serve American Indian patients regularly participated in the study.

Themes.

Researchers identified three thematic categories across both American Indian and health care provider data: 1) relationships inform resilience; 2) prejudice stymies resilience; and 3) resilience is shaped by place.

Relationships inform resilience.—Literature indicates the importance of relationships for wellness and survival.[43–45] American Indian interviewees noted the importance of supportive family members and people in their extended social networks in successful making healthy changes. A resilient participant describes how working to plan meals with a family member helps her to make changes towards healthier eating:

> I have another sister that lives here in town and we help each other with trying to eat healthy. So lately we have been sharing meals. Like planning meals together. She asked me last week if we could sit down together and write out a menu for our week, cuz she's a single mom too and she has two kids. (American Indian participant, female)

In addition to working with family members, participants spoke about the impetus for better health beginning with a desire to provide a healthy role model for young people in their lives.

> I know that my kids are watching me, my daughters. I want to be an example to them of how to work through things, how to overcome things and so I always keep that in mind. (American Indian participant, female)

Stories of siblings, nieces, and nephews as young children were a reason for seeking improved health. Resilient participants reported that these were facilitators of physical activity: positive social influences gained from supportive friendships, social connectedness in the community, and support from others working to make healthy change. Resilient participants also reported a community sense of health and wellness as an important motivator for their overall health. One person stated:

> I think that's how my community is physically active, because they participate in a lot of running events and a lot of tournaments and anything that is to do with being active. I think that my community was a big help to my weight loss, because without that I wouldn't have done those activities (American Indian participant, male)

Another resilient participant spoke of an active desire to place themselves in relationships that would be useful for health:

> You gotta put yourself around people that are healthy and you start doing healthy things as well. (American Indian participant, male)

The ability to relate to others who are healthy or to model health was evident in discussions with resilient participants; however, resilient participants were also quick to point out that relationships can also prove detrimental for health and wellbeing. Participants cited family relationships as integral to their health and wellness, as well as a source of ongoing stress.

> She's sort of mentally unstable, she isn't really that autonomous, she needs rides places so she's a big stressor in my life but she's my sister so I have to do it. (American Indian participant, female)

Resilient participants identified relationships with health care providers as important resources. In particular, resilient participants who had long-term relationships with their providers discussed interactions with providers as an important aspect of their health-seeking lives. These relationships were described as open and trusting, supportive of healthy changes, and involved encouragement of the ability to follow through with treatment recommendations:

> My cardiologist is the one that helped a lot with the changes. He was very open and just made me feel comfortable at the same time being able to give me directions on all of this. (American Indian participant, female)

In addition to positive interactions with providers, resilient participants expressed appreciation for those providers who "look at the whole picture" (i.e., look beyond clinical indicators) and health care services that incorporate American Indian concepts of wellness. Health care providers also spoke of the importance of positive patient-provider interactions; however, many providers expressed frustration over not being able to address fully the needs and concerns of their American Indian patients.

> The most difficult aspect of my day? I think definitely trying to be compassionate and listen to the patients but being on limited time. (Health care provider participant, female)

Prejudice stymies resilience.—Racism and prejudice in many forms are indicators of poor health outcomes, in part due to the ongoing and long terms stress that people must endure when living in conditions of inequality.[46] Resilient participants described instances of negative interactions with non-Native people involving racist attitudes and behaviors towards American Indians. In discussions of challenges to health, one participant told a story of encountering public racism:

> It was during a football game and we were going back to our apartment, and there was this White guy on the side started saying, "Hey chief, hey Geronimo, hey Crazy Horse," as we went by going I wanted to fight him but I knew it was a bad idea so I just keep on, keep on walking. (American Indian participant, male)

Others talked in more general terms about such ongoing racist experiences:

> I do see a lot of White folks that talk down to you or down to me or like I didn't know what I was talking about or what I am doing and like I know. (American Indian participant, female)

Resilient participants also described situations in which they felt discomfort in mostly White non-Native environments:

> My friends that I had met at [college] they're like different nationalities, and mainly Anglos. I met a lot of people, like in volleyball class, in all these physical activity classes, and I felt like I was the oddball. (American Indian participant, female)

This participant's discussion of feeling like an "oddball" is particularly notable when the university is surrounded by tribal lands and has a high percentage of American Indian students.

Discussions of racism also affected perceptions of provider interactions. While resilient participants often described positive interactions with people in the health care system, several participants described instances of racist and reductionist behaviors.

> One provider I saw was like, oh you had a nine-pound baby, you must have had gestational diabetes, and I said no I didn't. I didn't exactly have it, I probably was pretty close to it and he said, no, no, you had it, we know you had it. It runs in you Native American women. (American Indian participant, female)

For resilient participants, everyday experiences of discrimination in community and health care settings were a psychosocial stressor and impacted the perceived quality of care received from providers. Results from provider interviews supported resilient participants' accounts of negative provider attitudes towards American Indian health. One provider stated that American Indian languages have *"too many verbs"* and do not allow for patients to accurately convey or understand health-related information. Similarly, another provider expressed frustration that American Indian patients simply *"don't get it"* referring to understanding nutrition, because of their *"culture."* A nonphysician provider working in a nutritional support program stated that many of their American Indian patients were *"unmotivated"* and only sought support care *"because the doctor told them to be in here.… they don't care if they're overweight."*

Place shapes resilience.—Resilient participants discussed structural factors that promote health and wellness including the availability of healthy foods, economic security, and proximity to health care facilities and places to engage in physical activity. Resilient participant described how the availability of these structural opportunities was linked to place:

> Like the rez, we don't have access to like really fresh produce, and it's really expensive. Even if we have access to it, like the supermarket or the grocery store they, their produce aren't fresh. Because it's from like hundred miles away and it's expensive because of the transportation. So that's what's making it really hard. (American Indian participant, female)

> I see it with my grandma, she has a hard time getting to a doctor when she needs to. And it's always, okay, who can take her on this day? Who's willing to, you know, drive her two hours to Gallup [NM] or one and half [days] to Fort Defiance [AZ] and be with her all day? That's what it would take. (American Indian participant, female)

> There's not that many jobs there so I can't get a job in the summer time because they're already all taken up and I'll have to travel over here to Flag for my job this summer and also to go to school. (American Indian participant, female)

Health care providers recognized the same challenges but often attributed problems to patient ignorance or inability.

> I think some that can be in that matter of education, because for example like the Farmer's Market on Fourth things are very affordable. More affordable than Safeway but I think that might be a matter of, you know, just the education. People whether they know or not that that kind of thing exists. (Health care provider participant, female)
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> They may want it so bad, but they can't do it right now because of all the obstacles. (Health care provider participant, female)

In analyses of Wellness Maps, researchers identified both supports and stressors related to place. Illustrations of family members, friends, food, and places to exercise in the community indicate the importance of these aspects of wellness for participants. Many Wellness Maps included drawings of trees, suns, mountains, and geographical landscapes next to written words such as "home" and "family" pointing to the significance of place-based connections in combination with social connections in conceptualizations of wellness. In addition, many Wellness Maps included images of people engaging in physical activity in outdoor areas together with others. American Indian participants' illustrations of stressors included places, transportation difficulties, and images of the self with worried or sad looks on the faces. Drawings often included pictures of fast food restaurants with low-prices on food items indicating the financial incentive to purchase and consume these types of foods.

Discussion

In this research, researchers explored resilience and wellness strategies among American Indian adults in northern Arizona supported by and facilitated through relationships with family members, health care providers, and the wider community. The ability to achieve wellness requires that people navigate external challenges shaped by varied sociocultural and spatial dynamics in ways that indicated resilience. Challenges included stressful relationships, family obligations, experiences with public racism, feelings of isolation in a non-Native environment, and access to food and employment. Wellness strategies included role modeling healthy behaviors, working with family members to prepare nutritious food, and surrounding oneself with like-minded members in the community. Resilient participants cited instrumental and emotional family support for wellness behaviors as very important in the facilitation of healthy change. As reflected in the American Indian and health care provider participant interviews, providers assigned blame to American Indian patients and ignored the ways in which American Indians can leverage supports to achieve health and wellness.

Results from this research are consistent with the literature on resilience among American Indians. Our study builds on previous findings that American Indians identify and use social supports to achieve and maintain resilience and health.[11,12,47–49] Results are also consistent with literature in which American Indians have pointed to stressors associated with family dynamics and lack of economic opportunity as challenges to resilience.[6,10]

Disparities in health care among non-White racial and ethnic groups have been extensively documented.[50] Research shows that access, patient values, and clinical appropriateness do not explain these disparities but instead point to potential interpersonal factors as the cause[51]

and that patients from minority groups rate the quality of interpersonal care lower than White patients rate it.[52–56] In addition, there is evidence that stereotyping and bias from health care providers affects clinical decision-making.[57–58] This research documents racism and stereotyping among some health care providers serving American Indian patients and may be associated with wider patterns of health disparities among urban American Indian peoples in Arizona. There is an urgent need for interventions and trainings geared towards health care providers in northern Arizona that are targeted and provide culturally-appropriate decision aids that help providers improve care delivery for urban American Indian patients in ways that minimize stereotyping and racist attitudes.

These data indicate that many urban American Indian patients view positive relationships with health care providers as an integral component of their journey to wellness through healthy change. Positive relationships with health care providers involve communication that is open, honest, and respectful. Health care provider communication strategies that consider a patient's values and preferences affect health care systems in positive ways and are associated with patient satisfaction with care delivery, increased adherence to treatment recommendations, successful self-management of chronic diseases,[59–64] and improvement in clinical outcomes in diabetes management, hypertension, and cancer.[61–62,65]

This research supports population health management strategies that place relationships at the center of service delivery. Relationship-centered care is an approach that involves relationships developed and maintained by health care providers, the health care team, patients, and the wider community.[66] Within the relationship-centered care paradigm, the provider's relationship with the patient is deemed most important; however, this relationship also considers the patient's family, social support network, and the community in which the patient lives.[67] This research shows the importance of relationships in achieving healthy change and demonstrating resilience. Health care providers who have knowledge of the sociocultural dynamics of a community, Native health care providers and community health workers (CHWs) for instance, are positioned well to engage the community in ways that contribute to overall community health. The authors suggest that the relationship-centered care framework[67] be used to inform policy and procedural changes in health care systems that serve American Indian patients.

Study findings may not be generalizable to all people affected by health inequity; however, this work provides a detailed description of how urban American Indians in northern Arizona understand and engage in healthy change. This study has the following limitations. First, the insider status of community researchers may have affected responses from participants. Researchers attempted to mitigate this possibility by having multiple team members analyze the same data and through group discussion of research results. While the insider status of community researchers may have had the potential to bias results, the insider perspectives of the community researchers allowed for the identification of subtleties and complexities associated with demonstrating health resilience. Second, there was a disproportionate participation of female American Indian adults and female health care providers. Lastly, the age of resilient participants was not taken into account in the analysis, which did not allow for understanding how resilience may differ throughout the life course. However, themes were consistent across genders and participant groups.

Results illustrate how some American Indian adults work toward greater wellness despite low incomes, little access to resources, and racial discrimination. These findings indicate that some people within a population affected by health inequity can demonstrate the ability to become healthy through leveraging existing supports to overcome external barriers. The results, most importantly, do not indicate any value for the idea that all people can become healthy and well if they just try hard enough, or any outcomes that suggest people who do not become resilient are responsible for their own ill health. Instead, study findings demonstrate knowledge among people that providers do not always see.

Findings highlight a need for health care providers to build their understanding of the lives of people who face hardship while also having access to effective tools that support resilient practices. Ideally, these tools would allow providers to connect patients to integrated clinic and community resources and leverage patients' existing social support networks.

Finally, there is a need to develop policies that support existing wellness practices. These policies need to be effective in supporting health behaviors and are culturally appropriate. The authors suggest that these policies incorporate a relationship-centered care framework[67] so that these policies align with locally-relevant concepts of health and wellness. There is a need for procedural recommendations that seek to improve the efficiency of health care systems that serve American Indian patients in northern Arizona. This approach may be applicable to other populations suffering from health inequities.

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