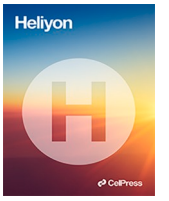
Heliyon 10 (2024) e33456

Contents lists available at ScienceDirect

Heliyon

journal homepage: www.cell.com/heliyon



Research article

"We rely on each other": A qualitative exploration of rural Eastern Region Native American experiences during the COVID-19 pandemic

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ARTICLE INFO

Keywords:
Native American
Public health
COVID-19
Cultural respect
Qualitative research
Rural

ABSTRACT

Background: Native American communities suffered disproportionately negative effects during the COVID-19 pandemic, yet no research has explored the experiences of rural Eastern Region Native Americans.

Methods: Informed by the Native Reliance Model and Indigenous Standpoint Theory, we conducted a qualitative descriptive project in the Spring and Summer of 2022; data included semi-structured interviews and focus groups with 24 individuals representing five South Carolina tribal groups.

Findings: Thematic analysis yielded four emergent themes: 1) *"Let's just finish the Indians off": Pandemic distrust rooted in historical and contemporary Native American experiences*; 2) *"We have been misled": Making sense of conflicting public health information*; 3) *"I'm not giving it to some innocent person": COVID-19 mitigation behaviors as Native American cultural practice*; and 4) *"We put the plan in place": Self-advocacy and action as a source of Native American pride and responsibility*.

Interpretation: These participants demonstrated resiliency grounded in family and tribal ties, even in the face of personal losses, economic struggles, and healthcare barriers. To strike a balance between cultural traditions and public health recommendations, public health practitioners should 1) build partnerships with community leaders, elders, and tribal health authorities to facilitate the development of culturally respectful interventions that address specific health concerns in the context of historical traumas; and 2) implement alternative methods of communication and engagement to ensure equitable access to healthcare services in rural locations, such as collaborating with community organizations, deploying mobile health units, and utilizing traditional channels of communication within these communities.

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https://doi.org/10.1016/j.heliyon.2024.e33456
Received 26 September 2023; Received in revised form 15 June 2024; Accepted 21 June 2024
Available online 22 June 2024

1. Introduction

Native Americans[1] (NAs) are disproportionately affected by various health inequities in the United States (US), including chronic disease such as cardiovascular disease and hypertension [1], as well as communicable diseases such as SARS-CoV-2, the causative organism of COVID-19 [2]. It is well known that the COVID-19 pandemic differentially impacted racial/ethnic minority communities [3]. However, NAs were arguably most negatively impacted by the virus, whose loss in life expectancy related to the pandemic has been calculated to be more than four times greater than Whites, reducing NA life expectancy at birth from an already startlingly low age of 72 to 67 years [4].

Qualitative research has explored the unique challenges NAs faced during the COVID-19 pandemic, including vaccine decision making among NAs living in urban [5] and reservation [6] settings, barriers to educational delivery [7], perceptions of COVID risk [8], testing [9], and impact on economic resources [10]. However, very limited research has focused on COVID-19 pandemic experiences among East Coast tribes [11], whose contexts and challenges may be different than tribes located within other US regions. For example, while the Eastern Region is comprised of 27 states, only 12 have federally recognized tribes, and of the approximately 326 federally administered reservations, only 31 are located east of the Mississippi river [12]. Therefore, the majority of the Eastern NA population is embedded within rural communities, often poor and underserved, with more limited access to Indian Health Services and culturally appropriate care than other areas of the US.

Thus, the purpose of this theory-informed, qualitative descriptive project was to explore the experiences of rural NAs living in South Carolina during and following the COVID-19 pandemic, including perceptions of disease prevention and mitigation strategies, as well as interactions with governmental and non-governmental agencies. We present findings from 24 participants representing five South Carolina-based tribal groups.

2. Theoretical frameworks

Conduct of project activities was guided by the Native-Reliance Model (NRM) [13], a culturally appropriate and strengths-based framework developed to address unique aspects and worldview of NA culture, especially related to health and wellness research, as well as Indigenous Standpoint Theory (IST) [14], which posits that Indigenous peoples have a unique and valuable perspective on the world informed by their cultural, historical, and spiritual experiences. The NRM model recognizes the significant historical trauma and ongoing oppression experienced by NAs, which can lead to intergenerational trauma and psychological distress, while also emphasizing the resiliency inherent in NA practices, ceremonies, storytelling, and community. Relevant constructs for this project include *being responsible* (e.g., caring for others), *being disciplined* (e.g., sharing the vision), and *being confident* (e.g., having a sense of self-worth). Grounded in social justice and decolonization, IST asserts the necessity of incorporating NA community members in all aspects of knowledge generation and interpretation - particularly relevant when considering NA experiences of structural health inequalities - as well as highlighting ongoing NA resistance to colonization and marginalization in order to preserve native cultures, languages, and knowledge. IST framework constructs include *unique intersections and structural health inequalities for American Indians; integrating Indigenous knowledge with Western research orientations and methodologies;* and *ensuring benefits of research for American Indian communities*. To enhance study cohesiveness and theoretical integrity, these frameworks informed all phases of study conduct, including the development of the interview/focus group guide (Table 1), data analysis, presentation of results, and implications.

3. Methods

The project was conducted among NAs residing in rural South Carolina, home of one federally recognized tribe, nine state recognized tribes, four state recognized groups, and one state recognized special interest group [15]. Project activities were approved by a university-based institutional review board and were organized by the Consolidated Criteria for Reporting Qualitative Research [16]. Informed consent was obtained prior to participation and each participant received a $25 gift card at the end of the interview. See Fig. 1 for study flow.

3.1. Participant recruitment

Inclusion criteria included individuals 18 years and older who lived in South Carolina and self-identified as NA. Participants were recruited at NA events (e.g., annual pow wow) and settings (e.g., Native American Studies Center).

3.2. Data collection

In-person interviews and focus groups were conducted by RMD , a nurse scientist and qualitative methodologist; SC, faculty from the USC-Lancaster Native American Studies Center; MSN, an epidemiologist with a background in health disparities; and JDT, a research assistant trained in qualitative data collection. Six focus groups consisting of 2–6 individuals and four individual interviews

[1] Terms used to describe indigenous communities in the United States include “Native American”, “American Indian”, “First American”, “Indigenous American”, and “Native”; for clarity we have opted to use Native American throughout this paper except when alternative terminology is used in constructs from cited literature [13,14].

Table 1
Sample interview/focus group questions.

Global Opening Question	Sample Probe	Theoretical Constructs Addressed
How has COVID-19 affected you personally and/or your family?	How do you think the COVID-19 pandemic has affected social relationships within your community and social groups?	Being Responsible (NRM) Integrating Indigenous Knowledge (IST)

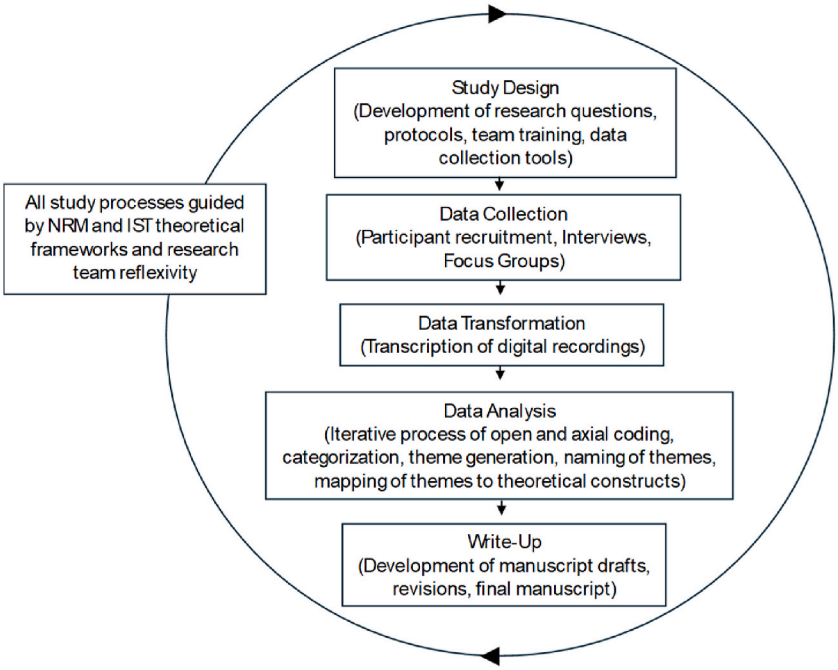

Fig. 1. Study flow diagram.

were conducted in Spring/Summer 2022. Both the interviews and focus groups lasted between 20 and 60 min. To facilitate participation, two interviews were conducted virtually using a secure video conferencing platform; the remaining interviews and all focus groups were conducted in person. In-person interactions were audio-recorded; virtual interactions were video-recorded.

3.3. Data analysis and reflexivity

NVivo 13 was used to manage data and facilitate analysis. After professional transcription, thematic analysis was employed to analyze the qualitative data following the process outlined by Braun and Clarke [17]. First, our research team, with diverse backgrounds in nursing (RMD, JDT), community engagement (RMD, SC), criminal justice (HMB), and public health (MSN), familiarized ourselves with the data through iterative readings of transcripts and immersion in the data. Led by RMD and HMB, both experts in qualitative analysis, the team then engaged in a process of open coding, followed by categorization of codes based on their shared meaning and congruency with constructs from the theoretical frameworks. Themes emerging from the categories were identified, reviewed, refined, and validated through discussions among the entire research team, at all times considering how our personal and professional experiences informed the analytic process [18].

3.4. Role of the funding source

The funding source (see acknowledgements) had no involvement in the project design, data collection, analysis and interpretation, writing of the report, or decision to submit this paper for publication.

4. Results

Twenty-four individuals representing five South Carolina tribal groups (Catawba Nation, Pee Dee, Wassamasaw, Cherokee, Pine Hill Indian Community Development Initiative) participated. Ages ranged from 20s to 60s, educational attainment from second grade to college. Four theoretically informed themes emerged from the data analysis: "*Let's just finish the Indians off*": *Pandemic distrust rooted*

in historical and contemporary Native American experiences; "We have been misled": Making sense of conflicting public health information; "I'm not giving it to some innocent person": COVID-19 mitigation behaviors as Native American cultural practice; and *"We put the plan in place": Self-advocacy and action as a source of Native American pride and responsibility.* Themes are illustrated by relevant participant quotes (delineated by quotation marks in text or in block quotes) and lightly edited for clarity (e.g., removal of dysfluencies). Relevant contextual details are bracketed. Participant demographics (e.g., gender, tribal affiliation, community role, age) are omitted for confidentiality.

"Let's just finish the Indians off": Pandemic distrust rooted in historical and contemporary Native American experiences.

Findings in this theme were related to the IST theoretical construct of *unique intersections and structural health inequalities for American Indians,* harkening back to a history marked by medical exploitation and unethical experimentation. The initial offering of vaccinations to NAs sparked concerns that this early access was potentially "biological and chemical testing on the population". A community member shared:

> We know what you did with the African Americans [Tuskegee Syphilis Study]. No, we don't [want to receive vaccines]. When you get to round three, let us know.

Another added:

> The government has a pretty bad track record on secret experiments, not only Tuskegee but feeding the uranium to children [MIT-Quaker radioactive oatmeal study [19]]. I was in the military … I know about the dozens of times that they sprayed cities, that they sprayed naval craft. As a Gulf War veteran, I know that they did it to me and my health – I've already gotten my share of experimental vaccines. I'm good.

Experiences of contemporary events further intensified feelings of marginalization and exacerbated pre-existing distrust of governmental agencies:

> That level of panic took me back personally to 9/11 [2001 terrorist attack on the US], and that feeling of what are we supposed to do? Where is a safe place to be? Is anywhere safe? The CDC [Centers for Disease Control and Prevention] doesn't even have a plan. WHO [World Health Organization] doesn't have a plan.

As many communities experienced early in the pandemic, personal protective equipment (PPE), a less invasive mitigation strategy, was difficult to access. However, for these NA communities, this unavailability was interpreted as political gatekeeping and reinforced perceptions of being targeted for *experimental* practices rather than preventative:

> So we filed for a … $2,000 grant for PPE. And we were denied that grant three times. I ended up calling Minority Affairs and asked if COVID was being used as a political genocide tool against Native Americans because to tell us we can't have PPE, that's what it looked like to me. Let's just finish the Indians off. There's not that many of them left. And immediately they found funds.

Similarly, while NA leaders were committed to providing access to COVID testing for their communities, decisions as to how those supplies were distributed were perceived to be driven by motives other than the needs of their community, further dampening enthusiasm for partnering with public health-focused governmental agencies:

> We'll just promote it [COVID testing] … you have this facility right here where you can dump all of these resources into it that can be the hub, but they chose to go to the church down the street instead. So why? Is it political? Is it a race for funding? Is it getting the data? You know somewhere along the way, public health turns into something else. I'm not sure what to call it yet. But the public health effort gets lost.

"We have been misled": Making sense of conflicting public health information.

Findings in this theme were related to the IST construct of *integrating Indigenous knowledge*, as well as NRM theoretical constructs of *being disciplined* and *being confident.* These participants were overwhelmingly proactive in seeking out COVID-19 information during the pandemic, with some participants even consulting academic, peer-reviewed literature. However, public health messaging from governmental agencies was viewed as suspect, in part due to constantly changing advice and information as the pandemic wore on (e.g., mask or no mask, efficacy of vaccines):

> All the changing in the messages – I didn't trust none of them to start with, and now with the changing, the flip flopping back and forth … I know everything ain't true. Don't get me wrong. But when they're sitting there on TV and they do interviews and you listen to them, and then somewhere else later down the road it's different. Everything's changed, you know?

Instead, most relied on the messaging or actions of trusted community members (e.g., tribal chiefs, tribal nurses, local physicians) to inform their decision-making, and community leaders took that responsibility very seriously. One shared how they decided to be vaccinated:

> The fact that other tribal members were getting it. My uncle, who is vice chief of our tribe, him and his wife, went and got them and he said, "Are you going to get it?" And I said no. He said, "Why not?" I said, "Because I don't believe in it." He said, "Well, [we] went and got it." I said, "Well, good. I hope you don't get sick, you know?" You know, you trust other tribal people.

Many of these participants followed public health recommendations, even when they clashed with NA cultural practices. However, when the community began to suffer COVID deaths, some began to question the veracity of the information, as well as whether the benefits of adhering to guidelines was worth the pain and community disconnect it caused:

> The Native American community … didn't understand why we can't gather … They believed they were going to be protected … when it hit personally, I believe, when it was a loved one that got sick or died that they kind of like, yeah, this is real. This is happening to us. You know, when you go to a funeral and you got loved ones that are not getting out of the car because they are sick and they have a virus, but they had to be at the funeral because that paying your respects is a big thing.

As the pandemic continued, for many, doubt in public health messaging was replaced by the sentiment that they were actively "being misled" by government representatives. For example, none of these participants trusted the accuracy of at-home COVID testing; either they refused to use them or they wanted validation from another sources (e.g., physician-obtained test):

> My concern with the at-home test would be that there would be too many false negatives … if you go in the doctor's office, they have the know-how, they've had the training, they know how to do it, what they're supposed to be doing.

And several participants relayed stories they had heard about testing results that led them to avoid at-home, return-by-mail tests:

> There's too many reports that I know directly secondhand of nurses that have returned unopened boxes, unused, only to have a report come back to them of, oh, your test came back positive.

> I know somebody who took five tests. Opened them up, put them in the thing, never tested nothing, put all five in there, three of them came back positive.

Many participants were angry over what they perceived to be duplicitous information and public health advice they received – for one participant, it was vaccine efficacy information that changed after they had agreed to be vaccinated to protect their families:

> The only reason that I even received the vaccine to start with was because they, number one, guaranteed – and I say they as CDC – guaranteed at the time if you get the vaccine you won't transmit it. You can't pass it …. So I did. That was the only reason. And then after I found out it was only like an 80 percent chance that the vaccine would keep you from getting it, I was actually very mad.

Others related care and advice they or family members received after contracting COVID that they perceived to be subpar or outright misleading, especially as most lived in extremely remote, rural areas with little access to follow-up or emergency care. An individual who was told to quarantine at home after testing positive for COVID related:

> They told me … there was nothing that I could take, and in reality now they got these infusions they can give you. They didn't check me to see if I had pneumonia or if I had a cold or if I had this or that. All they said, I had COVID, go home and don't do nothing until you get ready to die.

Two others added:

> We have been misled. The thing is, if you're going to send a man home and quarantine him with a deadly disease and never check up on him … I mean, what's up with that?

> They shouldn't mislead people and tell them, "Go home and don't come back to the hospital till you're about dead, you can't breathe." Do you know how long it takes this man [indicating another focus group participant] to get a rescue squad to his house? An hour and a half to two hours.

"I'm not giving it to some innocent person": COVID-19 mitigation behaviors as Native American cultural practice.

Findings in this theme were related to the NRM theoretical construct of *being responsible*, as well as *integrating Indigenous knowledge* from IST. Even in light of negative experiences, most followed public health guidelines, revealing valuable insights into the participants' conceptualization of NA community, harmony, and consensus that intersected with and informed COVID-19 decision-making. Three individuals in conversation shared:

> We don't have an established boundary of community here, and it's like that in a lot of places, especially this side of the Mississippi, and we're just within the dominant society … This [a community center on two acres of tribally owned property] is our community right here. This is our reservation. When we're here we work together in everything that we can do. We try to harmonize. And even though one might not agree, we try to work around to where we can all understand and try to get the agreement to where even if we disagree we still – we push forward. Consensus was how we used to govern. Instead of having a policy where half the population's going to be upset, that was how it was done, was through consensus. And it may be, you know, there's three or four different ideas, but council gets together and they whittle it down and figure it out where everybody agrees, okay, that's the good way to do it.

This conceptualization extended to how the community viewed individual COVID-19 decision-making. Unlike other dominant communities, these participants did not experience stigmatization if they decided to be vaccinated or tested:

> Amongst ourselves, nobody fought. I respect his choice to make that decision [to be vaccinated] for himself, and he respected my choice to make my decision.

> We love each other here. We try to understand each other. Everybody's not going to agree on everything. If these fellows wanted it [to be tested], that's your problem and that's your decision. Not mine.

Thus, this supportive community, with its shared cultural identity and commitment to fostering a sense of belonging, facilitated

virus mitigation behaviors largely driven by the desire to protect others and the community. Indeed, *being accountable* on behalf of family and community, a NRM theoretical construct, even in the context of fear of what might happen to themself, was a primary driver of obtaining the COVID vaccine:

> I'm going to be honest, I was dead set against it [the COVID vaccine]. If you can come up with something that quick then how good is it? I was very suspicious of it at first just because it was so new. And I thought, well, I'll take the chance, see what it does to my body. I know it's new … I'll take the chance of being a zombie as long as I know I'm not giving it to my grandchildren, I'm not giving it to my grandparents, I'm not giving it to some innocent person.

Some participants felt compelled to consent to vaccination so they could fulfill the responsibilities of their tribal leadership roles:

> These meetings that we're talking about … we get thrown out [for not being vaccinated] and these meetings give us resources. So I just finally went ahead and got my vaccine so I wouldn't get thrown out of another meeting. We got a big meeting coming up - I wanted to get to those places where we could get resources for our tribe.

Another added:

> I lived all through it and never got it [COVID-19 infection]. I just went ahead and took the thing. I mean, I didn't want to. We need resources. I didn't want to knock them out of resources again, so I just went ahead and took it so we can get to the meetings and maybe land a grant for this tribe.

"We put the plan in place": Self-advocacy and action as a source of Native American pride and responsibility.

Findings in this theme were related to IST constructs of *unique intersections and structural health inequalities for American Indians* and *ensuring benefits of research for American Indian communities*, as well as the NRM construct of *being responsible*. Negotiating community needs during the pandemic was made even more challenging in the context of lack of federal recognition for the vast majority of SC NA communities. One individual shared:

> Everything comes down to money. The CDC had put out a grant announcement for tribes and tribal communities, and I called because, one, federal grants – it's been pretty much coined that federal funds are for federal Indians. And then at the state level you've got state-recognized tribes and tribes that are not state-recognized, and there is a big debate about how much attention should go to either. But we fit [because we are] a state-recognized, nonprofit tribal organization. So I called about it and said can we file, they said, "Yeah, definitely." So we filed. We got the grant, and then they turned around and said, "You can't have the money because you're not federally recognized." And I actually fought them … I contacted [senator's office] and I said, "Nowhere in the notice or in the booklet does the word federal even appear." What does appear is the Plain English Act. And I said, "They should've been plain and in English what they wanted," because we were plain and in English about what we were wanting to do and why. We never got that funding. So we're reluctant to even bother with federal grants.

Therefore, tribal chiefs led individual and community-based responses in the face of resource barriers (e.g., limited access to PPE, healthcare and broadband accessibility issues related to rurality, severe poverty, food insecurity), building on community knowledge, programs, and relationships developed prior to and during the pandemic:

> There's only two roads in and out [of the community]. For once, being out in the sticks was an advantage … if we can reduce the need to leave then it reduces the exposure rate. We started doing food distributions, and we got grant funding from No Kid Hungry, and we were told it was the first time No Kid Hungry had ever funded South Carolina. And then long story short, that kind of developed into what we didn't expect, and what started out with a $650 food distribution in a tent next to the fire department, turned into I think it was $22,000 of food a week going to nine different tribal communities across the state.

These initiatives, which they extended to their non-native community members, nonetheless reflected NA values in their conceptualization and implementation, as well as attention to the importance of NA views and experiences on the development of future interventions:

> We developed Indigenous First Steps, and it's open to anybody - it's not native-only. We ended up creating that program, because that to me was this gaping hole. We had so many things to overcome [during the pandemic] … but we never stopped to think about the kids in reality. You know, Native American viewpoint is, everything we do is for the seventh generation ahead of us, whatever we do today, the seventh generation is going to benefit or not from. So that was a program that developed because of that. The idea was I can't save the world, but I can do my best to save my people right here.

5. Discussion

The pandemic brought to light longstanding inequalities and challenges that NA communities face in accessing quality healthcare, education, and economic resources. While findings are not representative of all NA communities and are limited by the small sample size inherent in qualitative research, this qualitative study, informed by the Native-Reliance Model and Indigenous Standpoint Theory, nonetheless gave voice to the unique pandemic experiences of these Eastern Region NAs.

The pandemic amplified the structural and systemic issues that NAs have faced for centuries, including historical trauma, poverty, and inadequate infrastructure. The findings from study highlight the urgent need for policies and interventions that address the specific and intersection contextual challenges and circumstances faced by tribal groups living east of the Mississippi. The stories shared by

these participants reflect resilient communities able to maintain strong family and tribal ties during the pandemic, even in the face of personal losses, economic distress, and healthcare access barriers. While lack of clear and consistent public health messages exacerbated historical distrust of government and affected uptake of virus transmission strategies (e.g., masking, vaccination), consistent leadership and a commitment to respect for others facilitated their ability to respond to community needs.

A critical experience relayed by these participants was the exacerbation of ongoing access barriers to basic resources faced by many rural communities during the pandemic, including limited healthcare, food, and protective supplies. However, for these Eastern Region NA participants, when these resources were made available by outside entities, they were perceived with historically informed suspicion. NAs have long endured a complex history fraught with discrimination and systemic violence, resulting in intergenerational transmission of trauma that has engendered a deep sense of mistrust towards institutions and authorities, including the healthcare system. This study revealed that a pervasive knowledge of historical malfeasance by governmental agencies and actors toward NAs and other marginalized communities affected perceptions of COVID-19 public health mitigation strategies. Community and public health practitioners should foster and cultivate trusted relationships with existing NA leaders, support networks, and community structures during times of health that can be rapidly leveraged during times of public health crisis. Empowering community members as health ambassadors, organizing community forums and dialogue sessions, and engaging in open and culturally respectful conversations can engender a sense of shared responsibility and collective action towards public health goals. Public health messaging should be developed and implemented within locally situated agencies and disseminated through traditional channels of communication. Finally, to ensure that the "benefits of research with Indigenous communities … remain within those Indigenous communities"[pg.464] [14], future research on culturally tailored public health interventions informed by these findings must incorporate NA community members into the research team and in all aspects of research conduct.

The cultural and religious practices of Eastern Region NA communities must be understood and respected when developing public health strategies. Because of the lack of federal recognition, the vast majority of SC tribal communities do not have access to traditional lands and reservations as seen among NA tribal groups west of the Mississippi River. Yet these participants carved out dedicated community spaces and places to hold communal gatherings, religious ceremonies, and traditional healing practices, which held immense significance within the entire tribal community. Community and public health interventions must respect these place-based cultural practices when promoting safety measures to mitigate the spread of infectious diseases. Engaging community leaders, elders, and cultural experts in the planning and implementation of interventions can help balance cultural traditions and community/public health recommendations.

6. Community/public health implications

The results of this project fill an important gap in our understanding of NA COVID-19 pandemic experiences and underscore the importance of acknowledging and addressing the historical and contemporary contexts of disenfranchisement, systemic marginalization, and resultant distrust in healthcare systems, agencies, and their representatives when designing public health interventions. Community and public health practitioners must recognize this history and acknowledge the need to rebuild trust and establish open lines of communication. Approaching community engagement through a strengths-based perspective will facilitate the development of relevant, culturally respectful strategies and interventions designed to improve health care access and ultimately, health outcomes.

Declarations

The authors declare they have no conflicts of interest.

Funding

This work was supported by the Centers for Disease Control and Prevention, Award No. 1 NH75OT000099-01-00.

This study was reviewed and approved by the University of South Carolina Institutional Review Board with the approval number: Pro 00114822.

All participants/patients provided informed consent to participate in the study.

The datasets generated and analyzed during the current study are not publicly available due to confidentiality and privacy for participants but are available from the corresponding author on reasonable request.

CRediT authorship contribution statement

Robin M. Dawson: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Hunter M. Boehme:** Writing – review & editing, Writing – original draft, Funding acquisition, Formal analysis, Conceptualization. **Stephen Criswell:** Writing – review & editing, Writing – original draft, Investigation, Formal analysis, Data curation. **Julia Dunham-Thornton:** Writing – original draft, Investigation, Formal analysis. **Melissa S. Nolan:** Writing – review & editing, Writing – original draft, Supervision, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Robin M. Dawson reports financial support was provided by Centers for Disease Control and Prevention. Hunter M. Boehme reports financial support was provided by Centers for Disease Control and Prevention. Melissa S. Nolan reports financial support was provided by Centers for Disease Control and Prevention.

Acknowledgements

Chief Michelle Mitchum and Chief Pete Parr; Chris Judge, Native American Studies Center, University of South Carolina - Lancaster; Isabel Dayrit; Lisa Collins, Tribal Administrator, Wassamasaw Tribe of Varnertown Indians; and The Dorothy and Gaylord Donnelley Foundation.

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