"It Adds to The Stress of the Body": Community health needs of a state-recognized Native American tribe in the United States

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Abstract: While many of the health disparities, brought on by the cruelties of settler colonization, that affect Native American and Alaskan Native communities and individuals at high rates have been documented, the health risks impacting non-federally recognized tribes are less explored. In this manuscript, we explore the challenges non-recognized tribes face and how without Tribal sovereignty, autonomy, and resources, it is more difficult for non-recognized tribes to provide care and resources for the members of their communities. This study took place in the Gulf South regions of the United States, where there are environmental factors pertaining to industry, global warming, environmental racism, and rurality that further impact the quality of life and rates of cancer, respiratory illness, and reproductive health issues in the Native American communities that live there. In addition, tribes without federal recognition have increased challenges in addressing the lack of access to health equity and may not have the health resources or programming available to them that exist for federally recognized tribes. To explore these topics, a qualitative description methodology was used to conduct 31 semi-structured interviews with women from a state-recognized Native American tribe in the Gulf South to understand their healthcare experiences and concerns. Participants in this study described: high rates of cancer, vehicle accidents or collisions common, barriers to exercising, physical injuries common, chronic illnesses common in the community, loss of family members, and physical violence. These findings indicate that state-recognized tribal members may need increased, improved, and culturally contextualized healthcare programs within their communities, in addition to full recognition of their tribal sovereignty rights. This study begins to address important gaps in the research exploring the full scope of the health risks and challenges affecting non-federally recognized tribal members, while also highlighting their resilience in the face of settler colonialism.
Keywords: Indigenous, Native American, American Indian, Community Health, Community Support.

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Settler colonialism has contributed to a range of risk factors and health problems impacting Native American people. On a global scale, cancer incidents impact Indigenous populations at high rates (Segelov & Garvey, 2020). In the Southern United States, Native Americans are represented in this global trend of high cancer rates in Indigenous populations, along with increased incidents of chronic health risks (Burnette et al., 2020; Melkonian et al., 2019; Perdue et al., 2014; White et al., 2014). Overall, there is a higher incidence of cancer and cancer risk factors among people living in the Southern United States than in other regions of the country (Islami et al., 2022). Unfortunately, there is limited research tracking the occurrences of cancer in subpopulations of Native American people, so the full impact of cancer disparities for individual tribes is often unknown (Segelov & Garvey, 2020). Consequently, for this particular tribe we do not have specified prevalence rates. More research around identifying the environmental factors that impact Native American people is essential in securing better community health outcomes. In addition to lacking the necessary amounts of subpopulation health research, there are healthcare shortages in rural areas where many Tribal communities live. Because of distance, cost, and distrust of some Western health providers, treatment for disease and illness is especially burdensome for many Native Americans people (Jaramillo & Willging, 2021; Liddell et al., 2018; Liddell et al., 2020; Liddell & Lilly, 2022a; 2022b; Zuckerman, et al., 2004).

Vehicle accident fatalities occur at the highest rates among Native American communities (Pollack et al., 2012; Sehgal, 2020). Factors relating to the rural nature of many Tribal areas, like higher speed limits and limited policing for cell phone use and traffic safety, contribute to the high rate of vehicle accidents impacting Native American communities (Pollack et al., 2012; Sehgal, 2020). There have been safety policies implemented on larger reservations to reduce the risk these risks but not every tribe has had the ability to adopt similar measures, and this particular tribe is dispersed throughout the state.

As a result of the impact of settler colonialism, and its undermining of egalitarian gender norms that were often present pre-colonialism in many Native American communities, and the U.S. government's lack of accountability for non-Native American perpetrators of violence, Native American people of all genders face high rates of intimate partner or sexual violence as compared to other populations (Fedina et al., 2022; McKinley, 2015; Rosay, 201). Individuals who identify as Native American self-reported alarmingly high incidents of having experienced physical and/or sexual violence according to the 2010 National Intimate Partner and Sexual Violence Survey (NIPVS). The data from NIPVS revealed that 84.3 percent of all Native Americans have experienced physical and/or sexual violence over the course of their lifetime (Rosay, 2016). Of those instances, 55.6 percent of Native American women and 27.5 percent of Native American men have experienced sexual violence. Furthermore, following sexual assault, 38.2 percent of females and 16.9 percent of males were unable to get the physical and mental healthcare services they needed (Rosay, 2016). The demand for more community medical and mental health services available for Tribal communities and Native American people is essential since interracial acts of violence are so often committed against Native Americans.

Apart from sexual violence and assault, Native American people experience physical violence and emotional violence, like stalking and threatening, at extremely high rates. More than 4 in 5 Native Americans have experienced violence in their lifetime (Rosay, 2016). Not only have a notable share of Native Americans also reported that they or family members have experienced violence, but many have also indicated that these encounters have been due to discrimination. In a study by Findling et al. (2019), 38% of Native American respondents indicated that they or a family member had experienced violence because they were Native American. The trauma associated with experiencing or witnessing violence, especially in childhood, can lead to devastating mental health

outcomes such as an increased risk of addiction, suicide, and a risk of reduced life expectancy (D. Brown et al., 2009). Compounded with experiences of discrimination, the disparate rates of violence that Native Americans experience contribute to generational trauma and cycles of oppression.

Findings have illustrated that traditional enculturation practices such as hunting, traditional food and medicine, and engaging in spiritual practices may be connected to improved physical and mental health amongst Native American populations (Liddell et al., 2022a; Liddell et al., 2022b; McKinley et al., 2018; McKinley, Lesesne, et al., 2020). Engaging in traditional tribal lifestyle activities is correlated with more physical activity and lower levels of psychosocial stress (Bersamin et al., 2014). However, many of these cultural traditions have been lost or hindered by historical oppression, consequently negatively impacting Native American mental and physical health (Liddell et al., 2022a; Liddell 2022b; McKinley et al., 2018; McKinley et al., 2020). This combination of this cultural interruption and lack of safe spaces to exercise further contributes to negative health incomes amongst Native American populations (John-Henderson et al., 2022; McKinley, Lesesne, et al., 2020; Vickery & Hunter, 2015).

The occurrence of early deaths at higher rates in Native American communities has negative health consequences for the community in whole. Experiencing the loss of a loved one has far-reaching individual and community health implications that are compounded by the close-knit and family-oriented nature of tribal communities (McKinley, Lesesne, et al., 2020; McKinley, Miller Scarnato, et al., 2022). High occurrences of domestic and intimate violence can cause tensions that may negatively impact the degree of community support and interrelation that is important for tribes, especially for tribes that already lack resources due to their limited sovereignty (McKinley, Miller Scarnato, et al., 2022). Exposure to the effects of illness, injury, and violence takes a toll, and many Native American families are impacted emotionally, spiritually, and financially by watching loved ones suffer (D. Brown et al., 2009; McKinley et al., 2020; 2022). In tribal communities that value close relationality with extended family and friends, the prevalence of untimely and preventable deaths amongst so many of their community members are especially traumatic and the effects of these losses have been shown to be felt more acutely (D. Brown et al., 2009, McKinley, Miller Scarnato, et al., 2022).

Health disparities exist for many Native American people, but previous research on Native American tribes had tended to focus on specific health outcomes, with less focus on the connection between health outcomes, and linking the cause of health disparities to structural barriers. Little research specifically investigates how infrastructure barriers like lack of federal recognition impact the health experiences of non-federally recognized tribes (Burnette et al., 2019; Canales et al., 2011; Cohen-Fournier et al., 2021). The limited data that does exist tends to focus on services that are provided through IHS, which state-recognized tribes do not have access to (Theobald, 2019). Moreover, there is a lack of availability and accuracy of health data for Native American people. Krieger (2019) notes that there is a historical trend of inaccuracy when recording vital statistics like deaths, classification of deaths, births, and US Census data. Native Americans are consistently the most undercounted racial/ethnic group in the U.S. Census. In the Post Enumeration Survey (PES) that was conducted to assess the accuracy of the 2020 Census, results for Native Americans and Alaska Natives were estimated by the PES to be undercounted by 5.6% (U.S. Census Bureau, 2020). In 2010, tribal members living on reservation lands had the highest undercount of all groups at 4.9% (U.S. Census Bureau, 2020). Census data determines federal, state, and local resource allocation, funding distributions, and policy decisions. Consistent undercounting results in negative consequences for all Native American communities and further complicates the process of applying for federal recognition.

Implications of Reduced Sovereignty

Because they lack federal recognition, some Native American tribes in the southeastern United States are denied the support and autonomy that is available to tribes with federal recognition. Additionally, they lack the ability to exert sovereignty over natural resources (Fitzgerald, 2015; Fletcher, 2006; National Conference on State Legislatures, 2020 Salazar, 2016). Defined as the exercise of self-government (Kalt & Skinger, 2004), sovereignty acknowledges legal autonomy over activities on tribal lands and exempts tribes from laws that could interfere with their traditions. This sovereignty is not a set of "special" rights but is rooted in the fact that Native American nations pre-exist in the United States and are consistent with treaty agreements made between tribal nations and the United States government (Kalt & Skinger, 2004). Due to political and historical factors, the tribe in this study has been unable to receive federal recognition and sovereignty, despite extensive documentation of their presence in the state and the fact that they have received state recognition (Fitzgerald, 2015; Fletcher, 2006; National Conference on State Legislatures, 2020; Salazar, 2016). Becoming a federally recognized tribe is not easy. The process is time-consuming, and expensive, and has been critiqued as being highly politicized and having guidelines that are not applied consistently (Crepelle, 2018a, 2018b; Fitzgerald 2015; Fletcher, 2006).

Without federal recognition, tribes have limited power in advocating for health equity measures, receive less federal support, have limited access to outside resources, and may struggle to exert tribal sovereignty over their land and resources (Fitzgerald, 2015; Fletcher, 2006; Salazar, 2016). When a tribe lacks federal recognition, they are unable to access services from the Indian Health Services (IHS). Though IHS has been critiqued for not providing adequate or high-quality healthcare services, it is an important resource for many federally recognized Native American Tribes. IHS enables federally-recognized tribal members to receive health care services at no or low cost, supplanting the need to rely on private insurance, Medicaid, Medicare, or paying out of pocket. State-recognized tribes do not have access to these benefits and are forced to rely on private or public insurance, or to pay out of pocket (Fitzgerald, 2015; Fletcher, 2006; Liddell & Lilly, 2022a, 2022b; Theobald, 2019).

Despite these barriers, the immense resilience of tribal members has endured, and they have worked assiduously to protect and pass on cultural knowledge to younger generations (Liddell & McKinley, 2021; McKinley et al., 2019). Important cultural values for this tribe include self-sufficiency, tight-knit communities, valuing spending time together with family and community, humor, pride in identity, and others (McKinley et al., 2019). Still, a lack of sovereignty disservices tribes and complicates their access to additional resources. Notably, little research has explored the additional support that non-federally recognized tribes may want or need. This gap is especially problematic because programs or interventions that are not culturally informed are not only less effective, but they are also potentially harmful to Native American groups (Burnette & Figley, 2017; Gone & Trimble, 2012; Liddell & Burnette, 2017; Thomas et al., 2010). Services that cater to a particular cultural group's needs are more effective than those that focus on multiple groups (Griner & Smith, 2006). Furthermore, even when programs do utilize enculturated practices in interventions and treatments, such as the use of talking circles or sweat lodges, they often focus on the individual, rather than using a more collectivist, community-based focus (Burnette & Figley, 2017). Programs that are developed and recommended by tribal members themselves are needed to fill this lack of culturally informed resources.

Social support is often instrumental in Native American communities. However, the role of specific programs and interventions such as support groups has received less attention (Burhansstipanov et al., 1999; McIntyre et al., 2017), particularly in the case of non-federally recognized tribes. Social support in Native American tribes often includes both emotional and instrumental support (taking someone to their appointment, making breakfast) (Burnette et al., 2019; Beals et al., 2013 Buchwald et al., 2000; Lee et al., 2018; Liddell et al., 2018). Emotional support may take the form of listening and companionship (Burnette et al., 2019; S. Brown et al., 2015, 2017. Lee et al., 2018). Opportunities for social support to be regularly accessible, such as in the form of support groups, church, or other community gatherings, are important for well-being (Lee et al., 2018). Resources and services oriented around transporting community members, especially elders, to meetings and gatherings are also an important form of support provided by tribal members.

Programs that promote the growth and development of social support within the Native American community have been shown to improve the health of individuals (King et al., 2009). Kirmayer et al. (2003) describe historical oppression as "deliberate human actions and policies aimed at cultural suppression, oppression and marginalization" (p. 87.) Forms of historical oppression, including limited socializing as a parent, disrupting emotional expression, diminished personal identity, and limiting commitment to traditional values of culture and language, have all led to interruptions in familial and community life. Continued repair of these relationships is essential to mitigate the negative consequences of historical oppression and settler colonialism (Mohatt et al., 2011). While these issues commonly affect Native American communities, non-recognized tribes have significant difficulties in advocating for resources.

Insufficient data on Native American populations is often cited as a reason behind the inability to procure adequate funding and support for both federally-recognized and state-recognized tribes (Korngiebel et al., 2015; Van Dyke et al., 2016). Both public health policy and public health funding rely on accurate data. However, researchers have historically utilized a circular logic that excludes a Native-centered research approach, refusing to acknowledge both a wider definition of data and that Indigenous peoples—both inside the United States and internationally—are, and have been, expert data collectors, keepers, and users for thousands of years (Van Dyke et al., 2016). Not only do non-federally recognized tribes face issues regarding legal sovereignty, but they also face a lack of sovereignty over their own collection, ownership, and application of their own data (Bauer & Plescia, 2014).

This study is informed by, and builds upon, the previous work of Burnette et al. (2015, 2017, 2019, 2020) and in particular the framework of historical oppression, resilience, and transcendence (FHORT) (Burnette & Figley, 2017). This framework is distinct from many previous approaches to exploring the negative impacts of settler colonialism in that it acknowledges the negative impact of settler colonialism while also highlighting the ways communities are resilient in combating its ongoing negative impacts. Throughout this study, we endeavor to both note the gaps identified by community members while also showcasing the agency and resiliency of tribal members.

Purpose

First-hand information regarding community health concerns is essential in illuminating the health risks impacting Native American people living in isolated and rural areas, and for tribes that are not federally recognized. This study aims to prioritize the cultural values belonging to Native Americans living in the Southern and Gulf regions by directly involving and interviewing

community participants who are members of a Southeastern Tribe, and exploring the health needs they identify. By identifying community health priorities, this study will provide important data and information that will help guide health interventions and improvements in a way that culturally aligns with and respects the values of the Tribe. The specific research question driving this study is "What are the community health concerns and needs described by members of this Gulf Coast state-recognized tribe and how are they impacted by a lack of federal recognition?"

Methods

Research Design

This study employed a qualitative descriptive methodology, which is frequently used in semi-structured interviews and health-focused research as a pragmatic, naturalistic investigative approach (Sullivan-Bolyai et al., 2005). This methodology is considered a culturally congruent approach to research with Native American peoples (McKinley et al., 2014) and was considered appropriate for this study because it uses low-level interpretation, maintains cultural nuances, and highlights participants' voices, has been used previously with this tribe, and was advocated for by the community advisory board (McKinley et al., 2019; Sullivan-Bolyai et al., 2005). A qualitative descriptive methodology emphasizes research participants' voices and understandings, rather than abstract descriptions of experiences, which makes it especially useful for health-focused research seeking findings to inform interventions (McKinley et al., 2014; Sullivan-Bolyai et al., 2005). The findings discussed here emerged out of a larger project exploring the reproductive and sexual health experiences of tribal members (Liddell, 2020; Liddell & McKinley 2021; Liddell & Kington, 2021; Liddell & Lilly, 2022a; Liddell & Lilly 2022b; Liddell et al., 2022a; Liddell et al., 2022b; Liddell et al., 2022c; Liddell & Herzog, 2022; Liddell & McKinley, 2022; Liddell & Doria, 2022; Liddell, 2022; Liddell & Meyer, 2022; & Carlson & Liddell, 2022).

Settings and Participants

Members of one state-recognized Gulf Coast tribe participated in this research. The tribe's identity is kept confidential pursuant to agreements with the tribal council and in alignment with recommendations for conducting culturally sensitive research with Native American groups (McKinley et al., 2014). This tribe lives in an area of the Gulf Coast that has suffered significant environmental changes, including land loss and hurricanes. Tribal members are dispersed throughout a region characterized by waterways, wetlands, water management facilities, and oil production infrastructure upon which tribal members are economically and culturally dependent. Important cultural values within this tribe include self-sufficiency, generosity, family closeness, and advocating for others (McKinley et al., 2019). Tribal members have historically experienced educational discrimination, forced relocation, and denial of tribal recognition at the federal level which limits access to resources and hinders political autonomy.

We used purposive and snowball sampling methods to recruit and enroll adult females who identified as members of the tribe. Thirty-one women participated in semi-structured qualitative interviews for this research. Due to the considerable difficulties that tribal members have historically had in proving tribal membership (Cochran et al., 2008), we did not require proof of enrolled tribal membership for participation. Participants ranged in age from 18 to 71 years ($M = 51.71$). Most women (87.1%) had completed a GED or high school degree. About half of the participants (51.61%) had completed some form of educational training after high school. Most

women reported having some form of health insurance coverage (93.54%) and having at least one child (83.87%). Participants reported having two to three children on average. Women reported having their first child at around the age of 20, on average.

Data Collection

Tribal members served on our community advisory board. They helped develop interview questions, recruit participants, ensure that the research methods were appropriate and culturally relevant, interpret study findings, and disseminate study results. We also sought and received approval from the Tulane University's Institutional Review Board (IRB) [study #2018-467] and the tribal council's IRB. Interviews focused on tribal members' healthcare experiences. Interviews took place at participants' homes or in tribal community buildings, depending on participants' preferences. The third author conducted and digitally recorded all interviews with participant consent between October 2018 and February 2019. The interviews ranged in length from 30 to 90 minutes ($M = 66$ minutes). As recommended by the community advisory board, participants received a $30 gift card to thank them for their participation. All interviews were transcribed verbatim, using NVivo software for data processing and analysis (QSR International, 2015).

Data Analysis

We employed qualitative content analysis - a form of data analysis frequently used in qualitative descriptive research (Milne & Oberele, 2005) - as our analytic strategy. In this approach, codes emerge directly from participants' voices, and theory can inform results (Milne & Oberele, 2005). Following this approach, the third author listened to each recorded interview three times and then began an inductive coding process working from transcripts to develop an initial list of broad codes and themes. Initial codes were then refined into discrete codes for the final coding scheme through collaboration with the CAB and co-authors (Sullivan-Bolyai et al., 2005).

To ensure this study was carried out rigorously, this research adhered to Milne and Oberle's (2005) strategies of (a) flexible and systematic sampling; (b) encouraging participants to speak freely and openly; (c) creating accurate, verbatim transcripts; (d) using participants' language and experiences to drive coding; and (e) centering context throughout the analysis. We also conducted member-checking, inviting all participants who agreed to be contacted after the study with a summary of findings for review and feedback. This summary of results was provided to each participant at least twice. The third author also shared findings through presentations at tribal council meetings and events.

Results

Women mentioned a variety of community health concerns. The most common health concerns included: high rates of cancer; vehicle accidents or collisions common; barriers to exercising; physical injuries common; chronic illnesses common in the community; loss of family members; and physical violence.

Rates of Cancer

All participants mentioned the high rates of cancer within the tribe and in their own families. Most women felt that these rates were increasing and were concerned about what was causing these

high rates of cancer. Participant 1 said that unease and concern about cancer, along with the belief that high rates of it were being caused by something in the area, dissuaded one of her relatives from wanting to move back to the community. Participant 4 felt that one of the reasons cancer rates were so high was because of fish processing plants and described her experience with one near her house growing up:

> *They used to have a plant that they would work fish and it was so bad and it was all over and I said when we were young you couldn't hang clothes because your clothes smelled like that and we inhaled that all our life. I said, 'that could be what's causing all this cancer.'*

Participant 20 reported feeling that cancer was also increasingly common among young people and that there was a need for health education in this area:

> *My…little niece…she has to have surgery next Tuesday for precancerous cells. In her cervix, which is pretty, the doctors said she was fairly young for…she's 22…did she know about that? No. Of course they go for their checkups. I'm, I'm guessing, do they all [young people] go for the checkups? I have no clue, you know, but I don't think they have, I don't know of any classes that are, are just for women, or programs out there that are just for them, to educate them…on basic women's health…No, I don't know of any. Just you know, basic cervical cancer or I don't know very much other than I look stuff up and, and because my sisters are… in the medical field…. you know, you figure with breast cancer as high as it is…women are getting breast cancer so much earlier now, even though the doctor tells you, you don't have to get mammograms done until later. But the few people who I've known who have breast cancer…had it before they were 30.*

This participant noted that because of the high cancer rates in the area, it was especially concerning that few cancer-screening programs exist and that no cancer education programs are available in the community. This participant also states that she has had to make the effort to do research in her own time, and through speaking with family members in the medical field, to learn more about cancer because this information isn't readily available.

Vehicle Accidents or Collisions Common

Several women spoke about the loss of family members in car accidents or being in car accidents themselves at some point. Participant 11 recounted being hit by a car as a child and being hospitalized and Participant 22 stated that she had lost one of her children in a car accident, as follows. Both this participant's daughter and her grandchild died in the accident she described.

> *I had ridden my bike…in the the highway, and a car had hit me and I don't remember the actual, like I remember before and after…. I remember before when I went outside to ride my bike. And then I remember waking up in the hospital …. Everything in between. I don't remember so much, which is probably good.* (Participant 11)

> *At 21 I got married. I raised five children, five girls, my husband and I had five girls and they're all grown. Like I said, my last one, she was my baby girl and she, at 23, she passed away, her and the baby, in a car accident.* (Participant 22)

Barriers to Exercising

Women reported challenges in accessing safe places to exercise and finding the time to exercise. Some women had suggestions for increasing access to recreational activities, especially for youth. When discussing exercise, additional subthemes women mentioned included "general barriers to exercise" and "no location." Participant 8 felt that not only were there not a lot of recreational opportunities but that there were not locations for people to do these activities in, which was an important barrier for getting people to exercise regularly in the community:

> *I think there are not a lot of recreational activities. There are not too many for women down here…I don't think there are enough recreational activities for people to do to keep your mind off of either food or shopping or whatever…. There's like parks but they're like ones way down there or one's like over there. I think they need more sidewalks or like bike trails, and stuff because there are a lot of healthy people that live here that are very health conscious. And I just think there's not a big push or a big support in that, you know what I mean? There could be like a sports complex where there are tennis courts, like softball, baseball fields, whatever, but there's not any of that unless it's for kids or a school. So I think there could be a lot more of that kind of activity or like more artistic things I think, because just to distract the woman from eating because I don't think that's a good thing. But just give them something to do, you know?*

This participant also felt providing places to exercise would produce additional health benefits because people engaged in exercise and other recreational activities may be less likely to engage in less healthy behaviors, like overeating.

"We Have a Lot of Disabilities Because Our Guys Work Hard . . . The Body is not Designed to Do That Forever": Physical Injuries Common

Getting injured at some point in their life was a common experience for many tribal members. Women described family members getting injured on the job or in car accidents. Participant 15 described her concern that the occupations of many male tribal members were physically damaging to the body:

> *We have a lot of disabilities because our guys work hard and when they work on the boats, rowboats and so they have lower back problems or whatever. So that's a big…. And you know, these guys, to be an oysterman, or fisherman is very, very hard work and the body is not designed to do that forever.*

Participant 11 described her experience recovering from a severe car accident in a hospital after she was hit by a car and broke her leg, and described having to go through physical therapy following her accident to re-learn how to walk:

> *I remember spending the holidays. I remember, I remember Halloween and I remember the nurses being dressed up in Halloween costumes. I was in the fifth grade or sixth grade when it happened and they had to stop my leg because the way that it was broke, my foot was two inches shorter. My leg was two inches shorter cause they, of something that they had to do. And so I had to wear a lift on my shoe for a long time and I missed out a lot in school. And then I had to learn how to walk again and all those other things.*

"I Worry About . . . Access to Care": Chronic Illnesses Common in Community

All women expressed concern about what most felt were increasing rates of chronic illnesses among tribal members. The most common chronic illnesses beyond cancer included: "Alzheimer's disease," "diabetes," "heart diseases/problems," "high blood pressure," "obesity," and "stroke." Heart problems including heart disease, heart attacks, and other heart issues were commonly reported. Many women described either having high blood pressure themselves or having family members with this health issue. Increasing obesity was a concern for many women and was often attributed to changing lifestyles. Several women reported either having had a stroke themselves or having a family member who did. Many strokes were described as being preventable, but health practitioners missed the symptoms. Several women spoke about their experience with family members with Alzheimer's. When asked what health problems they saw as most pressing in the community, Participant 22 reported "A lot of Alzheimer's that's going on." Participant 17 noted what they felt were common concerns, in addition to stating that her mother had Alzheimer's:

> *Cancer is the, you know, most, you know, like high blood pressure, diabetes, you know, stuff like that. But I mean, cancer is the, most…because my Mama, my mama died or like had a heart attack…she had Alzheimer's, but it wasn't the Alzheimer's.*

This participant and others note that tribal members were often impacted by multiple health issues simultaneously. Diabetes was another important health concern reported by almost all women and was felt to be related to changes in diet. Participant 31 reported several health issues she saw in the community, and noted the interrelated nature of chronic health problems with health behaviors such as diet and smoking:

> *Diabetes, high blood pressure, obesity. These things, that's what I seen, you know, just in general, my mom had a stroke, I think about six years ago now, going on six years…and if she hadn't changed her eating habits to a healthier lifestyle, the doctor said she wouldn't be here. So, I mean it was serious, she was a heavy smoker, you know, so that's another thing, I mean it adds to the stress of the body.*

Participant 1 described how her mother's diabetes kept her from cooking the large Sunday meal that she used to cook for the extended family each week:

> *A lot of times, you know, she wanted that [to cook for everyone], but then after she got older, she got a, you know, she had diabetes really bad, then…she couldn't do it no more, and she started dialysis and stuff like that. So, she didn't do it no more.*

Participant 10 reported that her mother had lupus, in addition to noting the other chronic health issues she saw in the community: "Illnesses that can't, I don't really know that there's like a cause, but I tend to see like heart disease, diabetes, like my mother has lupus, and so I, I worry about like access to care." In addition to noting the high prevalence, access to care for these conditions was also a concern voiced by participants.

"In Six Months We Lost My Uncle, My Momma and Then. . . My Aunt": Loss of Family Members

Most women described the loss of a family member at some point in their life. Many of these losses were related to health complications. Many participants described experiencing multiple losses, sometimes in short time frames. Participant 17 described losing several family members:

> *You know… in six months, we lost my uncle, my momma, and then this past…last two weeks, last week, my aunt…. Six months we lost three of them, only have one uncle left and there were like, maybe, let me see, one, two, three, four, five, six, seven, seven or eight of them, so.*

Participant 22 described losing family members during Hurricane Katrina: "That's when they got killed, in Katrina. The other storm. The baby and my daughter."

"It was Such an Abusive Relationship that I was in. … I was a Survivor and I Survived It": Physical Violence

Several women described experiencing or seeing violence in their community. Some women reported experiencing domestic violence as children or adults. All women reported strength and resilience in being able to leave these relationships, though many also described worrying about youth and wanting programs for youth to teach them about healthy relationships. Participant 1 felt that her history of abuse had contributed to her current strength: "It was such an abusive relationship that I was in… I think that right there, brought me to who I am today, because I was a survivor and I survived it…" Participant 19 reported being abused as a child:

> *I was molested as a child. I had a brother-in-law who molested me when I was a little girl…. But a lot of people, they dwell on that. But I felt like being the people we were, and my mom always told us, "If anybody tries to do anything to you, let me know." I felt like I needed to tell her. It was kind of funny, because when I told her, she said, "Okay, I'll take care of that." She grabbed her broom, and she went to find him, and she beat the heck*

out of him. I was satisfied with it…. I saw him... and she was beating him, yeah. But my sister was at work, and she didn't know. I think it was not until maybe about ten years ago that she [my sister] found out.

This participant reported being satisfied with her mother beating her abuser and feeling that she did not want to seek formal punishment. This participant also described the feeling that it was important to tell her mother what had happened, and that her mother had stressed the importance of opening communication about abuse, while also noting that she did not tell her sister about her husband's behavior.

Discussion

Health disparities are widespread amongst Tribal communities and Indigenous populations globally, but Native American tribes that lack the autonomy and protections that come with federal tribal status face increased and unique challenges due to lacking autonomy and recognition as a Tribe. With cancer being the leading cause of death globally for Indigenous people (Garvey & Segelov, 2020), it was no surprise that so many participants in the study discussed the impact cancer had on their own lives. With higher rates of incidence and lower rates of survival, the reported lack of cancer education and prevention programs within this Tribe's community is especially troubling (S. Brown et al., 2015). Access to such programs has shown a strong association between cancer screening and improved general health, especially when they are culturally contextualized and specialized (S. Brown et al., 2015; McKinley et al., 2019; Perdue et al., 2014). Fostering these programs within Native American communities may be one avenue to promote wellness, but the lack of federal recognition and the corresponding access to healthcare funding and resources acts as a barrier to this endeavor.

Obesity was also a common health concern. According to participants, there are barriers to exercise and healthy nutrition options that impede preventive health measures. European colonization significantly impacted Native American dietary habits, taking away traditional foods and largely replacing them with carbohydrates (Bays et al., 2022). Compounded with problematic delivery of commodities to reservations (e.g., shopping in food deserts with food stamps), heightened consumption of carbohydrates among Native American communities often leads to diabetes and progresses to End-Stage Renal Disease, a primary cause of death in Native Americans with diabetes (Bays et al., 2022). Furthermore, policies and technologies such as limitations on the freedom to hunt and lack of access to insurance coverage contribute to the prevalence of obesity, diabetes mellitus, and metabolic syndromes among Native Americans (Andolfi & Fisichella, 2018; Burnette et al., 2020; Liddell & Lilly, 2022a; Liddell & Lilly, 2022b).

Additionally, safe places to recreate, like bike lanes or hiking paths, are lacking in the community and would offer affordable and easy access to exercise and fresh air. Lack of access to facilities and resources that provide opportunities for physical activity has negative implications for community health outcomes and disproportionately impacts communities that have limited access to financial resources, such as this state-recognized Tribe (Taylor et al., 2007; Vickery & Hunter, 2016). Participants also noted the lack of education and awareness around preventative health care and would like to see more educational resources made available to them. Since Native American youth face higher obesity rates, preventative health measures and access to nutritionally substantial foods would offer protective factors in promoting individual and community health outcomes (Schell & Gallo, 2012). While there are substantial barriers associated with restoring traditional cultural practices in Native American communities, education programs centered on

enculturation practices have been identified as a method to increase physical exercise and overall mental well-being (Bersamin et al., 2014; McKinley Lesesne, et al., 2020). Increased access to recreation resources and enculturated education may be avenues to promote community wellness, meeting the concerns of this Tribe regarding a lack of these kinds of opportunities.

Some women reported experiencing domestic violence either in their childhoods or adult past. All women described the strength and resilience it took to leave these relationships. Many worried about young community members and expressed a desire for programs for youth to teach them about healthy relationships. Interventions that incorporate Native American traditions and access to culturally responsive advocacy services have shown promise as effective pathways to healing and recovery from the high rates of IPV within tribal communities (Giacci et al., 2022; Rosay, 2016). The role of specific programs and interventions such as support groups is under-researched (Burhansstipanov et al., 1999; McIntyre et al., 2017) but access to social support is important for overall well-being (Lee et al., 2018; Liddell et al., 2018). More research is needed to understand the role such social support plays within the communities of non-federally recognized tribes.

The loss of a family member at some point in life was another important theme amongst the participants. Many of these losses were related to health complications and chronic illnesses, like diabetes and heart disease, which were reported at high rates in the community. Tribal members also identified losing loved ones to vehicle accidents and to other accidental injuries as events that have caused emotional pain and turmoil. Industry and employment opportunities that exist in their region often are very physically demanding and dangerous, and because of this, many participants experienced physical injury themselves or within their families. The occupational risks of jobs in the region, like working in a fish processing plant, caused concern due to the risk of exposure to carcinogens. Higher rates of mortality and injury within tight-knit communities like this Tribe are connected with higher depressive symptoms and a concurrent threat to well-being (McKinley, Miller Scarnato, et al., 2022). Frequent loss within the Tribe compounds these effects and has implications beyond each individual loss, impacting communities as a whole (McKinley, Miller Scarnato, et al., 2022). Conversely, improved access to community resources and improved overall community health can have positive impacts for tribes that are not federally recognized.

Historical oppression has distorted familial and community life within Native American communities. This oppression, which is rooted in policy and other interventions with the intent to suppress the cultures and traditions of Native Americans (Burnette & Figley, 2017; Kirmayer et al., 2003), has multiple effects: it has limited parental socializing, disrupted emotional expression, diminished personal identity, and limited commitment to traditional values of culture and language, all of which weaken social support. Significantly, individual health improves in response to programs that rebuild social support and facilitate enculturation within the Native American community (King et al., 2009; McKinley et al., 2019). Strengthening supportive relationships can mitigate the consequences of historical oppression (Mohatt et al., 2011). In fact, continued repair of these relationships and recognition of the cruciality of a community-based cultural focus is critical to repairing historical oppression's harms. While these realities are common to all Native American communities, non-recognized tribes face significantly greater obstacles in obtaining resources to support programs.

The sentiments and observations expressed by participants in this study speak to the long-standing inequality and persistent health disparities that Native Americans have faced in the United States. For this state-recognized tribe, these inequities are rooted in the barriers they face due to their lack of federal recognition. We recognize that Indigenous governance systems vary across the global context, but the destructive impacts of colonization on Indigenous sovereignty and

infrastructure are felt across the world. Discriminatory policies that prevent tribal sovereignty are rooted in a lack of, and gatekeeping of, accurate and relevant tribal data (Carroll et al., 2019; Rainie et al., 2017; Walter, n.d.). This gap itself is rooted in the impacts of colonization, as non-Indigenous norms and priorities define data and inform how it is collected and used to shape policy and distribute essential resources (Carroll et al., 2019). This is a global trend, and as such, there is value beyond the United States in understanding the intersection between barriers to sovereignty and systems of governance.

Limitations and Future Research

This study's findings are specific to the Tribe whose members were interviewed. While many tribal communities face similar issues, these findings are not meant to generalize Native American health concerns, even within similar state-recognized tribes or other tribes on the Gulf Coast. Data was gathered from firsthand accounts through self-reported interviews. All interviews were conducted in English, which was found to be a potential limitation as many tribal elders do not primarily speak English as a first language. The study's primary focus was to gain insights from female community members; as a result, male members' stories and experiences were excluded, although participants did reflect on the health needs of the entire community, reflecting the value many tribal members place on the holistic well-being of their community. Future research should consider including male community members to gain their perspectives and lived experiences regarding community resources and programming. Additional research may also want to specifically focus on exploring the perspectives of healthcare providers or leaders in the community.

An additional limitation to this study and all others that examine health in Native American communities is an overall lack of research on the infrastructural barriers tribal members face when navigating healthcare. While there are no easy fixes to these complex data issues, public health researchers must continue to collaborate constructively to improve the amount and methods of research. This will be a complex and timely process that necessitates full inclusion of Native American health experts, organizations, and tribes, and that includes non-federally recognized tribes.

Conclusion and Implications

Throughout the study, participants often addressed a desire for increased and improved health services needed in their community. Moving forward, it is important to note that health practitioners avoid using a one-size approach when it comes to interventions and program needs. White or non-Native American healthcare workers should understand that desires around treatment will be highly contextual to specific tribes and regions. To provide care with a level of cultural competency, practitioners need to prioritize understanding the ways historical trauma and racism may impact Native American patients' trust in non-Tribal healthcare systems. It is important that healthcare workers recognize that Native American patients may also participate in traditional methods of healing or reject a recommended treatment plan because it does not align with their tribe's beliefs or customs. Practitioners should be encouraging patients to self-advocate in navigating their treatment plan and show respect for other cultural customs. Building trust between practitioners and patients that could restore trust in healthcare professionals by Indigenous patients who have experienced medical discrimination in the past is key to more consistent and compassionate care in the future. The results of this study have also informed the creation of the

Framework of Integrated Reproductive and Sexual Health Theories (FIRSHT) conceptual framework (Liddell & McKinley, 2022). This framework weaves together Indigenous critical theory, reproductive justice, resilience, eco-systems, and life-course concepts to better contextualize the unique health needs of non-federally recognized Indigenous tribal members. We advocate that future researchers similarly utilize holistic frameworks when conducting research on complex social justice topics that require analysis and approaches that incorporate multiple lenses and theories to articulate nuanced issues and develop innovative solutions.

The legacy of colonialism continues to impact Indigenous populations across the world. As this study indicates, in the United States this legacy manifests as a series of barriers to legal sovereignty, which result in long-standing healthcare inequity, environmental violations, and disputed demarcation of reservation lands, among many other things. Across the world, research continues to prioritize methods of data collection that are conducted externally and are not rooted in Indigenous norms (Carroll et al., 2019). As this study demonstrates, a lack of sovereignty results in the perpetuation of healthcare inequity. Methods of governance that result in these inequities should be questioned, as well as the information that is used to determine sovereignty. Globally, enhancing Indigenous governance of their own communities and their own data is necessary for combatting the ongoing negative effects of colonialism.

Declarations

Ethics approval: Tulane University IRB approval and Tribal Council approval was granted before beginning research.

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