



2022

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### Recommended Citation

Liddell, Jessica L. and Lilly, Jenn M., ““There's so much they don't cover:” Limitations of healthcare coverage for Indigenous women in a non-federally recognized tribe” (2022). *Social Service Faculty Publications*. 27.

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## “There's so much they don't cover:” Limitations of healthcare coverage for Indigenous women in a non-federally recognized tribe<sup>☆</sup>



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### ARTICLE INFO

#### Keywords:

Indigenous  
Healthcare  
Health insurance  
Women  
Health disparities

### ABSTRACT

Access to healthcare is an essential component in addressing health disparities. However, the limitations of insurance coverage, and other barriers in paying for and accessing healthcare have seldom been researched for Indigenous peoples. In addition, state recognized tribes do not have access to the healthcare services provided by the Indian Health Service, and there is a need for research documenting their unique healthcare needs. Qualitative description was used to conduct 31 semi-structured interviews with women from an Indigenous tribe in the Gulf South to understand their experiences in paying for healthcare services. Participants described: (1) Discrimination Based on Perceived Ability to Pay for Healthcare; and (2) Limitations of Healthcare Coverage, with sub-themes (a) Difficulties Understanding Coverage Limitations; (b) Inadequate Coverage; and (c) Limited Choice of Providers. These findings indicate that state-recognized tribal members may need specialized insurance programs, and more comprehensive coverage of healthcare services and medications. Future actions should promote tribal sovereignty and increase access to healthcare resources for state-recognized tribes.

### 1. Introduction

The long-lasting impact of colonization is seen in the continuing health disparities which impact Indigenous tribes at alarming rates due to discrimination and inadequate access to healthcare resources and education (Indian Health Service, 2019; Jones, 2006). These disparities influence the care Indigenous populations receive for acute and chronic health conditions and contribute to a life expectancy rate that is lower than that of any other U.S. population (Indian Health Service, 2019). The intersectionality of gender and race further exacerbates healthcare disparities for Indigenous women. Compared to White women in the U.S., Indigenous women are twice as likely to die from pregnancy-related complications (Centers for Disease Control (CDC), 2020; Kozhimannil et al., 2020). Indigenous women also experience higher rates of cervical cancer compared to the national average and are more likely to die from cancer compared to White women (Watson et al., 2014). These disparities exist despite Indian Health Services' (IHS) commitment to provide health services for federally recognized tribal members established and mandated through a history of treaties with the U.S. federal government (Jones, 2006; U.S. Department of Health and Human Services, 2016).

IHS has been subject to many critiques related to its delivery of

services, and role in perpetuating settler colonialism; nonetheless, it is often the primary source of healthcare services for many Indigenous people (Gurr, 2014; Jones, 2006; Theobald, 2019; Zuckerman et al., 2004). However, there are numerous state-recognized tribal members who do not have access to IHS services. State-recognized tribes are not recognized as Indian tribes at the federal level, and therefore, do not receive the federal benefits such recognition confers. State-recognized tribal members cannot utilize IHS resources and must rely on Medicaid, a federal-state assistance program that helps low-income people cover healthcare costs, or on Medicare, a federal health insurance program for people over 65, private insurance, or paying out of pocket. The majority of research exploring health disparities and their relationship to healthcare coverage for Indigenous populations has focused on IHS specifically, excluding the experiences of Indigenous people ineligible for IHS services. This analysis of healthcare access for members of non-federally recognized tribes helps fill a much-needed gap in research. Few scholars have explored how limitations in healthcare coverage impact the healthcare decisions of Indigenous individuals. What researchers have shown suggests that decision making is often based on perceived ability to pay for care, and not on recommendations of providers, or the individuals' desire for care (Jaramillo & Willging, 2021).

<sup>☆</sup> The authors thank the members of this tribe for their dedicated work and participation in this research.

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<https://doi.org/10.1016/j.ssmqr.2022.100134>

Received 6 August 2021; Received in revised form 7 July 2022; Accepted 8 July 2022

Available online 30 July 2022

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Around 50% of Indigenous people have healthcare coverage through private insurance, 43% utilize Medicaid, and around 15% are uninsured (U.S. Department of Health and Human Services, 2016). In the U.S., 25 million adult women are covered by Medicaid, which was expanded in many states under the Affordable Care Act in 2014 (Kaiser Family Foundation; 2019). Among women covered through this program, coverage is higher among women of color, single mothers, and women who have not completed a high school education (Kaiser Family Foundation, 2019). For women in their reproductive years, Medicaid is a particularly important healthcare resource, covering 67% of women in the U.S. between 19 and 49 and offering a variety of family planning services with no out-of-pocket costs (Kaiser Family Foundation, 2019). A recent report by the Kaiser Family Foundation (2019) found that “Medicaid is the largest single payer of pregnancy-related services, financing 43% of all U.S. births in 2016” (para. 15). While Medicaid coverage has proven to be vital for women's health, research has also shown that the care that Medicaid patients receive is often of poorer quality than that provided to those with private insurance (Ostrom et al., 2017; Weech-Maldonado et al., 2012).

We used a socio-ecological theoretical framework to inform the design of this study, as well as to guide our analysis, interpretation, and contextualization of results. The socio-ecological theoretical framework is apt for conceptualizing Indigenous women's barriers in accessing healthcare and has been utilized extensively in health research (McLeroy et al., 1988). We used the socio-ecological theoretical framework to consider the role of organizations, institutions and social structures, along with their impact on each other, in the framing of our research questions and analysis of results (Bronfenbrenner, 1995). As a result, individual and group actions are situated within the context of these systems and structures. This theory is congruent with Indigenous conceptualizations of health because of its emphasis on connection and the relationships between the environment, family, individual and community, in addition to its acknowledgment of the impact of settler colonialism on wellbeing (Burnette, 2013; Martin, 2001). In many Indigenous cultures, health is viewed holistically, and well-being is represented by balance and harmony between different systems (Martin et al., 2019). This is congruent with the embeddedness of the individual in their environment, which underlines this theory. This theoretical framework is useful in connecting findings to multi-level implications for health research and health interventions.

## 2. Purpose

This research explores the healthcare access experiences of members of a state-recognized Indigenous tribe in the Gulf Coast. We particularly focus on the role and impact of insurance in influencing these healthcare experiences. This study addresses an important gap, since little research centers the experience of non-federally recognized tribes in accessing healthcare, and to our knowledge, no studies explore their experiences in paying for healthcare. The overarching research question this manuscript addresses is “How does insurance coverage impact the healthcare experiences of Indigenous women in a non-federally recognized tribe?”

## 3. Methods

### 3.1. Research design

This research employed a qualitative descriptive methodology, which emphasizes maintaining cultural nuance and participants' voices (Sullivan-Bolyai et al., 2005). Qualitative descriptive research is a pragmatic form of naturalistic inquiry, often used to explore health-related topics since it uses low-level interpretation and prioritizes participants' words to aid in developing interventions (Burnette et al., 2014; Sullivan-Bolyai et al., 2005). In alignment with the aims of this study, qualitative description has been endorsed as a culturally appropriate research methodology for use with Indigenous peoples (Burnette et al., 2014).

Additional articles that have emerged from this research project include Liddell (2020); Liddell & Kington, 2021a; Liddell & McKinley, 2021b; Liddell & Herzberg, 2022a; Liddell & McKinley, 2022b; Liddell & Doria, 2022c; and Liddell & Lilly, 2022d.

### 3.2. Setting

This study was carried out with the participation and collaboration of a state-recognized tribe in the Gulf South region of the United States. We keep the identity of this tribe confidential to honor our agreements with the tribe and in accordance with guidelines for culturally sensitive research with Indigenous peoples (Burnette et al., 2014). Members of this tribe (about 17,000) live in the Gulf Coast, which has experienced substantial environmental changes, including frequent hurricanes and land loss associated with climate change. Tribal members rely on the area's wetlands and waterways for cultural and economic resources, and many tribal members are employed by oil production and water management companies in the region. As a result of settler colonialism, tribal members were forcibly displaced, discriminated against in educational and other institutional settings, and denied federal tribal recognition, hindering their political autonomy, and limiting their access to federal resources and benefits.

The tribal status of state-recognized tribes is acknowledged at the state-level only, a status which does not confer the same benefits as federal recognition, such as sovereign powers and a trust relationship with the federal government (Crepelle, 2018; Fitzgerald, 2015). Tribes that are denied recognition at the federal level are thereby denied the ability to establish tribal governments, protect tribal land by placing it in a trust, and access services provided by Indian Affairs and the IHS (Crepelle, 2018; Fitzgerald, 2015). The federal recognition process has been critiqued for being unnecessarily complicated and utilizing differing standards to determine federal recognition status throughout history (Crepelle, 2018; Fitzgerald, 2015; Fletcher, 2006). This process is also detrimental to tribes such as the one in this study, who have not been removed to reservations, as this usually entails more extensive federal government documentation of tribal members that can then be used to prove tribal affiliation (Crepelle, 2018; Fitzgerald, 2015; Fletcher, 2006). This process has also disproportionately impacted tribes located in the Southeastern region of the United States, where the majority of state-recognized tribes exist (National Conference on State Legislatures, 2020; Salazar, 2016). However, despite these obstacles, the tribe maintains many cultural traditions and values, such as family closeness, advocating for others, generosity, and self-sufficiency.

The state in which participants reside has a median household income of approximately \$49,000 and an estimated 18% of people living in poverty, according to the most recent Census data. Less than 1% of the state's population identified as American Indian or Alaska Native on the U.S. Census. The state consistently rates in the bottom five of the nation for overall health, with particularly high rates of low birthweight and infant mortality (United Health Foundation, 2016; 2019, 2021). The Healthcare Professional Shortage Area (HPSA) scores (ranging from 0 to 26, as established by the Health Resources and Services Administration) for the counties in which study participants reside range from 14 to 22, meaning there is a shortage of providers within these geographic areas. Additionally, there is a designated population HPSA for low-income peoples in these counties.

In 2016, the state expanded its Medicaid program, closing a previous coverage gap by making childless, low-income adults eligible for Medicaid. Under the expanded program, U.S. citizen state residents ages 19 to 64 with a household income of less than 138% of the federal poverty level are eligible for enrollment; low-income children, pregnant people, people with disabilities, and seniors 65+ remain eligible. State residents are automatically eligible if they receive certain other public benefits. Legislation to implement a work requirement for Medicaid participants was proposed, but not enacted. As of 2021, the state has seen a 71% increase in Medicaid enrollment since 2013, and a 50% reduction

in the uninsured rate from 2010 to 2019. About 40% of the state's population is now enrolled in Medicaid. In addition to federally required benefits, the state's Medicaid program also offers several optional benefits, including dental care, adult health screenings, public and mental health clinics, hospice care, and home and community-based services. Medicaid spending for the state was about \$12 billion in fiscal year 2020, which is higher than surrounding states.

### 3.3. Participants

We employed a purposive sampling strategy, recruiting thirty-one adult, female tribal members to participate in the study through snowball sampling. In purposeful sampling, individuals who are particularly knowledgeable about the research area of focus are sought out (Cresswell & Plano Clark, 2011). In this case, participants who identified as members of this tribe, and as women over the age of 18 were identified. In a review of qualitative descriptive health disparities studies, the sample size was generally between 20 and 50 participants (Sullivan-Bolyai et al., 2005). We used the average number of participants used in other qualitative descriptive approaches as a guide and conducted life-history interviews with 31 participants. Saturation was achieved at 27 interviews. The remaining interviews were still conducted to verify saturation, and to honor previous agreements with the tribal members.

Proof of enrollment in the tribe was not required because tribal members have historically faced great difficulties in applying for membership (Cochran et al., 2008). The average age of participants was 51.71 years, and ages ranged from 18 to 71 years. Most participants (93.54%) indicated that they had some type of healthcare coverage. Of these participants, 21 stated they had private insurance, 5 that they had Medicaid, 6 that they had Medicare, and 4 that they were covered under multiple forms of insurance. Most participants (83.87%) had at least one child, and on average, participants reported having two to three children. In general, participants who were mothers reported having had their first child around the age of 20. The majority of participants (87.1%) had earned a high school diploma or GED, and 51.61% reported continuing education or training after high school.

### 3.4. Data collection

Prior to data collection, we obtained approval from Tulane University's Institutional Review Board (IRB), as well as the tribal council's IRB. This study was guided by two community advisors from the tribal community. These advisors provided input and oversight to ensure the research was appropriate in its aims and approach and conducted in a way that was culturally relevant. They also assisted in developing interview questions, recruiting interviewees, and disseminating study results.

The first author (PI) conducted semi-structured interviews with the thirty-one study participants between October 2018 and February 2019. All participants provided verbal, informed consent to participate and to have their interviews digitally recorded. Interviews lasted 66 min on average, ranging in duration from 30 to 90 min. Participants were interviewed at the location of their preference, usually in tribal community buildings or participants' homes. A semi-structured interview guide was used. This guide included questions such as: "How do you usually pay for healthcare?" and "Are there things that make it harder for you to get care?" For a full list of interview questions please see Liddell & Kington (2021a). All interview participants received a \$30 gift card for participating, based on the recommendation of the community advisors. Verbatim transcriptions were made of audio-recordings and we used NVivo software to analyze data.

### 3.5. Data analysis

We employed an analytic approach, often implemented in qualitative descriptive research, called qualitative content analysis (Milne & Oberle,

2005). This approach allows theoretical frameworks, such as the socio-ecological framework, to inform findings, while employing inductive analytic methods that allow codes to emerge from participants' voices (Milne & Oberle, 2005). The socio-ecological theoretical framework informed the research design, questions, and data analysis. An analytical approach in which the interaction between healthcare systems and their impact on Indigenous health helped formulate the study's creation. Participants were asked questions about the different healthcare systems with which they interact, and the discussion of results includes an exploration of relationships between systems and participants reported experiences.

Qualitative content analysis is often used in three distinct ways in qualitative description studies. These three approaches include: conventional coding, directed coding (where codes that are predetermined are utilized), and summative (where qualitative findings are interpreted through quantitative methods) (Hsieh & Shannon, 2005). Conventional qualitative content analysis was utilized here. Analysis was conducted by the first author and proceeded in the following steps: (1) listened to each interview recording three times; (2) reviewed written transcripts to create an initially broad list of codes and themes; (3) conducted refined coding to develop an analysis scheme made up of distinct codes (Sullivan-Bolyai et al., 2005).

We followed Milne and Oberle's (2005) guidance for standards of rigor in qualitative research, applying the following strategies: (a) sampling that is both flexible and systemic; (b) facilitating free and open speech from participants; (c) accurately transcribing all interviews verbatim; (d) utilizing the actual words and experiences of participants in coding and analysis; and (e) centering context in analysis. Further enhancing the rigor of this study, all women who consented were contacted for member checks. These participants were sent a summary of the results for review and asked for their input at least two times. One participant declined to participate, and two members provided e-mails that were no longer valid. The first author also presented a summary of results to tribal members at community events and at tribal council meetings.

## 4. Results

Participants described a variety of themes related to their experiences using, accessing, and paying for insurance and healthcare services. These themes included: (1) Discrimination Based on Perceived Ability to Pay for Healthcare; and (2) Limitations of Healthcare Coverage, with sub-themes (a) Difficulties Understanding Coverage Limitations; (b) Inadequate Coverage; and (c) Limited Choice of Providers. Concerns related to paying for healthcare were mentioned a total of 59 times by 24 women.

*"If We Wouldn't Have Had Insurance ... It Was a Little Different Without Insurance":* Discrimination Based on Perceived Ability to Pay for Healthcare.

Discrimination based on perceived ability to pay for healthcare was described by many participants. Some women reported feeling that women with private insurance were viewed more positively and treated better than those without insurance or those on Medicaid.<sup>1</sup> Participant 14 (covered by Medicaid) reported feeling that there was a difference between doctors who accepted Medicaid and those who didn't: "You go to a doctor's office that doesn't accept Medicaid and one that does ... and it is very different." Participant 15 (covered by private insurance) reported an experience with her daughter where she felt that providers assumed her daughter could not pay for healthcare and that she was treated poorly as a result. She felt that this was because her daughter was young and was perceived as being an unwed, un-insured parent:

<sup>1</sup> Nationally, 42% of births are paid for by Medicaid [26].

My daughter is very young looking. She's 28 years old and she looks like she's 15. She has a child ... the two-year-old had a seizure and we had to rush to the hospital .... Her husband wasn't there yet and ... in the emergency room, they treated her like she didn't know [what] she was doing with her own child. The baby quit breathing on us, and I did CPR three times before we got to the hospital and they treated her like ... "oh, so your mom's got your child." ... [they asked] "What's your kind of insurance?" They thought she was going to say this, that [that it was Medicaid] and she said, "it's my husband's work insurance." They said, "you're married?" ... And she said, "yeah, this is my husband's thing [insurance card]. And he's, he's parking the car, he's coming." So once, once he [the husband] got in they were fine.

This participant went on to describe how this experience left her daughter not wanting to go back to the hospital where she had been poorly treated:

"Mom, I don't want to go to that hospital. Let's go to the other one because you know how they're going to treat me?" [I said] ... "yes, of course" ... we go to the next hospital, this one here. And the doc comes in and says, "okay mom, tell me what's going on with this baby. What's going on with the baby, momma, come fill me in." I just sat back and said, "now this is a good thing" .... They [the other hospital] thought she was a single mom .... Young girl. And when I take her to her doctor visit, people would stare at her and I told her, "I'm gonna [sic] get you a shirt made" .... "I'm like 21, eight months pregnant, I'm married and yes, we do have insurance" [laughs].

As this woman described, healthcare providers made many inaccurate assumptions about her daughter that negatively influenced the care she received. Despite this extremely negative experience, the participant was able to demonstrate resilience and strength in being able to laugh at the situation, while also affirming her commitment to continuing to stand up for her daughter, and in seeking care at a hospital where they felt less discrimination. However, it is also important to note that her daughter had private health insurance, despite the stereotype of the hospital staff that she didn't. Having private health insurance allowed this woman the option of choice in what facility she went to, a choice that is not available for all tribal members. This quote demonstrates the importance of family members supporting and advocating for one another in the healthcare system, particularly amongst Indigenous women. It also shows the value of humor for many Indigenous people in this tribe.

Participant 22 (covered by Medicare) reported feeling that she didn't experience discrimination when she gave birth, and in part attributes this to having had insurance: "At the time, I didn't. I didn't feel none [discrimination]. The kids were born and that was it. I didn't feel anything like discrimination. I guess what helped [was that] because we had insurance .... If we wouldn't have had insurance, some people said, it was a little different without insurance." This quote demonstrates the importance of having or being perceived as having health insurance in regard to quality of care. Discrimination based on perceived ability to pay in healthcare contexts was a prevalent concern. These experiences were severe enough to impact some women's willingness to seek services from those providers in the future. Participants also mentioned that those without quality private insurance received sub-standard care. The right to receive high-quality care irrespective of insurance type or status was undermined for the women in this study.

Tribal members who were uninsured often described visiting the "charity" hospital that provided services free of charge to low-income patients. Participant 24 (covered by private insurance at the time of her interview, but describing an earlier time period when she was uninsured) recalled receiving a lower quality of care when she gave birth at this hospital, where she was in labor for 7 h in the waiting room before being seen by a doctor: "It [the wait] was because we went to charity hospital, but where they put in line of, you know, whoever's the sickest I guess." This participant later went on to state that if she would have had

insurance, she would have gone to a different hospital- "if [I] have insurance I would go to [name omitted]"- suggesting that she would have received higher quality care elsewhere. Participant 6 (uninsured) compared her experience as a patient paying out of pocket to her niece's experience as a Medicaid patient at the same hospital, stressing the difference in wait times:

Me and my niece ... used to go to the doctor together .... I paid out of pocket. Well, she [her niece] had Medicaid and just because she had Medicaid I passed [got in to see the doctor] faster than her and he'd stay there for hours. I found that wasn't right because she was on Medicaid... we'd have to wait ... hours with her because she was on Medicaid. The people who paid would go faster. I didn't find that was right.

In many women's experiences, discrimination based on perceived ability to pay influenced healthcare experiences, negatively impacting the care and responsiveness they received.

#### *"Your Insurance Probably Won't Pay for It": Limitations of Healthcare Coverage*

Participants frequently noted perceiving or experiencing limitations of what their health insurance would cover as they navigated their healthcare needs. In some cases, participants' accounts revealed the inadequacy of healthcare coverage in meeting their healthcare needs. These findings attest to the complexity of health insurance coverage stipulations, as participants would often seek needed care without knowing which services would be covered to what extent until they were informed or advised by their doctors. Limitations in coverage often shaped women's healthcare decision-making processes, as they had to consider their economic circumstances, in addition to healthcare needs. We identified three sub-themes relating to limitations of healthcare coverage: (a) Difficulties Understanding Coverage Limitations; (b) Inadequate Healthcare Coverage; and (c) Limited Choice in Providers.

**Difficulties Understanding Coverage Limitations.** Several participants described having a difficult time understanding what services were covered, to what extent, and with what frequency. For example, Participant 22 expressed concerns that her Medicare coverage limited the frequency of preventive screenings:

Medicare told me I don't need a pap smear. But, because I still have my ovaries, the nurse practitioner, I go to the Women's Clinic. They told me, yes you do, because you still have your ovaries ... The doctors, they told me I didn't need to do that no more ... They told me that now I don't have to do it every year, I can do it every two years. That's Medicare. That I was doing it every year. My colonoscopy, that's every 10 years, but I've been doing it every five years because they find a polyp. When they find a polyp, they do it every five years.

In the case of this participant, she believed that important preventive screening services were not available to her as frequently as she needed them because her health insurance coverage limited the frequency of these preventive services. The information she received from her insurance provider and her healthcare provider conflicted, causing further difficulty in understanding how often the services she needed would be covered. Participant 11 (covered by private insurance) expressed her concern that it was particularly hard for elder tribal members to navigate the complexities of the healthcare insurance system:

I think just navigating .... the language of, of what's what, I think a lot of people like my grandfather right now .... were just having that conversation about how he's switching [insurance]. He's going to save hundreds of dollars, but the weekend before when I was there ... I had to have my uncle ... explain to him everything, you know, if he's getting sick, you know, if he goes into the, you know, the hospitals, this is how much he's paying a day ... he just swore that the health

plan that he had was perfect ....Until somebody really got there, read the fine print, and then it was like, you know, oh, okay ... but navigating that language ... for a lot of us, because even me, you know, it is hard ... I don't read the fine print ... if they say it's okay, if my job says it is okay ... I'm just going to go with the majority ....I trust you guys and if that's what you got, but I'm not reading.. I'm honestly not reading the fine print ... being broke down into bit sizes and making sure that we really know what we're getting ourselves into because ... when it's going to come time to use it ... we put ourselves in these positions of trusting ... what other people are saying and not doing our own homework on the, on what we're paying for ....I think ... that's a challenge.

As has been mentioned previously, this participant felt there was a need for insurance literacy and education for tribal members to learn about the benefits and limitations of their insurance options. In each of these accounts, participants made proactive efforts to inform themselves about coverage limitations, but still experienced difficulties in understanding what the insurance company would cover.

**Inadequate Coverage.** Participants also described the inadequacy of their health insurance coverage, which sometimes covered a very limited amount toward prescriptions, office visits, and treatment. Inadequate coverage shifts the responsibility to pay onto the insured, leading to prohibitively high out-of-pocket costs. In these cases, socioeconomic limitations combined with inadequate coverage caused participants to go without or limit the frequency with which they utilized services and medications. Participant 8 explained that due to limitations in prescription coverage, she couldn't afford her medications, even though she was covered by Medicaid:

I was on birth control from 12 to 18. Very consistently on birth control. Then once I graduated high school and went into college my ... I don't know what was up with my Medicare, Medicaid, whatever I had. It was just the medicine was \$90. I was like, "I don't know if I want to spend that every month." I was off and on .. I've been off and on with it for the last four years, three years. Like right now I'm currently off it.

Although this participant had always consistently taken birth control, because of the high cost of paying out of pocket once her insurance changed, she was no longer able to afford it. The high cost of birth control left her without access to this important family planning support. Participant 23 (covered by private insurance) also identified the cost of medications, even with insurance, as a barrier for tribal members: "I think it is ... because of ....not having money and being poor and the cost of, the cost of going to doctor, the cost of the pills and stuff like that ... Like how you gonna pay for it." This participant felt that anticipating or experiencing high out-of-pocket costs was an important reason some members were resistant to seeking medical care in the first place.

Oftentimes, necessary services were only partially covered by insurance, leaving tribal members with high out-of-pocket costs, as Participant 31 (covered by private insurance) described:

We do have insurance, however I am still currently paying on my hysterectomy ....Not all of it [was covered] ... our medical insurance, it's not the greatest ... I mean its insurance and it covers a portion, but we're still left with a large chunk, so we ended up getting into an FSA [flexible spending account], because we have, with three children. And thankfully we did it last year because my son ended up in the emergency rooms twice. The medical bills that ... the medical insurance don't cover. We were able to pay with that. I wish I would have known that, you know, years ago, and that's another thing, that if we would be told about the importance of these things when you're enrolling in insurance, I mean, it's there, but when you don't know how important it could be, when you won't know what difference it can make you know, in your financial situation, it plays a big part in that.

As this participant's experience demonstrates, the amount of a major procedure that insurance covered was very limited, leaving the family with a significant economic burden. This participant also stressed the importance and need for increased knowledge about insurance and FSA's for tribal members.

Another participant described her experience of preventive services not being covered, forcing her to pay out of pocket for a service recommended by her doctor. Participant 1 (covered by private insurance) said her provider recommended she get a colonoscopy performed as a preventive measure because of her family's history of cancer, even though it wouldn't be covered by her insurance:

He [the doctor] says, "I would highly recommend, I know you young, your insurance probably won't pay for it, but I highly recommend that you get a colonoscopy because the chances of you getting, a cancer, has increased by 50% because of your dad." And so, my sister and I, my sister's in her thirties, early 30s and thank God she went because they pulled 16 polyps out of her. And if that, she'd have waited till the age, at 50, she wouldn't have made it ....And so her and I we both go to, we'd go regular now and every single time there's polyps being pulled from us. Every single time. But thank God we do the prevention.

Participant 20 (covered by private insurance) also expressed concerns about tribal members paying out of pocket due to limitations in insurance coverage. She described how a family member's feeding treatments for her daughter weren't covered by Medicaid:

Her insurance wouldn't even cover her feeding treatments ... because ... she wasn't born that

way ....she have to pay out of pocket for all of her milk. So just ... healthcare ... They reform and they don't reform ....coverages, accessible healthcare ... I think even after the women have the babies, then they lose their Medicaid. So a lot of times they're left with those gaps in insurance. So what do you do in those cases when you can't afford healthcare? You don't go to the doctor. And you know, the kids can get Medicaid, but you're not getting help for yourself .... when people complain about having to pay for health insurance ... you pay for car insurance all those times ... instead of getting preventative care and people say, "oh, well, whatever," but then you go to the hospital because you've been neglecting your, your blood pressure. Now you're having a stroke and that's costing taxpayers tens of thousands of dollars when it could be costing you a couple of hundred dollars every now and again.

This participant also pointed out that although pregnant women are covered, this coverage lapses soon after childbirth, representing a significant gap in healthcare access. This participant also draws a connection between preventative care, the need for expanded healthcare coverage, and the long-term government cost of not providing preventive measures.

Many participants shared the perception that their health insurance coverage was not comprehensive enough, severely limiting the accessibility of services related to mental health, dental health, and vision. Participant 10 (covered by private insurance) noted that insurance not covering mental healthcare was a healthcare access barrier for some community members: "I've heard a lot of complaints around, like it's bad enough the social stigma around mental health. So, when someone actually decides that they want to do something about it and then they have, are having trouble getting their insurance to cover it." As this participant states, not having coverage for mental healthcare is especially problematic because of the already existing stigma surrounding mental health services. Participant 19 (covered by private insurance) noted that most participants don't have access to dental care, even if they do have health insurance: "One of the things that I think that is most lacking ... for the [tribe name] people altogether, is dental, free dental care. There is no way that an adult can get dental care." This participant felt that if the



tribe had federal recognition, they would have access to some of the dental healthcare programs and services that are available to federally-recognized tribes. Vision care was another area not typically covered by insurance, as described by Participant 2 (covered by private insurance):

I have insurance here ... But they don't provide vision and you know, I know our teeth are important. Well we can eat without teeth. Seeing is more important than eating with teeth ....most of us here wear glasses ... the lenses was \$400 ....Just the lenses.

Although this participant was glad to receive dental insurance through her employer, paying for her glasses was a barrier.

Participant 20 (covered by private insurance) described barriers to achieving her fertility goals because of the limitations of her insurance coverage. When asked what this participant would have done in her quest to fulfill her fertility desires, if cost had not been a concern, she stated:

I would've probably done in vitro then ... it wouldn't have probably been, it wouldn't have even been a thought ....I would have done that ... even after with a tubal ligation, I would have probably had the reversal and possibly the in vitro then.

This participant continued to express her wish that insurance covered more fertility services:

But there's so much, they don't cover. Insurance, if insurance would just cover more stuff. .... Even the Clomid [a treatment for infertility] is really expensive ... I mean, nothing was, was cheap. And then even if you can get Clomid, will, your insurance cover it And that's the simple stuff as simple as far as infertility, it's taking a pill, but then your insurance just sometimes won't cover any kind of infertility treatments.

This participant was also trying to get weight loss surgery, and wished that insurance would cover it:

I been trying to get the weight loss surgery, but ... our insurance won't cover. For the sleeve ....it doesn't make any sense because then you're going to pay for, in most cases, diabetic treatment forever. Or pay for high blood pressure treatment, heart disease instead of paying for maybe a little one-time surgery that will probably knock all of those things out. Are they backwards?

This participant pointed out that this was a short-sighted approach for her insurance company to take, since without the surgery they would continue to pay for other forms of treatment to manage the health conditions caused by her weight. Different plans cover varying services at a range of levels, and clearly a need exists for a more comprehensive range of services to be available to meet the needs of tribal members.

**Limited Choice of Providers.** In addition to limited coverage of services and treatments, participants also reported limited choices in providers and specialists due to their insurance networks or lack of insurance, sometimes resulting in receipt of sub-standard care. Participant 3 (covered by private insurance) felt that without insurance, tribal members were forced to go to doctors that didn't care and didn't prioritize their patients: "People do not have the funds to go to doctors. The doctors who they go to in some cases, don't really care ... It is like they have to hurry you through." Participant 25 (covered by private insurance, but describing a time in life when she had Medicaid) felt that because she had to go to a training hospital where their Medicaid coverage was accepted, the care she received was poorer and the attending providers were inconsistent:

All the times that I've been ... to see the doctor. It was almost like a new doctor's appointment every[time]... new physician every time, you know, cause it's a training hospital or whatever. So just a new

physician and they starting off fresh, not looking at what was previously done for these patients.

Because choice in providers was limited, participants felt the quality of their care suffered, reporting negative interactions with providers and no continuity of care.

Participant 15 (covered by private insurance) described being robbed of her autonomy when she was denied a choice in picking her doctor due to unforeseen and expensive complications during childbirth. Even though she had pre-paid for the delivery of her child, because she had a premature delivery, this participant was unexpectedly transferred to the local free hospital:

The hospital was paying the, you know, that I had paid, prepaid couldn't deliver the baby because they didn't know for sure if he was five pounds. So they transferred me to the charity hospital here in [name omitted], waiting on me to get through to become a state case and once the state would take over they would have sent me to [nearby city] ... because the cost of delivery for what the type of delivery I had was \$60,000 ....If I'd have stayed at ... the private, private hospital and not the charity hospital ....You know, my, my specialist said, you know, we cannot, I can't ask you to pay \$60,000 when I can call someone at the hospital here, at the charity hospital and transfer you by ambulance.

Participant 25 (covered by private insurance) described needing to pay out of pocket for fertility specialists, although she had insurance: "I was paying out of pocket ... I had insurance, but I was paying the insurance [out of] pocket. Cause I needed it to be able to see my fertility doctors and things like that." As this theme demonstrates, one's ability to select and access a preferred provider, especially in the case of specialists, was dependent upon their type and level of insurance coverage.

Participant 20 (covered by private insurance) expressed her preference for more holistic doctors and felt that this would increase the number of tribal members willing to go to see Western doctors with holistic training/approaches, but noted that many times those doctors would not be covered by insurance: "If they [tribal members] can be exposed more to holistic doctors, or at least have that option, that option is not always available."

Different types of insurance coverage also provided varying levels of access to appointments with preferred providers. Participant 17 stated that she has an easier time scheduling appointments in a timely manner now that she has Medicare: "The only problem that I had is like the clinics were hard to get into ....especially, the urology clinic. Now I have ... Medicare. So, I went to a private [town name] orthopedic and they took real good care of me." In contrast, Participant 20 (covered by private insurance) felt that her mother now had worse coverage now that she had Medicare: "It'll take her months before she gets appointments."

This participant also went on to describe their difficulty in finding and seeing a fertility specialist, and in having it covered by insurance:

There are not very many fertility specialists in this area ....[and] it's not always affordable to be able to see the fertility specialist. Insurance doesn't always cover it ... It's, it's, it's not cheap ... we were able to see the regular gynecologist. We didn't have to get to the point to see the specialist. But ... I know one girl, she has to see ....the specialist for the Polycystic ovaries. But so many people that have polycystic ovaries are not able to access the health care to be able to have children. Because I mean, I guess you have to see this specialist and insurance doesn't always cover those things, they'll cover Viagra, but they don't want to cover birth control ....fertility treatments are, it's, it's expensive ....My insurance now will not cover it.

These experiences in seeking care demonstrate the ways that limitations in services, treatment, and providers accumulate to disadvantage patients and severely restrict their healthcare options.

## 5. Discussion

This analysis of how health insurance coverage impacts the healthcare experiences of Indigenous women in a non-federally recognized tribe revealed the strong influence of economic factors on women's healthcare experiences. Women experienced discrimination within healthcare settings based on perceived ability to pay and reported significant limitations in the type, frequency, and quality of care they received due to inadequate health insurance coverage that shifted responsibility to pay onto the insured. This is consistent with a socio-ecological framework in which a woman's individual choices are impacted by the larger system of which she is a part. Socio-ecological theory also allows for an analysis of how structural barriers, such as poverty and discrimination, impact different sub-systems. This helps to explain, for example, how inadequate health insurance coverage impacts rates of engaging in preventative medical care.

Discrimination based on perceived ability to pay in healthcare contexts was mentioned frequently by participants. In many cases, individuals connected lower quality healthcare to their enrollment in Medicaid. This is supported by previous research stating that Medicaid patients frequently have healthcare experiences that are less respectful, and of lower quality than those experienced by patients covered by private insurance (Morris, 1997; Ostrom et al., 2017; Weech-Maldonado et al., 2012). This may in part occur because of perceptions about caps on the reimbursement for services under Medicaid, making providers feel disincentivized from spending additional time with those patients (Morris, 1997). Furthermore, health research has shown that women of color frequently see providers who are of a different race and class from their own, which is not surprising considering that physicians in the U.S. tend to be White and/or Middle/Upper-class (Street, 2007; Van Ryn & Burke, 2000). Researchers have also found evidence of provider bias against lower-income and racially marginalized patients compared to higher-income or White patients, which negatively influences the quality of care that Medicaid patients, who are more likely to be low-income racial minorities, receive (Street, 2007; Van Ryn & Burke, 2000).

These experiences were severe enough to impact some women's willingness to seek services from particular providers in the future. Participants highlighted the substandard care those without good private insurance received as result of bias. In formal medical education and training for providers, there is a lack of education on implicit bias, such as how to identify and reduce it in clinical settings. Implicit bias is present among a significant amount of healthcare professionals and leads to negative patient outcomes (Crawford, 2020). This led the American Academy of Family Physicians, in 2020, to introduce The EveryONE Project's Implicit Bias Training Guide, implemented to increase awareness on the topic, provide resources for providers and their healthcare teams, and to hopefully reduce negative patient outcomes (Crawford, 2020). Physician bias is a widespread factor affecting patient treatment and their outcomes, and culturally-specific interventions should be developed to address this issue. In healthcare settings, women reported being treated differently depending on their age, marital status, and insurance status, as documented by Participant 15, who described her daughter being mistreated by healthcare staff because of their perception that she was a poor, single mother. This example indicates that Indigenous women are most likely impacted by multiple factors, including their race, gender, age, marital status, and type of insurance in healthcare settings.

Although other research with this tribe has documented experiences of racial discrimination, particularly in educational settings, in this study, the majority of participants explicitly noted that they did not feel their negative experiences related to healthcare were racially motivated, although they similarly noted the broader issues of racial discrimination in the community McKinley et al. (2019). However, it is also important to acknowledge how issues of race and class are frequently intertwined, and how oppression based on race often has negative economic implications (Nazroo, 2003). In addition, participants were impacted by the racism

inherent in the federal-recognition process, which continues to deny federal-recognition to this tribe (Paschal, 1991). One of the benefits of federal recognition includes access to IHS, which, despite concerning criticisms of its provision of care, is an important and free source of healthcare for federally recognized tribal members (Gurr, 2014).

Participants' experiences in utilizing health insurance to access various forms of healthcare demonstrate the important role that economic factors play in healthcare access. Even with insurance, difficulties understanding coverage limitations, inadequate care leading to high out-of-pocket costs, and limited choices of providers were frequently identified as barriers to accessing care. Some women reported considerable difficulty in ascertaining which services would be covered and to what extent, which speaks to the complexity of health insurance plans. Many Americans lack a basic understanding of health insurance terms and details, which is required to successfully navigate one's health care choices (Tipirneni et al., 2018). Low-income populations and racial/ethnic minorities are more likely to have low health insurance literacy, which can lead to delaying or foregoing medical care (Tipirneni et al., 2018).

Within this tribe, educational discrimination prohibiting some tribal members from attending either Black or White schools (Bates, 2016) has led to limited educational opportunities, in addition to contributing to the need for healthcare literacy. Our findings suggest that improved health insurance literacy within the study population may limit the impact of economic barriers on healthcare access and utilization for insured tribal members, as research has shown that higher health insurance literacy is associated with "a lower likelihood of delayed or foregone care owing to cost for both preventive and non-preventive care" (Tipirneni et al., 2018, p. 1).

Additionally, participants noted that their insurance coverage was not comprehensive, leaving gaps in mental health, dental, and vision services. Tribal members shared the perspective that not having access to these essential services jeopardized their health, causing some people to forego care due to cost. Medicaid and traditional Medicare do not cover dental, vision, and hearing services, leaving significant gaps in care for enrollees (Katch & Van de Water, 2020, December 8; Willink, 2019) that need to be addressed through policy change. Some of the difficulty in accessing these services may be attributable to a lack of healthcare providers who accept varying forms of insurance in their area. The limited providers available may not accept Medicaid or Medicare (often due to low reimbursement rates) or may be out of network for private health insurance, making it difficult for tribal members to access services that will be covered.

Participant reports of being unable to access certain medications, services, and providers, due to coverage limitations and/or high costs, suggest that healthcare coverage alone is insufficient in assisting Indigenous women to meet their healthcare needs. These findings indicate that the right to receive high-quality healthcare, regardless of one's insurance status, is being undermined by structural barriers, including poverty and healthcare policy in the U.S. Although the Affordable Care Act (ACA) made significant strides in increasing access to and affordability of health insurance coverage, significant gaps remain (Galvani et al., 2020; Sommers, 2020).

Women frequently reported having to pay high out-of-pocket costs due to inadequate health insurance coverage for needed medications, treatments, and office visits.

As these findings illustrate, even those with health insurance often face economic barriers to receiving care, due to inadequate coverage, also known as being underinsured (Sommers, 2020). Low-income individuals are more likely to face financial barriers to care, as the combination of insurance premiums, high out-of-pocket costs and large deductibles represents a significant portion of their income (Galvani et al., 2020; Sommers, 2020). These findings illustrate how the continuing impacts of colonization, which has often led to disproportionate poverty rates for Indigenous groups, are then compounded by the current health insurance system.



Lack of federal recognition was an additional issue mentioned by participants, highlighting the impact of structural barriers which prevent tribes from receiving the benefits of recognition. Tribal participants experienced discrimination based on their Indigenous identity, but were unable to gain the formal benefits, such as healthcare, that come from being federally recognized tribal members. Increased resources and recognition of sovereignty of state-recognized tribes may be one important tool in addressing these barriers. Tribes which are federally-recognized receive additional resources for community centers, events, and outreach, which can also facilitate the health and wellbeing of tribal members (Crepelle, 2018; Fletcher, 2006).

### 5.1. Limitations and future research

Like other qualitative research, the findings of this study are not intended to be generalizable to other tribes. This study uses cross-sectional data, and future research would benefit from taking a longitudinal approach to assess changes in insurance status and experiences over time. Although many elder participants do not speak English as their primary language, interviews were only performed in English, which is an additional barrier. Further studies could include interviewing service providers to explore their views about the impact of insurance status and coverage on their patients. Additional research could also explore the impact of expanding healthcare coverage to cover services, such as midwives and doulas, or the use of Indigenous healers, as this may facilitate well-being and self-advocacy in healthcare settings (Ireland et al., 2019). In addition, although participants were asked about their current insurance status, in our interviews, participants described a range of healthcare experiences throughout their lifetime during which they may have had different insurance, or not had insurance. We tried to note this where relevant.

This study also did not compare federally and non-federally recognized tribal members and additional studies could more explicitly investigate similarities and differences in healthcare experiences between tribal members depending on recognition status. Comparative studies examining healthcare experiences amongst Indigenous women with differing forms of insurance coverage, particularly public versus private insurance, are also needed to elaborate on these findings. In addition, future research should explore how gender and race impact the experience of Indigenous patients in healthcare settings. Although the participants in this study did not explicitly describe these factors as impacting the type of care they received, and instead primarily focused on the role of type of insurance they had, previous research highlights the important role these factors may play (Street, 2007; Van Ryn & Burke, 2000).

## 6. Conclusion

Access to high-quality healthcare is an important tool in addressing the continuing health disparities experienced by Indigenous peoples. This research begins to address the existing gaps in knowledge related to the healthcare experiences of members of state-recognized tribes, who do not have access to IHS, and whose healthcare experiences have been infrequently explored. These findings indicate that inadequate healthcare coverage negatively impacted tribal member's ability to access quality healthcare services, and that members felt discrimination based on their perceived ability to pay. Contextualizing these findings within the socio-ecological framework highlights how economic barriers have negative impacts on health across all levels of the eco-system. To address these barriers, insurance coverage should be expanded for Indigenous peoples, especially those who are non-federally recognized, existing coverage should be more comprehensive to cover more services and providers, and out-of-pocket costs and deductibles must be reduced if

existing health disparities are to be meaningfully addressed. Additional improvements include the need for increased health insurance literacy and general improvements in the mechanisms through which patients can identify what services and providers are available through their insurance coverage.

### Ethics approval

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

### Funding

This work was supported by the Tulane School of Liberal Arts and the New Orleans Center for the Gulf South at Tulane University.

### Authors' contributions

The lead author (Jessica Liddell) conducted all aspects of the study conception and design. Material preparation, data collection and analysis were performed by Jessica Liddell. The manuscript was written in full by Jessica Liddell and Jenn Lilly.

### Availability of data and material

N/A.

### Code availability

N/A.

### Consent to participate

All participants completed informed consent before participating.

### Consent for publication

The lead author conducted all aspects of the study and consents for publication. Publication of data findings in a de-identified a format has been approved of by the tribal council.

### 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.

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