

“I Think [Western] Healthcare Fails Them”: Qualitative Perspectives of State-recognized Women Tribal Members on Elders’ Healthcare Access Experiences

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Abstract: Elder tribal members are important cultural and spiritual leaders and experts among many American Indian and Alaska Native (AI/AN) cultures. AI/AN Elders play a key role in the maintenance and transmission of traditional cultural knowledge and practices and are highly valued members of AI/AN communities. AI/AN populations face disparities in healthcare outcomes, and the healthcare needs of AI/AN Elders remain an understudied area of research, particularly among tribes in the South and for tribes who do not have federal recognition. Qualitative data was collected through semi-structured interviews among 31 women, all of whom are members of a state-recognized Tribe in the Southern United States. While the interview questions were specific to their own reproductive healthcare experiences, repeated concerns were voiced by the women regarding the health of the Elders in their community. Key findings captured several concerns/barriers regarding Elders’ healthcare experiences including: (a) Language and communication barriers between Elders and healthcare workers; (b) Prior negative experiences with Western medicine; (c) Lasting impacts of educational discrimination; (d) Concerns over self-invalidation; (e) Transportation barriers; and (f) Need for community programs. Issues related to these barriers have resulted in a concern that Elders are not receiving the full benefit of and access to Western healthcare systems. The purpose of this analysis was to highlight the concerns voiced by women tribal members on the health and wellbeing of Elders in their community. Opportunities related to the importance of prioritizing and improving AI/AN Elders’ healthcare experiences and access are also described.

INTRODUCTION

American Indian and Alaska Native (AI/AN) Elders are people who have acquired wisdom through life experiences, education (a process of gaining skills, knowledge, and understanding), and reflection (Younging, 2018). Across AI/AN cultures, Elders play a vital role as carriers of cultural and historical knowledge, memories, and traditions (Kahn et al., 2016; Pace & Grenier, 2017; Viscogliosi et al., 2020). The importance of this role is amplified in the context of colonization and cultural genocide, in which European American governments enacted policies and practices aimed to eradicate AI/AN practices, traditions, communities, and worldviews (Grandbois & Sanders, 2012). The cultural value of Elders, and concerns about their healthcare access, became apparent while collecting qualitative data among women from a state-recognized Southern tribal community. While the interview questions were meant to capture data specific to the reproductive healthcare experiences of interviewees, the topic of Elders was frequently brought up by interviewees. This phenomenon is likely due to the shared sense of collective responsibility to community and the interconnectedness common among Indigenous paradigms (SAHMSA, 2009; Wilson, 2001). To honor the concerns raised by the women interviewees, an exploration of the perceived barriers to Elders' health is described here.

Many AI/AN Elders today have lived through the implementation of some of the most violent colonial policies, including boarding schools, relocation to urban spaces, and linguistic and cultural termination (Struthers & Lowe, 2003). These traumas are exacerbated by contemporary and ongoing racial and ethnic discrimination (Beltrán et al., 2018). Furthermore, these historical and contemporary traumas are associated with negative impacts on both mental and physical health, culminating in an overall decrease in life expectancy (Beltrán et al., 2018; Jaramillo et al., 2021; Jones, 2006, Goins & Pilkerton, 2010). The social consequences of settler colonialism contribute to adverse childhood experiences and adverse adult experiences among AI/AN populations. This environment leads to continued intergenerational health disparities (Warne & Lajimodiere, 2015). Because Elders play a key role in the intergenerational transmission of knowledge, this discrepancy in life expectancy implies drastic challenges to maintaining AI/AN community integrity and continuation of vital cultural practices.

Although research into health disparities among AI/AN communities has long focused on measurable outcomes such as rates of chronic disease, mental health disorders, and life expectancy (Oré et al., 2016), contemporary research has pointed to the value of examining the multilevel factors impacting the health of AI/AN peoples, including “the interplay of biopsychosocial factors

within a socioecological system influenced by detrimental historical and contemporary social determinants” (Oré et al., 2016, p. 134). These multilevel factors do more than influence health outcomes; they additionally influence AI/AN Elders’ ability and desire to access Western healthcare resources and to do so as informed, consenting participants (Jaramillo et al., 2021).

AI/AN Elders often experience significant barriers in accessing Western healthcare (Jacobs et al., 2019; Kim et al., 2012; Willging et al., 2018; 2021). AI/AN Elders have been shown to see doctors less frequently than their white counterparts (Kim et al., 2012), in part due to prior negative experiences with healthcare providers (Jaramillo et al., 2021). When they do access healthcare, AI/AN Elders face communication barriers that include language differences and culturally insensitive communication practices, as well as the challenges inherent in gaining fluency with complex healthcare systems (Kim et al., 2012; Jaramillo et al., 2021; Marrone, 2007; Willging et al., 2018). Another relevant barrier is the issue of self-invalidation, which involves the continual invalidation of one’s lived experience. (Grandbois & Sanders, 2012, p. 390). This may impact how often Elders seek care and how they participate in decisions related to their health. Additional concerns in accessing healthcare include geographic isolation from healthcare services (Jacobs et al., 2019; Kim et al., 2012; Marrone, 2007; Willging et al., 2018) and chronic underfunding of the Indian Health Service (IHS; Jacobs et al., 2019; Willging et al., 2021).

Research has indicated that many Elders prioritize the cultivation of interpersonal relationships and communal identities over the individualist concepts of identity in which Western healthcare is rooted (Grandbois & Sanders, 2009). Successful maintenance of these interpersonal connections and communal identities is a key aspect of resilience among AI/AN peoples and communities (Grandbois & Sanders, 2009; Kahn et al., 2016; Oré et al., 2016; Teufel-Shone et al., 2018). Thus, the individualist focus of Western healthcare may be insufficient to meet the needs of Elders if it fails to incorporate social and communal aspects of health and wellness (Beltrán et al., 2018).

AI/AN communities are continually impacted negatively by the impacts of colonization, especially regarding poor health outcomes and chronic disease disparities (Warne & Lajimodiere, 2015). Strong social networks and connections to culture play a vital role in fostering resilience among AI/AN communities, despite colonization (Teufel-Shone et al., 2018). Social connectedness is also an important factor in successful aging and correlates with better health outcomes (Pace & Grenier, 2017; Viscogliosi et al., 2020). Research has found that when Elders engage in social life, they effectively bolster individual, familial, and communal wellness as well

as the wellness of the Elders themselves (Viscogliosi et al., 2020). Social participation that includes opportunities for intergenerational transmission of knowledge correlates with increased resilience among both Elders and youth (Kahn et al., 2016; Teufel-Shone et al., 2018; Viscogliosi et al., 2017), bolsters Elders' physical health and cognitive functioning (Viscogliosi et al., 2017), and is associated with lower odds of memory problems (Adamsen et al., 2021).

While cultural and social connectedness are key dimensions of resilience among AI/AN Elders and contribute immensely to their overall health and wellbeing, Western healthcare continues to focus primarily on physical and, to a lesser extent, mental health treatments that do not treat health and wellbeing holistically (Jaramillo et al., 2021). Unfortunately, research into AI/AN Elders' healthcare needs continues to be sparse, and many studies utilize IHS data, which only includes federally recognized tribes, as state-recognized tribes are ineligible for IHS-funded healthcare services (IHS, n.d.). For this reason, there is a significant gap in research relating to the healthcare needs of Elders in tribes that are not federally recognized. Additionally, lack of federal recognition significantly reduces access to healthcare for state-recognized tribal members, especially care that is culturally appropriate (Jaramillo et al., 2021).

This study builds upon previous work exploring settler colonialism and the resilience of Indigenous people and is informed by the Framework of Historical Oppression, Resilience and Transcendence (FHORT; Burnette & Figley, 2017). This framework is important because it contextualizes current disparities within the context of historic and ongoing settler colonialism, while also emphasizing the agency and resilience of Indigenous people in the face of these experiences (Burnette & Figley, 2017). This framework also highlights the interconnectedness between many Indigenous people and holistic conceptualizations of wellness that include community, family, social, physical, mental, emotional, spiritual, and environmental wellbeing.

The initial aim of data collected in this study was to investigate reproductive healthcare perspectives of women from a state-recognized Tribe in the South. However, to account for the overwhelming emphasis on the concerns of the healthcare experiences of the Elders' in their community, an additional analysis was conducted of findings specific to the experiences of Elder community members. This study aims to take a step in ameliorating the research gaps of state-recognized Tribal Elders by examining the specific healthcare needs and concerns regarding AI/AN Elders from the perspective of women community members. Given the importance of Elders in AI/AN communities and given that the healthcare needs of this population remain an

understudied area of research, this study aims to provide a Tribe-specific glimpse into the issues that impact Elders' interactions and participation with Western healthcare.

METHODS

Research Design

The broader study through which these findings emerged focused on the reproductive and sexual healthcare experiences of women members of state-recognized tribe in the South. These findings are described in Buxbaum et al., 2022; Carlson & Liddell, 2022; Doria & Liddell, 2023; Hogan & Liddell, 2023; Liddell, 2020; Liddell & Kington, 2021; Liddell, 2022; Liddell & Lilly 2022a; Liddell & Lilly, 2022b; Liddell & McKinley, 2022; Liddell & Doria, 2022; Liddell & Herzberg, 2022; Liddell & Meyer, 2022; Liddell et al., 2022a; Liddell et al., 2022b; Liddell et al., 2022c; Liddell 2023; Reese, Liddell & Dang, 2023; Sheffield & Liddell, 2023. However, when describing healthcare access experiences, a recurring theme that emerged was the importance of caring for the health of Elders in the community, in addition to obstacles and barriers experienced by these Tribal members. We believed that these themes are important and that they highlight the holistic and interconnected way that health is conceptualized in many Indigenous communities. In addition, the unique healthcare experiences of Elder community members in this tribe have not been explored and are, in general, under-researched for non-federally recognized tribes, further highlighting the importance of exploring this topic.

The lead PI for this study is a non-Indigenous White woman who was completing their PhD at the time of this study. The second author is an Indigenous PhD student, although not a member of the Tribe in this study. Both authors focus their scholarship on reproductive justice issues and topics and are committed to addressing health disparities. This study utilized a qualitative methodology and an investigative approach through semi-structured interviews utilizing questions following a life-course trajectory (Sullivan-Bolyai et al., 2005). This methodology has been successful in prior research with [Tribe name removed to protect confidentiality] and is a culturally competent research approach for working with Indigenous peoples (Burnette et al., 2014; McKinley et al., 2019). Additionally, this approach was pursued as it resists the possible colonizing influences of researcher interpretation by allowing participants to narrate and interpret their own lives, thereby preserving cultural nuances while maintaining the integrity of individual participants' voices (Creswell, 2007; Sullivan-Bolyai et al., 2005).

Prior to beginning this study, approval was received from the tribal council's internal review board as well as Tulane University's Institutional Review Board. Two women who identified as members of the Tribe composed our community advisory board (CAB) and worked with us throughout our study. The CAB members were both leaders in the Tribe who have worked previously with scholars doing research with the Tribe. The CAB assisted in recruiting participants, developing appropriate interview questions, and disseminating study findings. The CAB also helped to ensure that the research methods utilized were appropriate as well as culturally relevant. Out of respect for the need to conduct culturally competent research with Indigenous peoples and communities, agreements were made with this Tribe's council to maintain confidentiality regarding the Tribe's identity (Burnette et al., 2014). Written approval for the project was formally granted by the tribal council after a presentation on the project, discussion with tribal members, and a formal vote by the tribal council. Following the recommendations of the CAB, participants were assigned an ID number rather than a pseudonym. While many researchers utilize pseudonyms in qualitative research, others critique this practice as the assignment of pseudonyms presents a danger of researcher bias and because pseudonyms may not feel authentic for many participants (Allen & Wiles, 2016; Corden & Sainsbury, 2006).

Setting

All participants of this study were members of one specific state-recognized, Southern Tribe. The physical area where this Tribe is located has been affected significantly by climate change and land loss. Members of this Tribe have been negatively impacted socially and economically by factors such as forced relocation and educational discrimination. Additionally, this Tribe has been denied federal recognition, which has limited their access to resources. As noted in previous research with this Tribe, and reflected in the study findings, cultural values important to this Tribe include generosity, self-sufficiency, familial ties, and advocating for one another (McKinley et al., 2019).

Many Elders of this Tribe speak a different language other than English as their first language and are not as fluent in English (Maldonado, 2014). Among Elders that do speak English, literacy can be a challenge. Many Elders of this Tribe grew up during the Jim Crow era in which schools were segregated based on membership within one of two racial groups. This educational discrimination meant some tribal members were unable to attend either Black or White schools, limiting their access to English literacy (Maldonado, 2014). These literacy conditions make it

especially difficult to understand and communicate about complex medical terminology (Maldonado, 2014).

This particular Tribe has a matrilineal heritage (McKinley et al., 2019; Vinyeta et al., 2016) and women often act as caregivers for their extended family. Additionally, this Tribe maintains traditional healing practices, using prayers and natural medicines in healing illnesses (McKinley et al., 2019). However, some healing practices have become less common due to changes in intergenerational transmission of knowledge and likely due to environmental changes as well (Johnson & Clark, 2004; Maldonado, 2014). Thus, Elders who hold knowledge of these practices may be the only connection that younger generations have to these culturally significant traditions. Currently, most healthcare providers for tribal members are non-Indigenous and tribal members must access healthcare services at non-tribally run healthcare facilities. The tribe does not currently provide healthcare services, although affiliated programs offering dental care and other health services are sometimes offered through partnerships with other health entities in the state. The healthcare access experiences, particularly those related to insurance and healthcare access, are described in more depth in (Liddell & Lilly, 2022a; 2022b).

Participants

Both purposive and snowball sampling strategies were utilized to recruit participants. The CAB assisted with recruitment, sharing and posting flyers advertising the study at tribal community sites and with their social networks, and through word-of-mouth recruitment. Thirty-one women who met the inclusion criteria (self-identifying as women and as members of the tribe, and being over the age of 18) took part in semi-structured qualitative interviews with the first author. Proof of tribal enrollment was not required in consideration of the historical and contemporary challenges many tribal members face when asked to prove tribal membership (Cochran et al., 2008).

Data Collection and Analysis

All interviews were digitally recorded with participant consent by the first author (PI). Interview questions primarily concerned women's experiences with reproductive health. However, interviewees repeatedly brought up instances regarding the health of the Elders in their community, in addition to describing their own experiences accessing healthcare. Interviewees described both their experiences (as some of the interviewees were also Elders) in addition to describing the

experiences of Elders in their community. Example questions that were included are: “What health programs exist in the community? Can you tell me about your last experience seeing a doctor?” For a full list of interview questions please refer to Liddell & Kington, 2021. These interviews took place between October 2018 through February 2019, ranging from 30 to 90 minutes ($M = 66$ minutes). Interviews were conducted in tribal community buildings or in participants’ homes, whichever the participant found most appropriate. We followed the CAB’s recommendation of awarding a \$30 gift card to all participants as a thank you for their time. Every interview was transcribed verbatim, utilizing NVivo software to process and analyze data (QSR International, 2015).

For the scope of this study, we utilized qualitative content analysis, a type of data analysis frequently employed in qualitative descriptive research (Milne & Oberle, 2005). A strength of this approach is that it allows themes to arise directly from participant” words, while also being influenced by theory and previous scholarship (Milne & Oberle, 2005). The first author reviewed the recording of each interview three times, and afterward underwent an inductive coding process from the transcripts. A list of 157 broad themes and codes were derived from this coding process. The final coding scheme represents discrete codes refined from this initial list (Sullivan-Bolyai et al., 2005).

The research of this study followed Milne and Oberle’s (2005) research strategies of: (a) systematic, yet adaptable sampling; (b) encouragement for participants to express themselves openly and freely; (c) the use of accurate and verbatim transcripts; (d) utilizing participants’ own experiences and language to formulate coding; and (e) centering the analysis on context throughout. An invitation was extended to all participants to review and provide feedback on a summary of findings. Each participant received this summary of results more than once. The first author also presented findings at tribal events and tribal council meetings.

RESULTS

Participants in this study were women between 18 to 71 years old ($M = 51.71$). The majority of participants reported having health coverage (93.54%) as well as having one or more children (83.87%). On average, participants had two to three children. The average age women reported starting their families began around age 20. Additionally, the majority of women (87.1%) had their GED or a high school degree. Around half of the women (51.61%) had also completed educational training of some form beyond completion of high school or equivalent.

Twelve participants specifically identified the healthcare needs of Elders as being of particular concern and importance. Elder participants described their experiences in accessing healthcare and reflected on the experiences of other Elders in accessing healthcare. Participants who are non-Elders described the healthcare experiences they observed among tribal Elders. Women expressed concern for elderly community members, especially regarding their ability to access healthcare. However, it is important to note that women also described immense strength and resilience among Elders. Women also emphasized the important role family and community played in helping to support elder community members. Themes related to Elders' healthcare experiences included *Respect for Elders and concerns over loss of knowledge; Language and communication barriers between Elders and healthcare workers; Prior experiences with Western medicine; Lasting impacts of educational discrimination; Concerns over self-invalidation; Transportation barriers; and Need for community wellness programs.*

“We Heal Natural”: Respect for Elders and Concerns Over Loss of Knowledge

Participants described the respected and important role Elders held in the family and community, while stressing their concerns for Elders' health. Participant 25 (age 33) described the myriad health conditions experienced in the community and their effects on her immediate family:

We had 13 immediate family members die in our family within two years. My mom's dad and mom. Then my dad's mom, dad, and brother... My grandmother died in the backseat of my car of a massive heart attack on the way to the hospital... My Dad's dad, brother and mom all died of [heart] attacks. My grandma, my mom's mom died of cancer, lung cancer. She found out the Friday and she died in her bed the Sunday. These were all like non-expected deaths. And then our grandpa died of, he had congestive heart failure, but we lost all of them. All four of my great grandmothers... All, pretty much unexpectedly.

Additionally, participants noted that loss of Elders would mean a loss of cultural knowledge. For Participant 1 (age 54), this loss of knowledge, specifically knowledge relating to traditional healing practices, made it imperative to learn from her Elders while she still could:

Yeah, like I know with her like that knowledge too... that's another thing that's getting lost... She knows a lot. But like my dad, her son, he doesn't know anything. We don't know

it. So after her, yeah, we don't know much of it... So it's like we need to talk to her while we can, use that knowledge while we can.

Participants also described the movement away from traditional healing practices as a shifting relationship with healthcare. Participant 15 (age 52) expressed particular concern over this change: "Today's age, I think it's too much um, emphasis on, on the doctors and that, you know, medicine is better for you [than local traditional healers], which I don't exactly agree." Participant 13 (age 56) described this change as an increased dependence on Western medicine:

We depend on medicine. We depend on running to the doctor. We depend more on, yeah, drugs than the healing of what God created our bodies for, because we heal natural, you know, cause then way, way back when, there was nothing, no doctors.

This participant speaks to the value of self-sufficiency. Additionally, this participant attributed this shift less to a loss of knowledge and more to a loss of morality. When asked if she thought traditional knowledge was being lost, she replied, "I find the morals are getting lost, but not the knowledge. The knowledge is... it's keeping up with time."

"They Can End Up Not Getting Treated": Language and Communication Barriers

Participants noted that when Elders go to the doctor, they face myriad communication barriers that impact their care. The need for doctors to speak French was identified as being especially important for older tribal community members, in addition to the need for doctors to use clear and understandable language with all patients. Participant 25 (age 33) stressed the ways language barriers impede access to quality healthcare:

Most of our Elders only speak French, very little English to understand, you know? Like you given them this medication... if the doctors don't talk and you on this medication but they didn't tell you that you aren't supposed to take it if you want this other medication. There's a lot of side effects for that."

Many Elders spoke English as a second language, and in some cases, this was a barrier in seeking care. Participant 12 (age 68) described this: "They still have some that has a barrier with speaking English ... because they won't understand everything." Participant 20 (age 43) also felt

that not only did Elders sometimes struggle with English, but also that healthcare providers use often overly technical language:

[Language] that's too complicated, they [Elders] don't understand it and the doctors don't understand them and then they can end up not getting treated or they get treated for something they don't even have ... But sometimes they don't always have their families there ... I'm sure they do their best to be there, but ... I think they need someone on staff, just the same. To deal with our Elders... You know, they don't have somebody there with them who can, um, who can really [communicate] what's wrong with them.

Besides the language barriers presented when few medical providers speak French, women expressed further communication barriers that reveal cultural differences in patterns of dialogue between providers and Elders. Participants stressed the need for healthcare providers to spend more time with Elders and to ask questions in order to ensure their needs are addressed. Participant 25 (age 33) in particular felt that the healthcare system failed to adequately serve Elders: "I think [Western] healthcare fails them ... especially for our Elders ... I think it's just the time and that they want to put a patch on everything and hope that it gets better or something."

"Her Blood Pressure Would Go Sky High": Prior Experiences with Western Healthcare

As seen above, Participant 25 (age 33) identified distrust as a probable cause of Elders' reticence to communicate their healthcare needs. Additionally, Participant 17 (age 71) spoke to the ways that language and transportation barriers may lead to experiences of alienation, isolation, and distrust in the Western healthcare system when she described an experience in which her mother had difficulty getting a translator who could communicate in French. Not only did she lack access to a staff member she could speak to, she was also alone. This participant describes some of the barriers that prevented her mother from having family with her and the long-lasting impact this had on her mother's relationship to Western healthcare systems:

Because of the barrier of transportation ... and it's like, you know, you didn't have no rides to go and come, being far... she stayed over there by herself.... Cause my Mama was... she was nervous, and I guess whenever she had to go to the doctor, like even for a checkup, I mean her blood pressure would go sky high. And she was, I guess, you know, from being

by herself and stuff, it maybe reminded her of that, and you know, her blood pressure would go high. And then after when she would come home it would go down.

This participant describes her mother giving birth alone and having to recover by herself in a hospital away from her home and community and without the benefit of staff and providers who could speak to her in French. This participant also identifies her mother's high blood pressure as an indicator of the stress associated with Western healthcare.

Previous experiences of poor treatment contributed to other Elders' resistance to utilizing Western healthcare services as well. Participant 1 (age 54) described the poor treatment her father received and how it almost caused him to die:

My Dad had blood in the stool ... And he [the doctor] ... didn't tell my dad he needed a colonoscopy ... my dad had never had a colonoscopy ... The doctor should tell you when's your annual, because I didn't know... They don't tell you.

“They Get Dismissed a Lot”: Lasting Impacts of Educational Discrimination

AI/AN Elders face additional challenges in interacting with mostly white medical professionals. Some participants spoke about Elders' erasure from educational systems during the Jim Crow era. Participant 3 (age 71) described her mother's embarrassment about being unable to read or write due to this history of educational discrimination. Participant 10 (age 31) described some of the stigma experienced by Elders in healthcare settings, especially by those who were unable to read or write:

We had someone call here one day and I can't remember what the healthcare facility was, but I think it was in [area name]... And this woman's like, oh yeah. So we got a guy here, he says he's [tribal name]. Um, and I was just wondering if you had any services that could help him. I was like, okay, tell me a little bit about a situation that's going on. And then she's like, oh, well he can't read, so that shows some developmental disabilities. And I'm like, is he in your office? And she's like, yeah, he's sitting across from my desk. I was like.... I was like, please send him over here right now. He was like an older gentleman and so he came over and we, we got him some assistance. But I think just that mentality, like people don't understand the history of the [region] and I think, oh, people just, they're dumb. And so, I think they [Elders] get dismissed a lot.

In addition to educational discrimination, participants also noted that some Elders have their concerns dismissed by healthcare providers for unclear reasons, sometimes with dire consequences. Participant 25 (age 33) described her grandfather's experience being shuffled around the healthcare system:

“My dad's dad had been going to the doctor saying something's wrong, something is wrong, something is wrong, but they would just push him over to another doctor... Finally he had a stress test for the next morning and died in his bed that night.”

“Whatever the Doctor Says, They Do”: Concerns Over Self-Invalidation

Participants raised concerns over the ways some Elders defer to medical professionals' judgement without speaking to their own health concerns or needs. Participant 1 (age 54) noted the detrimental effects on community health when Elders and other community members put too much trust in medical systems that focus on treating symptoms without concern for the possible dangers therein:

Oh, the heroin right now... people that's older than me... they're hooked... Two of my cousins took me out and we were talking about [their] mama... she believed whatever the doctors say. She's an older person... and whatever the doctor give her, she's going to take. She had faith in the doctor... She got hooked and the doctors did it.

Participant 25 (age 33) also addressed the ways Elders defer to providers' judgement, often at the expense of trusting and validating their own experiences with their health:

They [the Elders] go to the doctor and whatever the doctor says, they do. And that's not always the case because you know your body a little bit more than, you know, the doctor only, and they're not, a lot of our Elders aren't open when they go to the doctor. [They say] “Oh I'm fine.” So the doctor can't really fully treat you if they don't know all the reasons or what's really going on.... [when asked why this occurs] It may be a trust issue... That's probably the main cause though.

“She Stayed by Herself”: Transportation Barriers and Community Support

Although some participants felt that access to reliable transportation was an important need for Elders, others noted the ways extended family and community members often stepped in to fill

this gap. Participant 17 (age 71) believed that transportation was a barrier, noting that Elders might otherwise be less self-sufficient: “Some of them are, like the older ones... some of them rely on, still on, they got that little bus... that bring 'em and so maybe transportation or some of them get to an age where they don't drive and you gotta have somebody to drive you.” Conversely, Participant 29 (age 42) felt that there were ample supports in place for Elders, while also noting that there may be community members without sufficient social supports:

Transportation is a big one ... if you're an Elder ... and you don't have transportation, you have to, uh, you know, there's the council on aging bus that you have, but you have to qualify for that and then they'll come pick you up and bring you to your appointments... but I don't think, from my experience, I don't think that the transportation is a big one for people that I know. Because people have big families... And you know, it's like, hey, can you take me to my appointment?... But if you don't have a family, which is kind of rare, or you didn't have any children to help you, you know?

Because medical services often exist outside of Indigenous communities, older community members and their families must travel a long way to access these services. As Participant 17 (age 71) noted in her description of her mother's experience, transportation is not only a barrier to accessing services but additionally impacts Elders' social connectedness: “Because of the barrier of transportation ... she stayed over there by herself.”

“They Put Them on So Much Medicine”: Need for Community Wellness Programs

Many participants described the ways community wellness programs might offer better preventive medicine, while bridging the divide between Western healthcare settings and their own community. Participant 23 (age 56) suggested providing community-based health fairs as well as integrating healthcare into existing community events: “The Tribe itself can hold more health fairs... And like when we have the Elder's fest, maybe have tables there and more people, um, offering screenings... that's something they could [do].”

Additionally, participants felt that health education might enable Elders to extend their quality of life. Participant 6 (age 52) noted the ways that education on topics of health and wellness might act as preventive medicine and reduce the number of medications Elders use:

Some of the [medicine] they're taking, it's just messing the old people up. A lot of them don't even remember what they do no more and back in the day, those people used to live long and still know what they're doing. These days, well I think it's all the medicine they are taking. They put them on so much medicine, they give medicine for this and then all of a sudden the medicine is working opposite on this and they've got to get them on medicine for this. And I think people need to learn how to eat properly and have a program where they could teach them... where they can learn how to eat right.

This participant stressed that Elders often experience negative side-effects to Western medicines. Because of this and other factors, many participants spoke to the value of alternative forms of healthcare. Participant 29 (age 42) described a community wellness center that had since lost most of its funding but continues to operate at reduced capacity: "We have a wellness center next door. Um, people go in there and they can, um, do the detox. Um, they can do acupuncture... they can get their blood pressure checked... it's great." Importantly, this participant also noted the value of wellness programs that go beyond Western definitions of healthcare: "We had tried to get someone to come do massages... like a student. Um, but it just, there weren't funds available to have them come in... But that would've been great too, it is part of wellness."

DISCUSSION

Given the significance of AI/AN Elders among communities and their roles in the transmission of knowledge and practices that, due to the forces of colonization, are at risk of disappearing, this study sought to examine Elders' experiences with Western healthcare systems perceived by women in their community. Overall women discussed their concern for the health of older community members and the healthcare barriers experienced by Elder tribal members. This is consistent with research done among other tribes showing that attention to the unique needs of AI/AN Elders is needed (Jaramillo & Willging, 2021; Thomas, 2011). The concern expressed by interviewees for other tribal members is also consistent with AI/AN values of taking care of vulnerable community members and respecting Elders (McKinley et al., 2019; Pace & Grenier, 2017).

Many participants expressed concerns that language and communication barriers impeded respectful treatment of Elders in healthcare settings, while stressing that healthcare providers often communicate in ways that undermine Elders' ability to access and understand healthcare. These

barriers reveal the need for multilevel approaches. On the individual level, Elders must have access to the resources and education they need to successfully navigate healthcare systems as consenting, informed participants (Jaramillo et al., 2021). On the systemic level, healthcare systems must ensure that providers – particularly those who identify with the majority population – have the training, education, and time needed to cultivate an ongoing practice of cultural humility (Jaramillo et al., 2021; McKinley et al., 2019; Walters & Simoni, 2002).

Unfortunately, there are currently no requirements that healthcare providers develop cultural competence or humility in working with AI/AN populations (Cordova-Marks et al., 2020). Elders in this study continue to experience the lasting impact of prior negative experiences with Western healthcare systems. Participants underscored the ways that negative experiences such as poor treatment and isolation, coupled with historical and present-day discrimination, have undermined Elders' trust in Western healthcare. This mistrust contributes to Elders' reticence to engage with Western healthcare and illuminates the pressing need to address issues of discrimination, poor treatment, and isolation among healthcare organizations and in policy (Jaramillo et al., 2021; Jaramillo & Willging, 2021).

However, participants also expressed concerns that Elders put too much trust in medical providers. While this may seem to present a paradox between trust and mistrust, the two may be differing reactions to the same issue. According to literature on the topic, “self-invalidation” occurs when an individual lives in an environment that continually invalidates their lived experiences, resulting in an internalized “tendency to invalidate affective experiences [and] to look to others for accurate reflections of external reality” (Grandbois & Sanders, 2012, p. 390). Thus, previous experiences of poor treatment may cause Elders to either avoid seeking treatment or to defer to providers at the expense of their own health, indicating a need for providers to engage Elders in making decisions regarding their medical care (Jacobs et al., 2019).

Processes of self-invalidation may additionally account for women's concerns that Elders' reliance upon Western healthcare often comes at the expense of traditional healing practices and cultural concepts of health and wellness. Contemporary literature suggests that Western healthcare fails to include holistic concepts of health and wellness common among AI/AN communities, instead opting for an approach that is “deficit-oriented, individual-focused, and decontextualized” (Oré et al., 2016, p. 150; Pace & Grenier, 2017). In eschewing AI/AN resilience, community values, and historical and cultural contexts, Western healthcare continually fails to address chronic health conditions among this population (Beltrán et al., 2018; Oré et al., 2016). According to

participants, Elders' reliance on deficit-oriented systems of healthcare, which disregard "the role of historical trauma and resulting disruptions in traditional health practices," often has drastic consequences, such as addiction, lack of treatment, and over-medication (Beltrán et al., 2018, p. 118). These outcomes indicate a need for culturally relevant, integrated healthcare interventions.

Healthcare interventions developed by and tailored to AI/AN communities may ameliorate some of the issues participants discussed. Many participants discussed concerns about Elders' ability to navigate complex healthcare systems. Research suggests that AI/AN Elders are better able to understand and access healthcare when they play an active role in the development and delivery of these services (Viscogliosi et al., 2020; Willging et al., 2018). Providing opportunities for Elders to act as leaders in healthcare settings and to collaborate on cultural sensitivity curricula for providers may offer a space in which knowledge is shared reciprocally between Elders and providers, leading to improved cultural competence among providers and increased health-related self-efficacy among Elders (Cross et al., 2021).

However, some participants stressed the need for community-based programs aimed at promoting health and wellness. Community-based models of health and wellness programming often integrate Western health-related knowledge into the context of AI/AN culture, history, and traditional knowledge. In these community-based settings, Elders have the opportunity to come together with younger generations and share their knowledge and wisdom, fostering reciprocal relationships in which knowledge is shared among generations, thereby leading to better health outcomes for all (Beltrán et al., 2018; Kahn et al., 2016).

Community wellness programs in which Elders can act as leaders show additional promise in mitigating some of the barriers brought up by participants, such as communication and transportation barriers, and have the added benefit of fostering social connectedness. Research has shown that across populations, social connectedness correlates with better health outcomes (Pace & Grenier, 2017; Viscogliosi et al., 2020). Thus, community-based health and wellness programs may serve a variety of functions in meeting Elders' healthcare needs.

Limitations and Future Research

While this study takes a step toward addressing the research gaps in the area of AI/AN Elder healthcare concerns, findings of this study came from the broader perspectives of women in the Tribe rather than exclusively from Elders themselves, although some of the women in the study were also Elders. Further research should be done that offers Elders opportunities to frame their own

experiences with healthcare and that specifically focuses on their healthcare experiences. Comparing women's perspectives with those of Elders may additionally reveal insights that otherwise are overlooked. Additionally, this study does not include the perceptions of male tribal members, which may provide unique perspectives on the experience of Elders' and Western healthcare. While the primary focus of this study was women tribal members' reproductive healthcare experiences, the experiences of Elders were repeatedly brought up by participants. This might also be a strength, since concerns about Elders' health emerged without prompting, indicating this was of particular importance to women in this study. Further limitations of this study include its use of cross sectional, rather than longitudinal, data. Future research should also explore the experiences of tribes in other regions, and both state and federally recognized tribes, as great diversity among tribes exists, and these results will not be representative of other tribes. Future research in this area will contribute further to our understanding about Elders' unique healthcare needs.

CONCLUSION

There is a significant gap in the research regarding healthcare needs of AI/AN Elders, particularly among members of tribes in the South and of tribes that are not federally recognized. Although the study initially focused on the more general healthcare experiences of women tribal members, particularly in accessing reproductive and sexual healthcare, the importance of Elders and the unique barriers they experience in accessing healthcare emerged as an important topic described by participants. In this manuscript we explore the healthcare experiences of Elders as observed by women members of a state-recognized, Southern Tribe. Findings suggest that Elders' health is of prime importance to community members. However, language, communication, and transportation barriers exist that limit Elders' access to quality healthcare. In addressing these barriers, participants suggest that integrated, community-based health and wellness programs might provide educational opportunities regarding healthcare, while allowing Elders to play an active role in community wellness and fostering intergenerational social connectedness. Healthcare facilities outside of the community can address these barriers by utilizing Shared Decision Making (SDM) models. Engagement in SDM with Indigenous patients has shown to decrease anxiety and increase the level of trust with physicians (Groot et al., 2020). This is an important component in dissipating the mistrust of Western healthcare systems created through settler colonialism.

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CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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