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# American Indian and Alaska Native Mental Health Research

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# Psychological Impacts of Historic Loss and Current Events Surrounding American Indian Boarding Schools

Kaitlyn Sebwenna-Painter, BA, Amoneeta Beckstein, PhD, and Sue Kraus, PhD

*Abstract: Historic loss and historic loss-associated symptoms were examined in a cross-section of 60 American Indian and Alaska Native students attending a Native American serving college that is also a former Indian boarding school. To measure awareness of current events regarding finding unmarked graves at boarding schools, authors developed and used the Truth and Reconciliation Scale. Levels of self-compassion were assessed in participants to determine if there was a correlation between negative feelings towards oneself and psychological risk factors brought forth as a result of how aware students were of current events surrounding former Indian boarding schools. Self-compassion was predicted to act as a protective factor and a positive coping mechanism for those most impacted by historic loss and intergenerational trauma. Participants reported thinking about, and being psychologically impacted by, historic loss. Psychological impacts were stronger in participants who were more aware of current reconciliation efforts and those who had higher levels of negative thoughts towards themselves. This suggests the possibility that current events, such as the finding of unmarked graves at former Indian boarding schools, might be increasing trauma responses in current students. Working to reduce negative thoughts about self and increase self-compassion may help buffer the negative impacts of the current truth and reconciliation work. Researchers and practitioners are encouraged to engage in more research and practice exploring the potential benefits of self-compassion for those adversely affected by historic loss, thus improving the likelihood of cultural revitalization from a broad perspective.*



## INTRODUCTION

Multigenerational trauma can be defined as the implicit impacts of trauma across generations in a familial line, as well as across cultural and communal lines (Danieli, 2007). The implications of multigenerational trauma arise when a family member has experienced a traumatic event, a series of traumatic events, or when multiple family members have experienced collective trauma. Trauma that has transgressed through generations can psychologically affect an individual's experience interpersonally and systemically (Chou & Buchanan, 2021). American Indians and Alaska Natives (AI/AN), as well as other Indigenous peoples in North America, have experienced mass trauma as a result of colonialism and cultural genocide (Brave Heart [*Hunkpapa* and *Oglala Lakota*]<sup>1</sup> et al., 2011; Pember [*Ojibwe*], 2016). Loss of land, culture, values, and traditions have been shown to heighten negative coping factors such as suicide, domestic violence, childhood violence, substance misuse, depression, low self-esteem, post-traumatic stress disorder (PTSD), and ancestral suffering (Altaha [*White Mountain Apache*] & Kraus, 2012; Brave Heart & DeBruyn, 1998).

In 1819, the Civilization Fund Act was put into place to prevent the transmission of Native American knowledge from Native families to their children (Pember, 2016). Shortly after the Indian Boarding School systems were established in 1824 in the United States, the Bureau of Indian Affairs (BIA) set out to standardize compulsory Western education amongst AI/AN communities (Brave Heart & DeBruyn, 1998). To give a sense of how ubiquitous this practice of using boarding schools to educate AI/AN children, it has been reported that by 1926 the majority (over 80%) of AI/AN children were attending boarding schools (Adams, 1995 as cited in The National Native American Boarding School Healing Coalition, n.d.). There were a total of 408 federal Indian boarding schools and possibly over 1,000 other institutions that all had the intention of changing AI/AN identities (Newland, 2022). There are approximately 90 that continue to operate today to some capacity (Newland, 2022). The acts of forced assimilation committed at boarding schools include, but are not limited to, punishment for children speaking their Native languages, destruction of traditional clothing, the removal of children's long hair stripping away their cultural pride, child abuse by school staff, lack of sufficient medical care, the absence of family contact, and even death (Pember, 2016). The historic loss of culture has resulted in

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<sup>1</sup> Alfred [Kanienkeha] (2009) recommends adding authors' tribal affiliations in-text as a small act of decolonization in recognition of their Indigenous status.

generations of AI/AN peoples being raised in communities that walk between the worlds of colonization and revitalization.

Prior to conducting the current study, some of the research on the intergenerational effects of boarding schools on individuals, families, and whole cultures was explored. Previous studies show that those who have experienced traumatic events or carry multigenerational trauma within them may lack or even fear self-compassion (Boykin et al., 2018; Germer & Neff, 2015; Winders et al., 2020; Zhang et al., 2021). Individuals living with low self-compassion levels are at a higher risk for negative behavioral patterns such as substance misuse (Phelps et al., 2018; Spillane [First Nations] et al., 2021), suicide, psychological distress, and dysregulated emotional effects (Chio et al., 2021; Dolezal et al., 2021), whereas those with high levels of self-compassion might have a higher chance of healing from historic loss and multigenerational trauma (Spillane et al., 2021). Cultivating self-compassion might serve as a protective factor against some of the adverse impacts and negative outcomes of historical trauma such as emotional issues, suicide, substance misuse, violence, etc. (Dolezal et al., 2021; Luo et al., 2021; Spillane et al., 2021; Valdez & Lilly, 2015). Therefore, self-compassion may extend as a protective factor for historic loss and might facilitate healing for individuals suffering from multigenerational trauma caused by the Indian boarding school systems. Given the often collectivistic nature of Native Americans (Bobb, 1999; Long [Nez Perce] et al., 2006), it is recognized by the current authors that self-compassion may operate differently among this population than has been seen in previous literature. However, to explore this is beyond the scope of this paper.

AI/AN children—often considered the ones who would be able to carry on their cultures—have historically been forcibly removed from their communities and put in boarding schools, resulting in both thousands of deaths and cultural genocide (Piccard, 2014). Since the initial discovery of 215 unmarked graves in Kamloops in May 2021, there has been a push for truth and reconciliation in Canada as well as in the United States (Labbé, 2022), leading to the discoveries of more unmarked graves in North America at varying locations where former boarding schools were located (Austen & Bracken, 2021). Given this context, as well as the rising discourse regarding cultural genocide (Gone [Gros Ventre], 2014), AI/ANs are likely experiencing unresolved grief and trauma brought forth by the lack of healing from historical loss (Bigheart [Seneca], 2021; Gone et al., 2019; Zephier Olson [Yankton Sioux, Mandan, Hidatsa, and Arikara] & Dombrowski, 2020). This has created potential risk factors for continued psychological harm in the form of processing historic loss and multigenerational trauma. Indigenous people of all ages

have likely found themselves psychologically impacted as they learn of some of the atrocities that occurred in boarding schools. It may be possible that some young Indigenous people are learning of these atrocities for the first time given their distance from the earlier generations that were more likely to have attended boarding schools. Regardless of age and boarding school attendance status, many Indigenous people may be seeking ways to cope that lead to healing the immense amount of cultural grief felt in AI/AN communities.

Altaha and Kraus (2012) found that AI/AN college students continued to experience historical loss and multigenerational trauma. The current study proposed that self-compassion might buffer the impacts of historical loss felt by college students as a result of the discoveries of unmarked graves found at former Indian boarding schools, as well as the recent acknowledgement of their own college's history as a boarding school and contributor to colonization. It is hypothesized that AI/AN students attending a former boarding school will be impacted by historic loss and trauma in light of the current events regarding unmarked graves. Self-compassion is predicted to act as a protective factor for students carrying the emotional burden of living with historic loss and healing multigenerational trauma; the more self-compassion that a student has, the less emotional burden they will likely carry.

## **METHODS**

### **Participants**

University Institutional Review Board approval was obtained prior to collecting data. The participants were 60 AI/AN undergraduates at a Native American-serving liberal arts college. The participants were members of 18 distinct tribes from varying regions of the United States, ranging from only 1 up to 28 participants from each tribe. All participants were at least 18 years of age, reviewed an informed consent sheet, and voluntarily participated. No compensation was provided. Besides asking self-identified tribal affiliation and ensuring participants were over the age of 18, researchers chose not to collect age nor gender to help protect participants' anonymity. While self-identified tribal affiliation was collected, in line with Norton and Manson [*Little Shell Chippewa*] (1996), it was decided to exclude this information from publication to further ensure participants' anonymity.

## Scales

### ***Historical Loss: Historical Loss Scale and Historical Loss Associated Symptoms Scale***

The Historical Loss Scale and the Historical Loss Associated Symptoms Scale (Whitbeck et al., 2004) were used to measure the impacts of historical loss on this group of AI/AN students. The Historical Loss Scale (see Appendix A) is a 12-item scale that measures how often participants think about losses such as loss of land, language, family ties due to boarding schools, loss of culture, loss of people to early death, among others (e.g., “The loss of our family ties because of boarding schools”). The scale ranges from 1 to 6, where 1 = *several times a day* and 6 = *never*. Lower numbers indicate more frequent thoughts of loss. The Historical Loss Associated Symptoms Scale (see Appendix B) is a 12-item scale that measures the psychological impacts of loss, asking how often participants feel sadness, shame, rage, etc. in association with the loss (e.g., “Feel like avoiding places or people that remind you of these losses”). This is measured on a scale from 1 to 5, where 1 = *never* and 5 = *always*. On this scale, higher numbers indicate higher psychological impacts.

### ***Self-Compassion: Self-Other Four Immeasurables Scale***

Compassion and negative feelings towards self and others were measured using the 16-item Self-Other Four Immeasurables (SOFI) Scale (Kraus & Sears, 2009; see Appendix C). This scale measures both positive and negative qualities, asking participants to rate the extent to which they felt this way toward self and others in the past week. The scale ranges from 1 to 5, where 1 = *very slightly or not at all* and 5 = *extremely*, with higher numbers indicating more compassion for positive attitudes and less compassionate feelings for negative qualities. Items include friendly, hateful, accepting, angry, joyful, compassionate, mean, and cruel (e.g., “Hateful - toward myself”). While this scale has not been validated specifically for AI/AN participants, it was used previously with a population of AI/AN college students (Altaha & Kraus, 2012). For the current study, Cronbach’s alpha for positive feelings toward self was .87 and negative self was .91, which indicate strong reliability.

### ***Impacts of Boarding Schools: Truth and Reconciliation Scale***

The current researchers designed a new scale (the Truth and Reconciliation Scale; see Appendix D) to measure participants’ awareness of current events surrounding boarding schools and the discovery of unmarked graves. The current first and third authors brainstormed questions that they thought would be relevant to this scale and came to consensus to use four items. The following questions make up this scale:

- 1) How aware are you of current events regarding the discoveries of unmarked graves at former boarding schools?
- 2) Do these current events impact your emotional well-being when thinking of former boarding schools?
- 3) Have you or any of your family members been impacted by the boarding school system?
- 4) Do you feel conflicted attending this college considering its past as a boarding school, and its recent acknowledgement of its history as a former colonizing institution?

Endpoints of the scale range from 1 to 5, where 1 = *very slightly or not at all* and 5 = *extremely*, with higher numbers indicating more knowledge of, and impact from, boarding school systems. No statistical tests (e.g., factor analysis) other than Cronbach's alpha were performed to determine applicability of this new scale. Cronbach's alpha for this newly developed scale was .68.

## **Procedure**

An email containing an informed consent form as well as a Google Forms survey questionnaire was sent out to the Native American and Indigenous Studies (NAIS) department, as well as relevant Indigenous student organizations. After a brief overview of the study was provided, students agreed to the informed consent form and then were prompted to fill out the questionnaire on their personal electronic devices. The scales were presented in the order they appear above.

## **Analysis**

Data was summarized with descriptive statistics for each scale, and Pearson Correlation Coefficients were calculated to examine the relationships between the Historical Loss Scale, the Historical Loss Associated Symptoms Scale, the Truth and Reconciliation Scale, and self-compassion. Regression analyses were used to determine which of these scales most strongly predicted the psychological impacts of historical loss.

# **RESULTS**

## **Historic Loss and Historic Loss Associated Symptoms**

Responses from the 12-item Historic Loss Scale had a minimum total score of 11 and a maximum of 68 with a mean of 29.07 ( $SD = 13.00$ ). This corresponds with average ratings between



“often” and “sometimes” for thinking about losses. The current college student participants appear to think about the loss of language, spiritual ways, losing people from their communities to early death, their trust in White people, and (most of all) the influx of substance use in their communities resulting from historic loss, among others.

The Historical Loss Associated Symptoms Scale scores ranged from 14 to 60 with an average of 39.20 ( $SD = 12.08$ ). Participants noted struggling most often with anger ( $M = 4.47$ ,  $SD = 1.47$ ), sadness or depression ( $M = 4.42$ ,  $SD = 1.54$ ), and anxiety ( $M = 4.13$ ,  $SD = 1.56$ ), and all of the symptoms listed had averages above the midpoint of the scale.

### **Self-Compassion**

The SOFI Scale, used to measure self-compassion, was split into the following two subscales: Positive Feelings Towards Self and Negative Feelings Towards Self. On the first subscale, (Positive Feelings Towards Self), the current participants’ mean was 3.30 ( $SD = .90$ ) on a 5-point scale, which indicates they seemed to be moderately friendly, joyful, accepting, and compassionate towards themselves. This is similar to the 3.32 ( $SD = .62$ ) mean found with college students when the scale was originally developed (Kraus & Sears, 2009). On the second subscale (Negative Feelings Towards Self), the current participants’ mean was 3.06 ( $SD = 1.17$ ), which was considerably higher and had more variation than the scores found by Kraus and Sears (i.e.,  $M = 1.57$ ,  $SD = .62$ ). Current participants seemed to have moderate levels of hateful, angry, cruel, and mean feelings towards themselves.

### **Truth and Reconciliation Scale**

Knowledge of current events including discoveries of unmarked graves at former boarding schools, family members impacted by boarding school experiences, and the impacts of this knowledge on emotional well-being were explored. Participants reported high levels of awareness of the discovery of unmarked graves at boarding schools ( $M = 4.10$ ,  $SD = 1.05$ ) and they reported quite a bit of both personal ( $M = 3.87$ ,  $SD = 1.21$ ) and family impacts ( $M = 3.65$ ,  $SD = 1.35$ ) on wellbeing due to current events surrounding residential schools. They were moderately conflicted about attending a school that had been a residential school ( $M = 3.20$ ,  $SD = 1.39$ ).

## Correlational Analyses

Using Pearson Correlation Coefficients with an alpha set at 0.05, historic loss symptoms were found to be strongly correlated with knowledge of impacts of boarding schools ( $r = .63, p < .001$ ) and significantly correlated with historic loss thoughts ( $r = .43, p < .001$ ), indicating that both past and current events might be predictive of being more at risk for the psychological implications of trauma. Positive feelings of self-compassion were found to be negatively correlated with historic loss symptoms, indicating the possibility that the more self-compassion one practices, historic loss symptoms are likely to decrease ( $r = -.269, p = .041$ ). On the contrary, those who reported negative feelings towards themselves had a higher chance of reporting historic loss symptoms ( $r = .499, p < .001$ ).

## Regression Analyses

Multiple regression was used to examine the impacts of historic loss thoughts, negative feelings towards self, and knowledge of boarding school events, the three variables that most closely correlated with historic loss symptoms (see Table 1). While thoughts about historic loss were clearly correlated with historic loss symptoms, when put in a regression model with the measure of boarding school impacts and negative feelings towards self, thoughts about historic loss was not a significant predictor of historic loss symptoms ( $B = -0.12, p = .26$ ); rather, current awareness of events related to boarding schools strongly predicted historic loss symptoms ( $B = 1.57, p < .001$ ). Negative feelings towards oneself remained a significant predictor of historic loss symptoms in the model ( $B = 0.66, p = .02$ ). It appears that the current events surrounding boarding schools are most likely more salient to the current participants and outweighs the impact of historical trauma. While knowledge of trauma seems to predict psychological impacts, lack of self-compassion might also play a significant role in predicting these impacts.

**Table 1**  
**Regression Analyses for Historic Loss Associated Symptoms**

Outcome	Predictor	B	SE	Beta	t	p	R <sup>2</sup>
Historic Loss Symptoms	Historic loss	-.210	.105	-.129	-1.14	.259	.478
	Current knowledge	1.570	.400	.463	3.94	<.001	
	Self-negative	.661	.281	.261	2.35	<.023	

## DISCUSSION

The impacts of historical loss felt by the current AI/AN college student participants seem to be prevalent, just as Altaha and Kraus (2012) found when assessing historic loss in other college students. The current study found high levels of historic loss and the psychological symptoms associated with that loss. Participants also reported impacts from current events such as the discovery of graves at former boarding schools and from family impacts of boarding school trauma. Descendants of AI/AN communities carry with them the reality that trauma exists in their familial lines. Participants who indicated that they have recurring thoughts of historic loss appeared to be more at risk for developing symptomatology aligned with psychological trauma, but notably, current trauma surrounding former boarding schools seemed to be more predictive of psychological impacts. Negative feelings towards self also appeared to predict psychological well-being.

Due to the recent discovery of many more unmarked graves (the current number of individuals found in unmarked graves at former boarding schools has risen to roughly 7,400 with continuous search efforts being driven in both Canada and the United States) and the subsequent news coverage, awareness of such has increased amongst Indigenous peoples. In light of this news, this study's regression analyses found that AI/AN students who were aware of the current events and who reported low levels of self-compassion tended to be more susceptible to historic loss symptoms. Negative feelings towards themselves subsequently might put them more at risk for carrying the burden of intergenerational trauma, possibly increasing their risks of being psychologically impacted by historic loss. Hence, since there is a great likelihood of more unmarked graves being brought to light through the current truth and reconciliation efforts, some AI/AN individuals will likely be more psychologically vulnerable, particularly those who have low self-compassion and high awareness of the results of these efforts. While historic loss itself did not predict historic loss symptoms in the regression analysis, this may have been due to a small sample size with limited power to detect this relationship. However, negative feelings towards self and current events around reconciliation were found to significantly predict historic loss symptoms. These factors appear to be more important than historic loss. This finding suggests working on self-compassion and handling reconciliation efforts very carefully may be important to wellbeing.

These data suggest that current events might be influencing both thoughts and feelings associated with historic trauma. Although Cain's [*Santa Clara Pueblo* and *Jicarilla Apache*] 1999

sample and Altaha and Kraus' 2012 sample were quite similar in terms of historic loss thoughts and feelings [i.e., means of 42.96 ( $SD = 19.30$ ) and 45.32 ( $SD = 11.92$ ), respectively], the average in the current sample was notably higher ( $M = 29.07$ ,  $SD = 13.00$ ) (note that lower scores on the Historical Loss Scale actually indicate more reported thoughts of historical loss). The current sample's historic loss associated symptoms ( $M = 39.20$ ,  $SD = 12.08$ ) were slightly higher than Cain's ( $M = 36.59$ ,  $SD = 12.95$ ) and significantly higher than the Altaha and Kraus sample ( $M = 25.15$ ,  $SD = 8.18$ ). This suggests that current events might serve as a trigger for AI/AN college students' thoughts, feelings, and symptoms related to historic loss. This finding might have significant implications in terms of mental health treatment and reconciliation efforts in regard to historical trauma.

With the reality of the college where the data was collected being a former boarding school in which children from different tribes were sent to receive a Western compulsory education, AI/AN students in this sample were likely aware of current events surrounding this issue. Although the cause of low self-compassion cannot definitively be pinned on the historic loss and the dissipation of cultural practices due to genocidal efforts prompted by boarding schools, this current sample of AI/AN college students do seem to have a decreased sense of self-compassion.

The chances of negative feelings stemming from intergenerational trauma spirals into an array of harmful coping mechanisms that add to the stereotype of AI/AN people succumbing to substance use, violence, depression, and PTSD (Brave Heart & DeBruyn, 1998). The majority of the current sample endorsed frequent historic loss associated with substance misuse (77.9% chose either "Daily" or "Often"). Hence, the current authors put forward a call to action to address the root causes of substance use among AI/AN peoples with culturally relevant treatments. Mohatt [*Sicangu Lakota* and *Oglala Lakota*] et al. (2011) discussed AI/AN culture-specific protective factors (e.g., connectedness protecting against suicide and substance misuse). It might be possible that self-compassion is an AI/AN culture-specific protective factor against intergenerational trauma. The current study found self-compassion to be related to reduced historic loss symptoms. With self-compassion possibly acting as a protective measure for alleviating possible historic loss symptoms, further research is needed to better understand how AI/AN peoples can process and heal themselves to reduce the presence of and passing on of intergenerational trauma in their familial lines and how to enhance AI/AN-specific protective factors.

With colonization tactics being a primary driving force of boarding schools, children who attended were subjected to comply with the expectations that they shift their inherent worldviews

and Indigenous funds of knowledge to assimilate. Therefore, to attempt to decolonize such assimilation, practitioners and community members can find ways to strengthen funds of knowledge [the assets, traditional practices, and complex variations of interaction within cultural groups, which provides valuable insight as to how varying AI/AN cultures are kept alive (Hogg, 2011)] in current and future generations of AI/AN peoples. This might be aided by psychoeducation and by emphasizing that practicing methods of self-compassion might have the potential to mitigate intergenerational trauma. Since self-compassion can be taught and learned (Germer & Neff, 2015; 2019), the current results might lend to possible implications for interventions that might help shift back to Indigenous worldviews and funds of knowledge. Those impacted most by the atrocities of cultural genocide exemplified by boarding schools could alleviate negative feelings toward self and others by recognizing that practicing self-compassion might alleviate historic loss symptoms.

AI/AN people can further set a strong foundation within themselves to identify courses of action focusing on putting an end to intergenerational trauma by instilling a secure sense of cultural identity. For many AI/AN individuals, spirituality is related to cultural identity. Given that the majority of the current participants endorsed historic loss symptoms related to spirituality regularly (63.4% chose either “Daily” or “Often”), it seems important to explore this relationship further and foster current and develop new spirituality focused healing interventions. Reclaiming tribal communities and cultural practices that were diminished due to the boarding school systems starts on an individual level with Indigenous peoples of this generation and generations to come, which can contribute to a powerful wave of revitalization on a communal level.

## **Limitations**

This study naturally had several limitations. While this was done to protect anonymity, one limitation includes the lack of assessing where participants fall in terms of age which could indicate where they fall generationally in their family, specific cultural aspects that have been lost within their tribes, and those who have been directly impacted by boarding schools being distinguished from those who are more impacted by learning of current events and truth and reconciliation efforts. Another limitation is the cross-sectional nature of the study and the small sample size with a limited number of tribes represented and very few members of each tribe. Furthermore, the fact that the current sample attends a former boarding school that is attempting to engage in truth and



reconciliation, participants are likely to be more aware of such efforts than other students. These factors naturally limit the generalizability of this study.

Other limitations are related to the new Truth and Reconciliation Scale that was developed. First, several questions could have been worded better. A number of items used the word “do” (e.g., “Do these current events impact your emotional well-being when thinking of former boarding schools?”) and were assessed with a continuous response rather than binary response option. These could have been reworded to better reflect the continuous nature that the authors wished to address; however, participants did not seem to have trouble rating the extent to which current events impacted them despite the imperfect wording. The next limitation was that no statistical tests (such as factor analysis) other than Cronbach’s Alpha were run on this new scale. Also, the Cronbach’s Alpha was relatively low. Despite these limitations, this new scale may be useful for future studies, particularly if these limitations are addressed.

## **Recommendations**

The authors recommend that college administrators at institutions associated with AI/AN boarding schools move forward with truth and reconciliation efforts. Such efforts might include searches for unmarked graves. In such cases, institutions should be prepared to support students through mental health support and empirical ways to enhance self-compassion. Truth and reconciliation should be accompanied by care, caution, and compassion to help mitigate possible unintended negative consequences.

It is recommended that this study be replicated in other settings with a larger sample and with many different tribes and with other ethnic groups who have suffered from intergenerational trauma. Both qualitative and quantitative longitudinal studies are recommended to further understand the relationship between self-compassion and historic loss symptoms, and how self-compassion (and how teaching it to AI/AN people) might act as a protective factor for historic loss and furthermore, intergenerational trauma.

## **CONCLUSION**

Historic loss and associated symptoms affect many AI/AN people. Boarding schools may have contributed to such symptoms. Recent events and news related to unmarked boarding school graves may have a negative impact on some AI/AN people. The current study developed a new

scale to measure awareness of these events that may prove useful for future studies. Participants who were more aware of the recent events and who had less self-compassion suffered more psychologically. The authors describe limitations and practice implications and offer recommendations for future research. With more empirical research, self-compassion may turn out to be a protective factor and one of the decolonizing prongs of a multipronged approach to decreasing the adverse psychological effects of historical loss; this may be particularly so in cases where that loss is more salient to AI/AN people due to the fact that news about boarding schools will likely be ongoing. It is important to be mindful of the effects of truth and reconciliation efforts as they may have both positive and negative consequences. Any such efforts should be approached with both caution and compassion.

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The authors declare that they have no conflicts of interest.



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## APPENDIX A

## Historical Loss Scale

	Several times a day	Daily	Weekly	Monthly	Yearly or only at special times	Never	DK/ REF
The loss of our land	1	2	3	4	5	6	9
The loss of our language	1	2	3	4	5	6	9
Losing our traditional spiritual ways	1	2	3	4	5	6	9
The loss of our family ties because of boarding schools	1	2	3	4	5	6	9
The loss of families from the reservation to government relocation	1	2	3	4	5	6	9
The loss of self respect from poor treatment by government officials	1	2	3	4	5	6	9
The loss of trust in Whites from broken treaties	1	2	3	4	5	6	9
Losing our culture	1	2	3	4	5	6	9
The losses from the effects of alcoholism on our people	1	2	3	4	5	6	9
Loss of respect by our children and grandchildren for elders	1	2	3	4	5	6	9
Loss of our people through early death	1	2	3	4	5	6	9
Loss of respect by our children for traditional ways	1	2	3	4	5	6	9

APPENDIX B

Historical Loss Associated Symptoms Scale

	Never	Seldom	Sometimes	Often	Always	DK/ REF
Sadness or depression	1	2	3	4	5	9
Anger	1	2	3	4	5	9
Anxiety	1	2	3	4	5	9
Uncomfortable around White people when you think of these losses	1	2	3	4	5	9
Shame when you think of these losses	1	2	3	4	5	9
A loss of concentration	1	2	3	4	5	9
Feel isolated or distant from other people when you think of these losses	1	2	3	4	5	9
A loss of sleep	1	2	3	4	5	9
Rage	1	2	3	4	5	9
Fearful or distrust the intention of White people	1	2	3	4	5	9
Feel like it is happening again	1	2	3	4	5	9
Feel like avoiding places or people that remind you of these losses	1	2	3	4	5	9

## APPENDIX C

## Self-Other Four Immeasurables (SOFI) Scale

	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
<b>Friendly</b> - toward myself	1	2	3	4	5
<b>Friendly</b> - toward others	1	2	3	4	5
<b>Hateful</b> - toward myself	1	2	3	4	5
<b>Hateful</b> - toward others	1	2	3	4	5
<b>Angry</b> - with myself	1	2	3	4	5
<b>Angry</b> - with others	1	2	3	4	5
<b>Joyful</b> - for myself	1	2	3	4	5
<b>Joyful</b> - for others	1	2	3	4	5
<b>Accepting</b> - toward myself	1	2	3	4	5
<b>Accepting</b> - toward others	1	2	3	4	5
<b>Cruel</b> - toward myself	1	2	3	4	5
<b>Cruel</b> - toward others	1	2	3	4	5
<b>Compassionate</b> - toward myself	1	2	3	4	5
<b>Compassionate</b> - toward others	1	2	3	4	5
<b>Mean</b> - toward myself	1	2	3	4	5
<b>Mean</b> - toward others	1	2	3	4	5

## APPENDIX D

### Current Impacts of Boarding Schools

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	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
How aware are you of current events regarding the discoveries of unmarked graves at former boarding schools?	1	2	3	4	5
Do these current events impact your emotional well-being when thinking of former boarding schools?	1	2	3	4	5
Have you or any of your family members been impacted by the boarding school system?	1	2	3	4	5
Do you feel conflicted attending this college considering its past as a boarding school, and its recent acknowledgement of its history as a former colonizing institution?	1	2	3	4	5

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# Recommendations for Optimizing *xaʔtus* (First Face) for Mental Health Training: Insights from Key Informants

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*Abstract: Native adolescents experiencing mental health challenges, including substance misuse, often prefer to seek support from their peers and other informal sources, which may be due to lack of access to, and cultural fit with, professional behavioral health services. xaʔtus (First Face) for Mental Health is a Tribal community-based intervention designed to strengthen networks of informal mental health support and open pathways to more formal support. We sought insights from key informants to optimize the planning, promotion, and delivery of First Face trainings to seven Tribal communities in the Northwest United States. We conducted three focus groups with (1) teens completing a residential chemical dependency program at the Healing Lodge of the Seven Nations (n = 10), (2) clinical staff representing the Healing Lodge's Behavioral Health Department (n = 9), and (3) community members representing educators and social service professionals at five of the Tribal nations that support the Healing Lodge (n = 6). Discussion generated planning, promotion, and training recommendations. Planning recommendations focused on showing respect for trainees' time by holding the training during convenient times and factoring in trainees' commitments to work and family, integrating the training into high school science or health education classes, and taking steps to protect trainees' physical safety in the age of COVID while avoiding "Zoom fatigue." Promotion recommendations highlighted community members' possible reluctance to become a First Face due to fear about the responsibilities associated with taking on this role and the need to emphasize the personal relevance of First Face training. In terms of training delivery, participants emphasized the importance of including engaging, interactive activities; instructing future First Faces in self-care; and acknowledging the impact of traumatic contemporary experiences on mental health, while at the same time preventing heated and distressing political debates. We describe our response to participants' recommendations and the rationale for those responses.*

## **INTRODUCTION**

Experiencing mental health challenges, including substance misuse, is alarmingly common during adolescence and young adulthood. Globally, 31% of people aged 10-19 experience clinically significant psychological distress (Silva et al., 2020). In the United States, the median age of onset is only 11 years for anxiety disorders and 20 years for substance use disorders; fully 75% of mental health conditions are established by age 24 (Kessler et al., 2005). If unresolved, adolescent-onset mental health conditions can create lasting personal and social distress.

In any community, at any age, seeking support for mental health challenges can be a daunting experience. Rickwood and Thomas (2012) define mental health help-seeking as “an adaptive coping process that is the attempt to obtain external assistance to deal with mental health concerns” (p. 180). Formal (e.g., professional healthcare providers) and informal (e.g., friends and family) sources are potential pathways to help for mental health concerns. Informal mental health support is highly valued and often accessed (Brown et al., 2014; Jorm et al., 1997), potentially because it reduces perceived isolation and stigma and enhances one’s ability to cope (as reviewed by Byrom, 2016).

### **The Role of Informal Mental Health Supports**

Adolescents often prefer informal sources of support and/or experience barriers to formal support. For instance, in a study of teens aged 14-16, 73% of participants were able to recognize signs of depression in a vignette, and nearly all thought it would be helpful for the character in the vignette to see a doctor or other healthcare professional. However, less than half thought that seeing a doctor or other healthcare professional would be helpful if they were experiencing the same challenges (Hernan et al., 2010).

Fear, embarrassment, shame, and self-consciousness are common barriers to seeking formal help (Hernan et al., 2010). Some adolescents also report lacking trust in and therapeutic alliance with their primary care providers, who would otherwise be positioned to serve as a first line of professional mental health support (Corry & Leavey, 2017). Boys and young men in particular are often reluctant to seek professional help because doing so threatens their sense of aligning with masculine ideals (Dowel et al., 2021; Lynch et al., 2018). Both girls and boys often prefer seeking mental health support from their peers due to peers’ relative availability, ease of access, and perceived positivity compared to formal sources (Burke et al., 2022).

## **Informal Mental Health Support within Native Communities**

Informal sources of mental health support are especially essential within communities that have been robbed of financial and other resources, including American Indian and Alaska Native (AI/AN) communities. The U.S. government has chronically underfunded the Indian Health Service (IHS; Lofthouse, 2022). Funding shortages, lack of staff and equipment, and relatively long wait times contribute to gaps in healthcare services, including mental healthcare. These gaps, combined with high rates of poverty, lack of insurance coverage, institutional racism, and other multi-level factors, contribute to persistently worse health outcomes among Native people (Blue Bird Jernigan et al., 2020; Lofthouse, 2022).

In Native and other under-resourced communities, researchers and advocates have explored the value of community-based initiatives designed to provide laypeople with tools to support those who are experiencing mental health challenges or crises. The most widely known program of this type is Mental Health First Aid (MHFA; Kitchener & Jorm, 2002; Morgan et al., 2018). MHFA trains community members to identify signs of mental health crises, intervene when appropriate, and provide a bridge between informal and formal mental health support, when appropriate. MHFA is moderately effective in improving trainees' knowledge of mental health issues and confidence in providing help, with smaller effect sizes for encouraging supportive attitudes and the self-reported provision of mental health support (Maslowski et al., 2019).

The current study represents a continuing effort to broaden and strengthen informal mental health support networks and improve mental health literacy among Tribal communities in the Northwest United States. We represent the Center for Indigenous Research Collaboration and Excellence (CIRCLE). CIRCLE's clinical partner is the Healing Lodge of the Seven Nations, a 45-bed adolescent residential chemical dependency treatment center in Spokane Valley, Washington. The Healing Lodge serves residents ages 13-17 through its 90–120-day intensive inpatient treatment programs. Although the Healing Lodge's primary focus is on the AI/AN population, its services are open to all adolescents. CIRCLE's academic partner is the Division on Addiction at Cambridge Health Alliance, a Harvard Medical School teaching hospital.

### ***xaʔtus* (First Face) for Mental Health**

Together with members of the seven Tribal nations that support the Healing Lodge, CIRCLE created a program designed to train community members to offer informal support for their family

members, friends, and acquaintances experiencing mental health struggles and, when appropriate, provide a warm hand-off to formal mental health support. Our manualized curriculum, *xa?tus* (First Face) for Mental Health, is rooted in Tribal traditions, healing practices, and conceptualizations of wellness and mental health. *xa?tus* (pronounced *hah-toos*) is the Salish word for “First Face.” In this context, it represents the first person to offer help and situational leadership in the event of a mental health challenge or crisis, such as a panic attack, possible addiction relapse, or traumatic flashback.

Based on the recommendations of working group representatives of the seven Tribal nations, First Face modules were created on the topics of addiction, trauma, depression and anxiety, self-harm, and interpersonal violence, with appendices providing extended discussion of self-care for the First Face, typical and atypical adolescent development, and intergenerational trauma. The need for community-wide education in these topics is apparent in representative epidemiological studies. For instance, Walls et al. (2021) found that by age 26, 77.3% of reservation-dwelling Native people in the Northern Midwest U.S. and Canada met the diagnostic criteria for a substance use or mood disorder, most commonly alcohol or marijuana use disorders. Both historical and contemporary mental health risk factors contribute to this risk. First Face training provides memorable and concrete action steps for the First Face to use when offering support for a mental health challenge or crisis. Each module is anchored with an engaging narrative illustrating a mental health struggle and the specific steps a First Face can take to offer informal support and connect the individual in crisis with more formal support, if desired. Healing Lodge residents contributed to these narratives and to the selection of manual artwork. First Face is designed for all Tribal community members but has a particular focus on adolescent struggles and optimal ways of responding to these struggles. First Face has elements in common with other community-based, culturally appropriate interventions designed with and for Native communities (Walters et al., 2020), such as the *Qungasvik* suicide and alcohol use disorder prevention program for Yup’ik Alaska Native communities (Rasmus, Charles, & Mohatt, 2014) and the Intertribal Talking Circle substance misuse prevention program for middle schoolers from three tribes (Choctaw in Oklahoma, Lumbee in North Carolina, and Ojibwe/Chippewa in Minnesota; Lowe et al., 2016; Lowe et al., 2022).

### **The Current Work**

Before training community members in the seven Tribal nations on First Face, we sought advice from knowledgeable Tribal sources regarding the planning, promotion, and delivery of the training. Specifically, we conducted focus groups with Healing Lodge residents (who represent

Native adolescents in recovery from substance use and mental health conditions), Healing Lodge staff (who represent behavioral health providers serving Native adolescents), and educators/social service providers within the seven Tribal communities that support the Healing Lodge. This last group of community members is knowledgeable of the experience of mental health struggles among families in their communities, as well as informal and formal support currently available within these Tribal communities.

In conducting these focus groups, we had three goals:

1. Understand focus group participants' thoughts and opinions regarding potential barriers to recruiting trainees and how we might overcome them.
2. Understand the potential impact of contemporary issues (e.g., COVID-19, racism, climate change, war) on a training program like First Face and how we can be sensitive to these issues.
3. Understand more general preferences for the training program and how we can reflect those preferences.

This paper describes our focus groups and the recommendations that emerged from them.

## **METHODS**

### **Participants**

Three non-overlapping groups of people participated in the focus groups. In total, 25 people participated.

The first group included 10 residents of the Healing Lodge. We recruited these participants by asking all current Healing Lodge residents if they would be willing to participate and provide feedback on our training plans.

The second group included nine staff of the Healing Lodge. We worked with the Behavioral Health Department Director, explaining the project and focus group purpose. One Healing Lodge staff member (CA) then sent an email to the Behavioral Health Department and invited all of them to participate in the focus group. We selected Behavioral Health staff members due to their professional experience in adolescent mental health/substance use.

The third group included six community members representing five Tribal nations. We recruited these participants via convenience sampling followed by snowball sampling.



Specifically, we promoted the focus group in an email newsletter sent to community members who have previously participated or expressed interest in CIRCLE's work. Many of these people had previously participated in CIRCLE's strengths and needs assessments within the Tribal nations that support the Healing Lodge (Whelshula et al., 2021), either as participants in those assessments or as community members who attended a research dissemination meeting (or both). Participants were educators/coaches, medical and behavioral health providers, social service providers, cultural leaders/elders, and legal professionals. Additionally, we assembled a list of potential participants by searching the education and social service websites of all seven Tribes that support the Healing Lodge and directly emailing those whose email addresses were listed. When community members expressed interest in participating, we followed up by asking them to contact others in their professional circles who might be interested.

### Focus Group Questions

The authors developed questions that addressed each of our three goals:

1. Understand focus group participants' thoughts and opinions regarding potential barriers to recruiting trainees and how we might overcome them.
  - a. What concerns do you think Tribal members might have about signing up for a First Face training?
  - b. Can you describe a training or other similar event that was surprisingly popular? What do you think made it work so well?
  - c. What would make you more likely to sign up for a training? Are there practical issues that might impact sign ups?
2. Understand the potential impact of contemporary issues (e.g., COVID-19, racism, climate change, war) on a training program like First Face and how we can be sensitive to these issues.
  - a. Lately, stress from the pandemic, climate change, war, and systemic racism have sometimes felt overwhelming, especially for communities that experience more than their fair share of harm. In what ways do you think concerns like this should be incorporated into the training, or not?
  - b. In what ways do you think community engagement has changed from before the pandemic to now?

- c. What could we do on our end to make people more comfortable attending an in-person training (i.e., mask, distance, ventilation, hand sanitizer)?
3. Understand more general preferences for the training program and how we can reflect those preferences.
  - a. Tell us about your most favorite training and your least favorite training. What made them your favorite/least favorite?
  - b. The First Face training will include sensitive topics related to mental health and addiction. Do you have any thoughts on how to make people more comfortable learning about and discussing sensitive topics?
  - c. What are the main cultural considerations we should keep in mind when we design our training?

These questions formed the basis of each focus group session. The Healing Lodge residents required some additional explanation about the questions. For instance, a facilitator helped residents understand the purpose of the First Face training by equating it with CPR and Narcan training, concepts with which they were already familiar.

## **Procedure**

All three focus groups were facilitated online via Zoom. Authors MBR, CA, and MB facilitated all focus groups, with MBR serving as the primary facilitator. The focus groups lasted approximately 1 hour and 15 minutes. The Healing Lodge residents assembled in person (with boys and girls in separate rooms) with CA and MB providing in-person support, but the primary facilitator (MBR) appeared remotely via Zoom. Participants in the two adult focus groups all connected remotely.

Because we considered this work to be quality improvement rather than human subjects research, we did not complete a formal consent process. However, all focus groups members verbally gave permission to record the sessions. To preserve confidentiality, Healing Lodge staff (CA and MB) retained the recording of the resident focus group and provided the remaining authors with only a transcript, stripped of any identifying details.

The first author reviewed transcripts of all three focus groups to summarize participants' responses to our guiding questions. When necessary, she reviewed the Zoom recording of the two adult focus groups to better understand participants' responses. In the first stage of content

analysis, she retained the original structure of the focus group questions and summarized themes that emerged across sessions in response to each question. In other words, she used a directed content analysis approach, identifying key concepts within predetermined categories (in this case, the original focus group questions; Hsieh, 2005). She did not require that all three groups (residents, staff, and community members) make the same observation in order for that observation to be included as a key concept; however, she observed that often, at least two groups, if not all three, responded similarly to focus group prompts. In the second stage, she imposed the broader categories of training *planning*, *promotion*, and *delivery* and identified recommendations that emerged across both sections and questions. Although validity/reliability checks are typically used when working with qualitative data, in this case the focus group questions and responses were fairly straightforward with minimal interpretation needed. Therefore, we did not impose such checks. Finally, the authors collaboratively examined each recommendation and developed a response to it. The co-authors had an opportunity at this point to move recommendations to different categories (e.g., from *planning* to *promotion*), but none did.

In terms of positionality, it is important to note that the first author is a non-Native researcher. She first became involved with Tribal participatory research when helping to complete a series of strengths and needs assessments with the seven Tribal nations that support the Healing Lodge; these assessments informed the development of First Face. She has been working with Healing Lodge for ten years. She recognizes her non-Native identity as a limitation in this work and is guided by the cultural knowledge and expertise of her Native colleagues, particularly co-authors CA and MW and working group representatives of the seven Tribal nations. To limit bias, she attempted to provide her colleagues with a straightforward summary of focus group members' responses, with minimal subjectivity.

The Northwest Portland-area Indian Health Board determined that this project did not meet the definition of human subjects research under the purview of the Institutional Review Board according to federal regulations. The Healing Lodge Board of Directors approved a resolution in support of publishing this manuscript.

## **RESULTS**

The results are organized according to the three goals and their respective focus group questions.

**Goal 1: Understand focus group participants' thoughts and opinions regarding potential barriers to recruiting trainees and how we might overcome them.**

*Question 1: What concerns do you think Tribal members might have about signing up for a First Face training?*

In response to this question, all participants from the three focus groups suggested that community members might be reluctant to sign up for a First Face training due to concern about what might be expected of them as a First Face. A Healing Lodge staff member described the concern this way: “Just like a sense of responsibility that you don't really want to have.... If the situation happens like that... and something goes wrong, then you feel that sense of responsibility.” Another staff member suggested that we could alleviate this concern by setting firm boundaries around a First Face’s responsibilities and communicating these boundaries—what a First Face will, and will not, be responsible for—in the training and even earlier, when promoting the training opportunity.

As we noted above, the facilitators tried to explain the concept of First Face training to Healing Lodge residents by comparing it to CPR or Narcan training. This might have created some confusion about the role of a First Face. For example, when asked why community members might be reluctant to attend a First Face training, one resident mentioned “being scared, you know, of being put in that situation of having to save someone's life.”

Finally, community members mentioned that some people might be reluctant to be trained as a First Face because it conflicts with the idea that they should “mind their own business,” a feeling that is “hard to get over.” When asked to elaborate, this community member said that “it's scary to delve into mental health, especially when it's the mental health of others.” However, she also thought that “it's nice to have these trainings because sometimes you can just be fearful of doing the wrong thing.” Other community members agreed with this last point, with one suggesting that “anyone who's on the front lines, that works with youth or adults in crisis or that could potentially be in crisis, should have all of these tools in their toolbox.” Another mentioned a lack of trust in formal social services and the possibility that First Face training will fill a gap by strengthening informal social support. Building on that point, a community member noted that First Face training will be helpful because, in her experience, young people in her community want to talk about substance misuse and intimate partner violence but find that adults are afraid or unwilling to discuss these topics.

All three groups also suggested that a demanding time commitment could make people reluctant to sign up for First Face training. A Healing Lodge staff member suggested providing “a

solid informational packet so that the person knows at least ... what they're getting into, the time constraints, and how they would be able to help.” Residents pointed to a need to minimize the time commitment as much as possible in order to keep teens engaged in the training. Community members agreed with minimizing the time commitment particularly for teen trainings.

***Question 2: Can you describe a training or other similar event that was surprisingly popular? What do you think made it work so well?***

The Healing Lodge staff and residents mentioned the need for training to be connected to one’s personal experiences. One staff member recalled a particularly effective training that “really kind of tied everything together... being able to relate it to yourself. So it wasn't just someone yakking at you. Like you actually got to take those things and think about them and apply them to yourself....” Picking up on this point, another suggested that we highlight the personal relevance of the training in our promotional materials: “A big obstacle, you know, is people find out about trainings or they get a flier in the mail. And if it doesn't seem relevant to them, then it's going to end up in the garbage.” Relatedly, a resident offered that Narcan training was perceived as useful because it was relevant to his own life.

All three groups recalled past trainings that were effective in part because they were interactive. A community member mentioned that this will be especially important when training teenagers: “I think the most important part is keeping them engaged. I mean, if it's just sitting there listening, it's not really beneficial for them – they fall asleep or they throw on the hoodie and airpods, you know they're not listening.” This community member described a past training that included effective icebreakers and recurrent interactive exercises that kept trainees engaged and socializing.

A Healing Lodge staff member who had previously completed White Buffalo Mending Broken Hearts training shared her view that this training “was absolutely riveting and emotionally powerful.” This prompted other staff members to discuss past trainings led by facilitators who demonstrated high emotional intelligence by creating safe spaces for sharing sensitive information and modeling reflective listening skills.

Finally, all three groups discussed the need to provide food and breaks.

***Question 3: What would make you more likely to sign up for a training? Are there practical issues that might impact sign ups?***

All three groups brought up the issue of timing: not just how long First Face training would take, but whether it would be held at convenient times. The consensus across all three groups was that the training should be broken up into smaller sessions, but that this would be a delicate balance.

While we should not try to conduct the whole training in a single day, spreading it up over too many days would result in trainees forgetting the material between sessions. Splitting it into two days seemed to be the preferred solution. Beyond that, there was little consensus regarding the optimal timing. Some Healing Lodge residents raised the possibility of completing First Face training during school hours, while some members of both adult groups raised the idea of holding the training over the weekend, which could help make the training more of a social event or even a weekend retreat.

This relates to the second point that all three groups made: different people have different needs, and we should provide options, both in terms of the timing and modality (in-person versus remote). With regard to timing, community members suggested that the training might need to be condensed for teenagers who have a shorter attention span, with the adult trainings expanded to cover intergenerational/historical trauma in more detail. Additionally, having separate training sessions for adolescents and adults could facilitate adolescent participation, as it would reduce fear of discussing sensitive topics in the presence of adults. We discuss remote training options in greater detail below (Goal 2, Question 3).

Both groups of adults suggested that we consider offering incentives. Two adults (one in the staff group and one in the community member group) suggested providing a door prize to all trainees, and another suggested offering small prizes throughout the training to encourage participation. For example, everyone who responds to a discussion question might be entered into a raffle for a small prize.

**Goal 2: Understand the potential impact of contemporary issues (e.g., COVID-19, racism, climate change, war) on a training program like First Face and how we can be sensitive to these issues.**

*Question 1: Lately, stress from the pandemic, climate change, war, and systemic racism have sometimes felt overwhelming, especially for communities that experience more than their fair share of harm. In what ways do you think concerns like this should be incorporated into the training, or not?*

This question elicited a spirited discussion, particularly among residents. On one hand, members of all three focus groups cautioned against letting our training devolve into a contentious political debate. Members of all three groups seemed scarred by political arguments that they had

previously witnessed or participated in. Some questioned whether the issues we noted were even relevant to the training. For instance, a resident said,

I just feel like bringing in something that is not involved with a situation, such as war or some political cause, causes a lot of arguing. And in this type of training, when we're all supposed to be listening, trying to get at one unified idea, separating ourselves through political views or racial tension isn't the best idea.... Because there's no reason to separate us.

Another resident was concerned that too much discussion of racism might be triggering to him. In response, another suggested that our facilitator provide a trigger warning and the opportunity for trainees to step outside the room.

On the same note, a staff member said, “I would always just say that political stances would be something not to talk about. That's something that I know sometimes gets talked about and it is really upsetting because everybody does have their own beliefs and their own values and morals and opinions. So just be sensitive to that.” A community member suggested that COVID-induced isolation has made it harder for people to hold difficult conversations and that, as a result, a great deal of sensitivity is needed in facilitating these conversations.

On the other hand, members of all three focus groups advocated for at least acknowledging these issues during the First Face training because of their impact on mental health. A resident put it this way: “A lot of things like the pandemic and racism *do* have an effect on mental health and you know, your society, and that's something worth talking about. But I feel like we should keep it more towards the mental health side and less of the political side.” Another offered, “I don't really understand how you can offer a training specifically to Native American mental health without touching on systemic racism.... So I feel like the training would be incomplete if we didn't include that on the side with intergenerational trauma.” Along these lines, staff members suggested that these very issues are what makes First Face training relevant and necessary for Tribal community members. One suggested making them part of the promotional material:

I think that all of these issues are a big reason why people would want to come to the training because it answers one of the questions as to *why should I go?* Because so many people are impacted that you might be helping yourself, or you might be helping a family member, or you could be helping a friend by coming. And learning what you should do.



And so taking these issues and making them part of the flier to help make it more a reason why I should go just, it affects me and my family and my friends.

It might be possible to strike a balance between these two positions by acknowledging these issues and their impact on community mental health at the outset of the training and guiding the discussion towards solutions rather than division. As one staff member put it, “I think just have a gentle, validating approach. We have been through a lot. Just normalizing that can be like offering a warm blanket.”

***Question 2: In what ways do you think community engagement has changed from before the pandemic to now?***

All three groups were in agreement that people are slowly getting used to socializing in person again and there is lingering fear of contracting COVID. A staff member suggested that people are more awkward now because, when it comes to in-person socializing, we are out of practice. This person continued,

I know, as far as teenagers... they were able to hide behind computer screens and phones for two years. And so now they're trying to come out of that. I heard them talking the other day that it's a really big struggle getting called on in group and in school and how embarrassing it is.... But for me... it wasn't just COVID that happened. There were riots, there have been mass shootings. There's been a war. There's been everything. So I think there's such a divide... I really think there's such a divide because it wasn't just COVID, there was so much happening, like a snowball effect in the last two years.

Despite this theme of awkwardness and fear of in-person socialization, a resident offered that they have become more vocal about social justice since the pandemic began; we infer that this change happened in response to catalyzing events like George Floyd's murder. “I am not staying silent. I feel like before the pandemic, there was a lot more silence. Things need to be talked about, like Black Lives Matter and ... we've gotten a lot better at that because of the pandemic. And because everyone was on social media and seeing all of that happened.”

Also, despite lingering fear of COVID, community members were in consensus that members of their Tribes are ready to socialize again. Those who work in domestic violence mentioned, if anything, their services became even more essential during the pandemic. One offered, “It was hard because we get to know the people in our community and we're accustomed

to talking up close and personal or giving a hug or at least a comforting hand on the shoulder or the arm, and COVID slowed down our work greatly.” Another mentioned that Elders in her community, in particular, are excited to be able to safely gather again.

***Question 3: What could we do on our end to make people more comfortable attending an in-person training (i.e., mask, distance, ventilation, hand sanitizer)?***

Participants had some strong opinions about attending a First Face training in-person versus remotely (e.g., via Zoom). Some participants across all three groups indicated that even if remote access were available, they would prefer not to use it due to “Zoom fatigue.” One community member put it this way:

I think we're just tired of Zoom. It's hard to pay attention, it's hard to focus. I mean, I'm sitting here at my desk and I'm still fidgeting and I'm moving, thinking, ‘Well, I could do this over here....’ I have a hard time focusing and staying within the meeting. So for me, I think we're ready, you know. Let's just do it.

Likewise, some residents mentioned their difficulty staying focused during remote meetings, and a staff member mentioned that kids with attention deficit difficulties, in particular, struggle with Zoom. Another staff member expressed dislike of remote trainings that are “blah, blah, blah, for 60 minutes, you might as well have a double screen, so you can work on your other stuff.”

At the same time, participants mentioned the benefits of at least providing a remote access option, including safety and convenience. A staff member mentioned childcare as a barrier to attending in-person trainings for those with young children and suggested a Zoom option for those who would otherwise be unable to attend. Across all three groups, the consensus was that we should provide a remote access option. As one resident said, “So like, basically, if someone needs to do online, they should be able to do it online. But if someone also needs to be able to come in, they can do that too.”

As far as other COVID mitigation strategies, participants were fairly evenly split between those who would prefer a mask mandate at an in-person event and those who would choose not to attend in-person if masks were required. At least one participant in all three sessions suggested trying to find an outside training location.

**Goal 3: Understand more general preferences for the training program and how we can reflect those preferences.**

***Question 1: Tell us about your most favorite training and your least favorite training. What made them your favorite/least favorite?***

Participants discussed some of their least favorite training experiences. The common thread was a lack of engagement. As an example, one community member said, “I’ve actually been in a training before where the facilitator was talking about themselves a lot, for a long, long, long, long time and, you know, I left the training like, ‘Okay, I didn’t really learn any of the things that they said I was going to learn. Basically, I learned a life story.’” Another community member mentioned “boring” trainings that involve reading written materials rather than active learning. A staff member said, “Any training that I just have to sit there and listen – I’m out, I don’t want to just sit there and have information fed to me. I want to be able to be involved somehow, or it has to be related to my job. Don’t just give me the information, I can’t stand that.” Participants contrasted these least favorite training experiences with positive experiences marked by a mix of engaging small group activities, some of which are designed to appeal to shy participants (e.g., contributing their thoughts by writing on large Post-it notes). A resident mentioned a basketball camp that was especially fun and interactive. These responses echo responses to Goal 1, Question 2.

There was consensus across both adult focus groups that role playing can be an uncomfortable but valuable experience. One community member said, “I would feel a little exposed role playing. It kind of makes you come out from that little comfort area where you can hide. But I can see the benefits.” Another added, “I would reluctantly do it, but it’s not something that I’m like, ‘Yes, let’s role play!’” As to the benefits of this pedagogical tool, one community member, who works as a youth prevention specialist, put it this way: “In my opinion role play helps to prepare for the real moments. I like to say it’s like running plays in practice – you can make the mistakes and fix them in practice. In the game, you cannot.” Another community member discussed batterer intervention groups that use role play to teach participants how to ask for help. Working through these scenarios results in “phenomenal” group discussions. After further discussion, both groups agreed that role playing should be considered as part of the First Face training, but that we should make trainees more comfortable by assigning role play in dyads rather than in front of the entire group.

***Question 2: The First Face training will include sensitive topics related to mental health and addiction. Do you have any thoughts on how to make people more comfortable learning about and discussing sensitive topics?***

Many of the residents have experience discussing sensitive information in group settings and based on that experience they advised us to “be patient and understanding” and watch for signs that someone is becoming uncomfortable. “Understand when you're crossing a line, like maybe seeing visual cues or even the way they're talking, the way they're acting, their body language, anything like that, just seeing how they're feeling in the moment, seeing whether they're comfortable or not, and adjusting what you're saying to that.” This relates to the importance of the facilitator's emotional intelligence, a topic that came up in response to Goal 1, Question 2. Another resident offered, “There's just some people like, no matter, you know, how comfortable you want them to be, they're not really comfortable talking in front of other people. So here we have one-on-one sessions so that we can go talk to somebody privately about what we have going on.” Adult participants agreed that some trainees will be uncomfortable if called upon to share personal experiences of trauma.

A resident advocated for creating a safe space from the outset of the training: “[Some people are] scared of being judged or of people thinking about them differently. So just letting them know that, whatever they say, they're still going to look at them the same. And like, there's just a safe place to talk about trauma, and what they say will stay in confidence.” A community member suggested that some Elders might be positioned to create this safe space.

On the topic of creating a safe space, Healing Lodge staff and community members emphasized the importance of normalizing mental health struggles. Acknowledging the widespread prevalence of mental health struggles from the outset of the training could help trainees feel more comfortable contributing to group discussions. This led into a discussion of setting boundaries. Some staff members acknowledged the importance of sharing lived experiences but cautioned us to mention from the outset that

Our goal here is to give you this training versus having group therapy. Soliciting their stories needs to be done in a way that's not encouraging people to talk for hours and hours and hours and traumatize other people with what they have going on. Engage people in their own stories, but don't let it turn it into a self-therapy session.

This staff member suggested that we provide clear parameters at the beginning of the training to avoid this situation.

Finally, community members suggested that we consider siloing the training, with mental health professionals, community members, and teens all participating separately. The rationale was that

Community members might be reluctant to talk in front of professionals... like it could be like me, a prevention worker, or a child support or enforcement worker, or a Tribal police officer, and then you have some community members who don't want to say anything that might incriminate themselves. And then the same with kids. If you have kids and mixed with adults, they're going to be like, 'Well that person knows my mom or dad or whatever.' So, I think if you want the best result, [creating separate trainings] would be the best way to go.

***Question 3: What are the main cultural considerations we should keep in mind when we design our training?***

In response to this question, participants in all three focus groups spoke about respect. They emphasized that it is essential for the facilitator(s) to show respect for trainees. Recognizing that different people have different learning styles, contribute in different ways, and hold different religious/spiritual beliefs was noted as an important way to show respect. Participants noted that facilitators can also show respect by making the best use of participants' valuable time and mental capacity (in other words, not overloading trainees with information). Finally, participants mentioned that the facilitator(s) can show respect by being inclusive, discussing the role of intergenerational/historical trauma in contemporary struggles, and offering instruction in self-care.

## **Results Synthesis**

We summarize these recommendations and our responses to them in Table 1. We organize the recommendations into three major categories: *planning*, *promotion*, and *delivery* of the First Face training. We address each in the discussion below.

## **DISCUSSION**

We designed *xaʔtus* (First Face) for Mental Health training to broaden and strengthen informal mental health support networks within Tribal communities while potentially providing a bridge to more formal support. Focus group participants' knowledgeable about the needs and priorities of future trainees provided a number of helpful recommendations regarding the planning, promotion, and delivery of this training. Many of these recommendations reflected participants' 2+ years of living with the COVID pandemic. We were struck by the commonalities that emerged

across our three groups of participants. In particular, adolescents in recovery from substance use disorders, their providers, and members of Tribal communities all were concerned with protecting future trainees' physical and psychological safety.

### **Planning Recommendations**

Planning recommendations focused on striking some delicate balances. First, with regard to timing, participants acknowledged that First Face training will require a meaningful time commitment but recommended that we show respect for trainees' time by offering to hold the training during convenient times, factoring in trainees' existing commitments to work and family. Evening and/or weekend sessions were suggested, ideally with multiple options to select from at each Tribal community. Participants noted potential trouble holding teen trainees' attention over a lengthy session, with a possible solution being to integrate the training into high school science or health education classes. This approach would, of course, require permission and logistical support from schools serving Tribal teens.

With regard to the modality of training, participants acknowledged the threat to safety posed by in-person meetings as long as COVID persists but also warned against possible "Zoom fatigue." Zoom fatigue results from a combination of factors, including technical obstacles, difficulty reading the social cues of others, constraints on physical mobility, uncomfortable self-evaluation from seeing oneself on camera, and unfavorable comparison to life before the pandemic (Bailenson, 2021; Shoshan & Wehrt, 2021). In short, participants advised us that while moving our trainings online would be an obvious option for protecting trainees' physical safety, it would come with a substantial well-being cost. Some participants recommended that we host a separate online training for those who are unable or unwilling to attend an in-person training due to the threat to physical safety, lack of childcare, or other barriers. We are reluctant to create an entire live, online First Face training because we feel that the full experience demands in-person interactions. However, we will consider creating an on-demand training experience that we promote as a "mini" training rather than as a full replacement for the in-person experience. In other research, AI/AN people have noted that such virtual spaces can promote inclusivity by (1) welcoming those who would otherwise have trouble attending in-person (e.g., caregivers, people in rural communities) and (2) allowing members to bring "their full selves to the space, children, pets, and all" (Buckingham, Schroeder, & Hutchinson, 2023, p. 13). At the same time, however, we would need to ensure that members have the technological access to virtual spaces

(Buckingham et al., 2023). In addition, we will make the in-person trainings as safe as possible, possibly requiring masks, soliciting proof of COVID vaccination, and/or holding them outdoors.

Community members also highlighted potential problems with asking fellow community members to share their addiction and other mental health challenges with stakeholders representing social services and law enforcement. We appreciate this concern for future trainees' psychological safety. We are reluctant to follow through with the resulting recommendation—creating separate trainings for different stakeholders—because our past research regarding adolescent recovery environments suggests the need and desire for better communication across Tribal stakeholder groups (Whelshula et al., 2021). However, we can and will set ground rules for confidentiality around what is shared and caution trainees not to share any information that might have negative consequences for them or their families as part of our broader efforts to set boundaries around sharing personal stories.

### **Promotion Recommendations**

All three groups of participants highlighted community members' possible reluctance to become a First Face due to fear about the responsibilities associated with taking on this role. This concern is justified. Informal mental health caregiving can place a substantial burden on the caregiver. This is especially true when the informal caregiving is offered frequently and when the recipient is experiencing a mental health condition of long duration (Byrom, 2017). One college student in Byrom's (2017) study described the burden of this responsibility in this way: "When I was trying to support her, it put a huge strain on my confidence and mental health, as I felt responsible for her; if I wasn't around to help her and something went wrong, it was my fault" (p. 205). Our curriculum does acknowledge the spiritual, emotional, mental, and even physical demands of mental health caregiving. However, it also conveys our vision of First Face assistance; specifically, we envision that First Faces will typically offer assistance on a more situational/ occasional basis than on an extended basis, in a way that parallels the provision of first aid. We also clarify in our curriculum that "serving as a First Face is not the same as being a professional healthcare provider or a traditional healer." Based on focus group participants' recommendations, in our promotional materials, we will take care to distinguish between a First Face and a professional mental healthcare provider. Also, we will specify that we envision First Face assistance to be offered on a situational/occasional basis and as bridge to professional help, perhaps using the analogy of a



layperson who provides first aid when the situation demands it. First aid might be a more helpful analogy than CPR or the Heimlich maneuver because we want to avoid making trainees, or potential trainees, feel that they will be responsible for saving lives. Specifically, we intend to train First Faces to always seek professional assistance in the event of any urgent medical situation or situation where the physical safety of the First Face or individual in crisis is at risk.

Additionally, based on participants' concerns in this area, we will consider developing a sustained opportunity for trained First Faces to discuss their experiences and provide mutual support. Trained First Faces could log onto a website or app that provides information and resources, including a refresher on the First Face steps, and receive peer psychological support from fellow trainees. Although a meta-analysis suggested that such interventions have very small beneficial effects on caregiver mental health, caregivers in the included studies all provided sustained care to adults experiencing chronic conditions, such as dementia (Sherifali et al., 2018). More research is needed to examine the impact of such an intervention on community members providing occasional/situational mental health support.

Another recommendation regarding promotion was to highlight the personal relevance of First Face training. We will act on this recommendation by providing language along the lines of, “*xa?tus* (First Face) for Mental Health training will teach you skills for responding to mental health and substance use challenges that are common in Tribal communities such as yours.” We also will highlight the various ways that one can act as a First Face, so that it is clear that there are many ways to increase personal relevance and comfort.

### **Delivery Recommendations**

In another expression of concern for future trainees' psychological safety, focus group participants anticipated that discussions of systemic racism, war, COVID, and mass shootings could become heated and distressing. Indeed, according to a poll conducted in the spring of 2019, 85% of American adults believe that political debate in this country has become more negative and less respectful over the last several years (Pew Research Center, 2019). At the same time, focus group participants acknowledged the mental health toll of these issues and resulting need for a program like First Face. We will strike a balance by acknowledging the impact of these and other traumatic experiences on mental health. Thereafter, we will frame the training session as solutions-focused rather than as an opportunity for political debates.

Role playing is an effective, active training technique commonly used in counseling/psychology and other helping professions (Gibbs, 2019). We anticipate that it will be part of the First Face training program, with Trainee A playing the part of a person in distress and Trainee B playing the part of a First Face (and vice versa). This activity will give trainees the opportunity to practice the First Face steps. It will also give trainees the opportunity to experience the First Face steps from the perspective of a recipient; more generally, playing the part of a person in mental health distress could meaningfully reduce stigma. We asked focus group participants how they expect trainees to receive this educational activity. Echoing published research in this area, focus group participants anticipated some awkwardness. Playing the part of the mental healthcare recipient is especially difficult; often, trainees lack the acting skills or desire to act out a mental health challenge or crisis, especially in public (Pomerantz, 2003). Awkwardness is exacerbated when trainees already know each other because it becomes more difficult to take on assumed identities (Pomerantz, 2003). Solutions offered in formal counseling/psychology training—substituting the role of the recipient with virtual reality or professional actors (Rogers et al., 2022)—are likely not feasible for First Face training. Additionally, these solutions would deprive trainees of the opportunity to take the perspective of someone who might one day receive their support. However, following participants' recommendations, we will try to minimize awkwardness by delaying the role-play activity until later in the training, when participants are more comfortable, and keeping it out of public display. We will also instruct trainees that no one is judging them on their acting skills, provide written cases in advance for trainees to review and familiarize themselves with, and provide tips for how to act out specific issues and mental health problems a First Face might encounter. An additional option is to set aside time for a trainer to act out the part of the First Face or individual experiencing a mental health challenge at the start of the role-playing activity before asking trainees to do so, which might also help reduce tension.

In addition to role playing, we will incorporate several other active learning activities into First Face training, minimizing the time participants spend passively receiving information. Some activities will ask participants to reflect privately on their own experiences to increase the relevance of the presented material. As participants intuited, active learning strategies are recommended in all adult learning, including mental health training (Beidas & Kendall, 2010).

Participants indicated that we could show respect to future trainees, in part, by offering instruction in self-care. This recommendation aligns with other research regarding the role of personal care in overall wellness with Native communities (Kading et al., 2019); it also aligns with

our creation of a manual appendix dedicated to the topic of self-care. This appendix explains why self-care for the First Face is essential, including possible emotional, mental, spiritual, and even physical challenges posed by providing First Face aid. It provides self-care strategies and tips, including a “four directions” wheel that includes strategies for protecting one’s emotional, mental, spiritual, and physical wellness. We will address these topics directly in the training, as well.

Finally, we will act on participants’ recommendations to acknowledge a “mind your own business” mindset. This mindset might reflect a desire for health privacy that is particularly acute in small, rural communities, especially communities with extended kinship networks (Tassell et al., 2012). First, we will acknowledge the cyclical relationship between this mindset and mental illness stigma—how stigma deters people from talking about their own mental health struggles or asking about others’ struggles, and how this secrecy reinforces stigma. To illustrate, a young person recently released from a mental health inpatient unit described his reluctance to discuss his struggles by saying, “I wouldn’t go telling people my business.” On the other hand, he noted that he would not be reluctant to discuss hospitalization for a physical health problem (Byrne & Swords, 2015, p. 69). Discussing this distinction between mental and physical health might be helpful for trainees. In an early segment of First Face training, we will ask trainees to consider the analogy between providing support for a mental health challenge and rendering first aid. Could they imagine someone being reluctant to provide the Heimlich Maneuver for fear of invading someone’s privacy? What might be the effects of such a mindset? We will explain that it is possible to offer informal mental health support while at the same time protecting recipients’ privacy and respecting their boundaries. Our narratives, which anchor each module and demonstrate how to be a First Face, illustrate how a First Face can protect a care recipient’s privacy to the extent possible.

## **Limitations**

To limit the burden on participants, we reduced the focus group questions down to those we considered most essential. Many other questions might have led to fruitful discussion, such as which mental health concerns are particularly relevant to their own communities, and what they would most like to see covered in the trainings.

Due to their experience in mental health and social services, our participants might have been more interested in First Face training than the population of future trainees. Including a group

of Tribal community members who do not have particular experience or interest in these areas might have resulted in different recommendations.

Following through on some focus group participants' recommendations or ideas that grew out of them, such as developing a separate on-demand version of the training and creating a virtual forum for ongoing education and peer support, would require additional sources of funding and might therefore not be feasible. Other recommendations, such as embedding the training into Tribal teens' schooling, would require substantial coordination with other parties.

As we discussed above, the first author independently summarized participants' responses to the focus group questions. Although their responses were straightforward with relatively little room for interpretation in comparison to most qualitative data, researcher bias is always possible and compounded by the independent process used in this study. In the interest of transparency, we include all participant observations in Table A1 along with the agreed-upon categorizations (planning, promotion, or delivery).

Finally, it is unclear whether these findings are generalizable beyond the communities of interest. Our intention was to improve the planning, promotion, and delivery of training only to these particular communities, and we did not attempt to recruit focus group members who would adequately represent other communities or settings.

## CONCLUSION

Culturally acceptable and feasible interventions are necessary to alleviate persistent health disparities affecting Native people. A limitation of many existing interventions is their focus on the individual level, rather than the community or policy levels (Blue Bird Jernigan et al., 2020). We designed *xaʔtus* (First Face) for Mental Health as a community-based intervention to strengthen networks of informal mental health support. For some Native people, informal support might be a preferred alternative to professional treatment approaches that are rooted in western concepts of health and illness and, therefore, culturally inappropriate. For others, informal support might be a bridge to more formal support. Our next steps are to plan, promote, deliver, and evaluate First Face trainings in seven Tribal communities.

A strength of this work is its incorporation of voices of multiple stakeholders, including teens in recovery from substance use disorders and other mental health conditions, alongside their providers and educators/social service professionals from some of their home communities. Focus

group participants provided valuable insights regarding how the training might be received by Tribal community members. Their responses to many focus group questions show concern for future trainees' physical and psychological safety, including recommendations for minimizing the burden that future trainees will assume, optimizing trainees' time involvement, and making the training interactive and engaging. As we will explain to trainees, we are hopeful that raising the collective knowledge and skills of a community to respond to mental health challenges will broaden the network of people who are capable of providing occasional mental health support to their community members, thereby meaningfully reducing the burden on any particular First Face.

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### **CONFLICT OF INTEREST**

The authors declare that they have no conflicts of interest.

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## APPENDIX

**Table A1**  
**Participants' recommendations and our responses to them as organized into planning, promotion, and delivery categories**

Category	Recommendation	Mentioned By	Our Response
<b>Planning</b>	Plan to provide food and breaks	All 3 groups	We will provide food and breaks.
	Hold the training at a convenient time; show respect for trainees' time by making the training no longer than it must be; consider an in-school option for teens	All 3 groups	We plan to provide First Face training over two consecutive days but will consider offering options so trainees can choose the time that is most convenient for them (e.g., 2 weekend days, 2 work days); we will also consider providing in-school sessions for teens.
	Acknowledge the potential for Zoom fatigue alongside trainees' fear of contracting COVID	All 3 groups	We will consider offering a hybrid approach, including a live training at each community alongside a remote, on-demand option. Ideally, the live training will happen in an outdoor location.
	Train community members, mental health professionals, and teens separately	Community members	While we acknowledge the rationale for this suggestion, we believe there is value in bringing different stakeholders together to share their perspectives. We will plan to offer combined training sessions but, as mentioned above, might also offer an in-school option for teens. We will provide ground-rules for confidentiality within the training.
<b>Promotion</b>	Highlight the personal relevance of the training	[ORG] staff and residents	In promotional materials, we will provide relatable examples of situations in which First Face training will be helpful.
	Explain the responsibilities of a First Face	All 3 groups	In promotional materials, we will clearly communicate the range of ways in which someone can be a First Face, taking care to distinguish between a First Face and a professional healthcare provider.

**Table A1**  
**Participants' recommendations and our responses to them as organized into planning, promotion, and delivery categories**

Category	Recommendation	Mentioned By	Our Response
<b>Delivery</b>	Acknowledge the "mind your own business" mindset	Community members	We will acknowledge this mindset at the outset of the training and its cyclical relationship with stigma. We will explain the need for providing informal social support in a way that respects community members' privacy and personal boundaries.
	Make the training interactive and engaging	All 3 groups	We will create a training session that combines lectures with frequent interactive activities.
	Provide incentives	Community members, [ORG] staff	We will provide incentives for completing pre- and post-training surveys. We will consider providing small gifts (swag) to those who participate in the training.
	Avoid contentious political debates	All 3 groups	We will strike a balance by acknowledging the impact of these traumatic experiences on mental health and frame the training session as solutions-focused.
	Acknowledge the mental health toll of racism, war, COVID, mass shootings, and other traumatic experiences	All 3 groups	
	Role playing can be uncomfortable but valuable	Community members, [ORG] staff	We will incorporate role playing into our portfolio of interactive activities but will minimize trainees' discomfort by offering it after trainees have gotten comfortable in the training environment and in dyads rather than before the whole group. With trainees' permission, facilitator(s) will observe the role playing to learn the extent to which essential skills are being learned. We will consider providing a tip sheet that trainees can reference during the role-play activity. It will give suggestions for playing the part of a First Face or someone experiencing a mental health crisis.

**Table A1**  
**Participants' recommendations and our responses to them as organized into planning, promotion, and delivery categories**

Category	Recommendation	Mentioned By	Our Response
<b>Delivery</b>	Elicit lived experience to make the training more relevant and meaningful, but minimize potential harm	All 3 groups	We will weave fictional stories into the training sessions. On a limited basis during group discussion, we will offer the opportunity to share personal stories, but at the outset of the training we will set boundaries regarding the purpose and confidentiality of these stories. We will also provide time for trainees to reflect privately on the relevance of the training material to their own lives. No trainee will be required to share any personal experiences.
	Offer training in self-care	[ORG] staff	We will provide a training module on the topic of self-care, including a review of specific self-care strategies for the First Face.



# **Complementary Alternative Medicine: A Culturally Centered Approach to Managing Chronic Pain from One American Indian Community**

Kellie Webb, LAT, Allyson Kelley, DrPH, MPH, CHES, Desiree Restad, MPH, Kelley Milligan, MPH, Sadie Posey, Andrea Engavo, and Eastern Shoshone Recovery Program Staff and Community

*Abstract: This evaluation explored the benefits of Complementary Alternative Medicine (CAM) within a reservation-based, State-certified outpatient treatment provider. The three CAM strategies provided were massage, acupuncture, and chiropractic therapies. The evaluation team worked with a peer recovery support specialist and tribal evaluation intern to co-create a one-page, eight-question, fixed-response instrument based on previous work in the community. Surveys were collected by the peer support specialist post-session with individuals receiving CAM therapies. Surveys assessed self-reported impacts, reasons for attending CAM sessions, and mental, physical, spiritual, and emotional health before and after CAM sessions. Paired t-tests were used to examine significant differences in mean scores before and after CAM sessions. A total of 40 participants completed the survey between March 2021 and March 2022. The evaluation found a significant increase in the mean scores for all measured self-reported health ratings: physical, spiritual, emotional, and mental. The greatest increase observed was for physical health ( $M = 5.32$ ,  $SD = 2.53$ ) and physical health after ( $M = 8.38$ ,  $SD = 1.60$ ) based on self-report data;  $t(78) = 6.46$ ,  $p = .0001$ . CAM sessions positively influenced participants; 83% ( $n = 33$ ) reported being more hopeful about their overall health and wellness. The holistic approach demonstrated promising results and potential benefits of CAM on overall wellness and belonging. Further research is needed to explore how CAM may be implemented as a culturally centered approach to managing chronic pain often associated with opioid use disorder.*

## INTRODUCTION

American Indians and Alaska Natives (AI/ANs) experience disparities in drug and opioid-involved overdose mortality rates when compared with other racial and ethnic groups (Centers for Disease Control and Prevention, 2022; O'Donnell et al., 2019; Mack et al., 2017). Between 1999-2019, opioid-involved overdose mortality rates among AI/ANs have seen a significant increase from 5.2 to 33.9 per 100,000 AI/AN persons (Qeadan et al., 2022). One national study calls attention to the devastating and disproportionate impacts of opioid overdose deaths on tribal lands; from 2006 to 2014 AI/ANs were 50% more likely to die of an opioid overdose than non-AI/ANs (Horwitz et al., 2020). Historical and political factors such as boarding schools, forced relocation, unresolved trauma, and discrimination contribute to health inequities and increased mortality among AI/ANs (Gone & Trimble, 2012). Poor working conditions, lack of economic opportunities, and limited social capital in communities are the primary drivers of opioid misuse (National Academies of Sciences, 2017). These factors, coupled with unregulated opioid prescribing practices, systemic issues with health care facilities and health service delivery in Indian country, and unfair marketing practices targeting AI/AN populations, have resulted in a significant drug crisis (Whelshula et al., 2021).

Western models of opioid prevention and treatment are often applied to AI/AN populations in an effort to address the current epidemic. Medication-assisted treatment (MAT) such as buprenorphine/naloxone is one intervention approach used in the US general population and in AI/AN communities (Lillie et al., 2021). However, AI/AN populations do not have equitable access to MAT providers (SAMHSA, 2021), and even when AI/ANs are in specialty treatment facilities, they do not receive medication for opioid use disorder (OUD) at the same rates as non-AI/ANs (Krawczyk et al., 2021). Rurality, previous negative experiences in health care settings, and differences in beliefs about Western medical models and approaches make it difficult to utilize MAT in AI/AN communities. Western models have historically pathologized addiction using stigmatizing terms and labels and punitive approaches. Some treatment models are based on power, where the clinician is viewed as superior and more knowledgeable about recovery (Kelley, 2022). Additionally, Western models emphasize the role of the individual in diagnosis, treatment, and recovery (Moghaddam & Momper, 2011). In contrast, Indigenous models of healing rely on culture, tradition, kinship systems, and community resources to heal (Kelley et al., 2015). Healing advocates are calling for opioid prevention and treatment approaches that integrate cultural beliefs, practices, community, and family to create conditions that support holistic wellness and connections (West et al., 2021).

Efforts to address OUD in AI/AN populations are somewhat limited. The National Institutes of Health (NIH) HEAL Initiative, launched in 2019, aims to integrate medication-based treatment into primary health care and addiction treatment settings using culturally appropriate methods (NIH, 2022). No outcomes from this research have been published. The Indian Health Service (IHS), a federal health program for AI/ANs, has developed several resources, funding opportunities, trainings, and recommendations for addressing OUD and pain in AI/AN populations (IHS, 2022). IHS work has resulted in increased funding to AI/AN providers and community health programs, but individual and community-level outcomes have not been published. The Substance Abuse and Mental Health Services Administration (SAMHSA) has expanded several opioid-related grants for communities and health centers that fund the implementation of evidence-based treatment and prevention programs (SAMHSA, 2022). SAMHSA grants have increased access to MAT and increased funding, totaling over \$6.6 billion in 2022.

Complementary Alternative Medicine (CAM) is increasingly being used to promote wellness and address chronic pain conditions typically treated with opioids (Axon et al., 2019; Jimenez et al., 2011). CAM (also called complementary health approaches, complementary therapies, or alternative pain management) approaches can come from the community, do not rely on Western models of health care and medications, and are more accessible and affordable. Although CAM strategies have been criticized for their cost, potential side effects, and limited rigorous evaluations to demonstrate efficacy, they are increasingly being used to promote optimal health and healing (Staud, 2011; Clarke et al., 2015). One study found that CAM strategies, including massage, acupuncture, chiropractic treatment, herbs and supplements, and prolotherapy, were widely used by patients receiving opioids for chronic pain but found limited evidence of whether this reduced the use of opioids (Fleming et al., 2007). While there are limited studies examining the effectiveness of CAM strategies, one rural community found that integrating CAM into primary care pain management helped patients reduce opioid use (Mehl-Madrona, 2016).

While multiple CAM strategies exist, this paper focuses on three: massage, acupuncture, and chiropractic therapies. Acupuncture is often used to relieve physical withdrawal symptoms, help with relaxation, and reduce drug and alcohol cravings (SAMHSA, 2015). However, systematic reviews of acupuncture for the treatment of opioids, alcohol, and cocaine have not provided any evidence of efficacy (SAMHSA, 2015). Chiropractic treatments may alleviate chronic pain and improve general health (Mann & Mattox, 2018), and massage promotes relaxation and feelings of well-being (SAMHSA, 2015). A review of massage therapy for chronic

non-malignant pain found varying levels of evidence for the treatment of chronic pain conditions (Tsao, 2007). The lack of evidence for CAM in general, and in the AI/AN population, requires formative research and evaluation to discern how CAM approaches are related to decreased opioid use. The current evaluation fills a gap in the literature by outlining the process of planning and implementing CAM sessions over a 12-month period in one rural AI community. Additionally, this work explores the self-reported impacts of participation in CAM strategies in a rural tribal community.

## **Community**

The Tribe is located in the Rocky Mountain region. With more than 2.2 million acres of rural land, the reservation is home to 12,500 tribal members. The Healing Center is a State-certified provider for substance use services as an outpatient treatment provider and provides integrated treatment services for substance use, mental health, and cultural resilience. Its mission is to provide community-based, integrated prevention and treatment services that encompass core cultural values and the Medicine Wheel teachings for individuals, families, and the community. Medicine Wheel teachings are based on the Wellbriety movement and traditions such as interconnectedness, service, belonging, spirituality, and honor (White Bison, n.d.). The Healing Center designed and implemented CAM sessions over a 12-month period. CAM sessions were funded with an opioid-related treatment grant from SAMSHA and were offered in two locations, one in a non-reservation border town and the other in a private room located in the reservation-based Healing Center. Sessions were open to anyone in the community, including non-AI/AN populations, and individuals without OUD or chronic pain issues. This approach is consistent with tribal values of inclusivity, kinship systems, and community. Utilizing a multi-pronged outreach approach, the Healing Center promoted CAM sessions on social media, printed posters, email communications, and word-of-mouth.

## **METHODS**

### **Designing the Instrument and Collecting Data**

The evaluation team and Healing Center utilized principles of community-based participatory research (CBPR) informed by Indigenous and community knowledge to design and

implement the project (see Table 1). The evaluation team worked in collaboration with the Healing Center and staff where co-learning, empowerment, and reflection were evident. Dissemination of findings and knowledge gained occurred at multiple levels (via graphical abstracts, presentations to staff and tribal leaders, and on social media). Consistent with these principles, the evaluation team and Healing Center co-created a simple one-page instrument with eight questions based on previous work in the community and with this population (Kelley et al., 2019; Kelley et al., 2017; see Appendix for instrument). Most questions were fixed-response, and no identifying information was collected, including participant status (community member, OUD participant, substance use disorder [SUD] participant, or professional), age, gender, sexual orientation, or location. This was important because it honors the tribal values of respect and privacy. It's also more inclusive and less stigmatizing for individuals who are seeking services for OUD at the Healing Center. Participants rated their overall health before and after attending the CAM sessions using a retrospective pre-post method (Skeff, 1992). This method was preferred over a traditional pre- and post-survey method because of challenges with recruitment, retention, and data collection capacity (Kelley, 2018, 2022). Pre- and post-health ratings were based on the Medicine Wheel domains of physical, spiritual, emotional, and mental health. Ratings were based on a 10-point scale where 1 = was very poor health and 10 = excellent health. The last question asked participants to write recommendations for improving future sessions (see Appendix). The Healing Center utilized a trained peer support specialist and a tribal evaluation intern associate, all members of the tribe. Together they collected surveys post-CAM sessions (at completion) with individuals receiving massage, chiropractic, and acupuncture services at the two locations. The tribal evaluation intern entered all data into Excel and sent the electronic data files to the lead evaluator. The lead evaluator then analyzed the data. The first author (KW) is a tribal member along with authors five (SP), six (AE), and seven (program staff).

## **Data Analysis**

All quantitative analyses were completed using SPSS (Version 26; IBM Corporation). Basic frequency counts and descriptive statistics were run first. Then paired t-tests were used to examine significant differences in mean scores before and after CAM sessions. Open-ended qualitative data were reviewed by all authors and summarized; no further analysis was conducted due to the limited number of responses.

**Table 1**  
***Indigenous CBPR principles and application in CAM evaluation***

<b>Principle</b>	<b>Evidence of Principle in CAM Evaluation</b>
Acknowledge historical experience with research and with health issues and work to overcome the negative image of research.	Limited data collection and invasive questions due to negative image of data collection, research, and surveys.
Recognize tribal sovereignty.	Tribal council approved CAM evaluation and dissemination of findings
Differentiate between tribal and community membership.	CAM sessions elevated tribal membership and access.
Understand tribal diversity and its implications.	Recognized in this evaluation, questionnaire, and use of tribal preferred language and questions. Realize that some Western data collection preferences are not welcomed, for example, health and substance use histories.
Plan for extended timelines.	Healing Center directed timelines and data collection schedules.
Recognize key gatekeepers.	Tribal peer recovery support specialist and tribal evaluation intern acknowledged as gatekeepers.
Prepare for leadership turnover.	Cross training of staff, although no turnover occurred.
Interpret data within the cultural context.	Tribal members (elders and youth) developed data collection instruments and reviewed data for cultural relevance.
Utilize Indigenous ways of knowing	Integrated into all planning implementation and reporting of CAM findings.

*Note:* Principles adapted from LeVeaux & Christopher, 2009; Kelley 2018; Kelley 2020

## RESULTS

Forty participants attended CAM sessions offered by the Healing Center from March 2021 to March 2022. Participants included clients with OUD receiving services from the Healing Center and other community members and professionals with wellness needs. Nine participants attended massage, 12 participants attended acupuncture, and 19 attended chiropractic sessions. Session attendance varied; the average number of CAM sessions attended by participants was 6.5 (Range = 1-20,  $SD = 4.47$ ). More than one-third (37%,  $n = 15$ ) of participants reported they have been to a CAM session before, and just 20% ( $n = 8$ ) responded that they would go to a CAM session on their own if the Healing Center did not offer these sessions.

Reasons for attending CAM sessions varied. The number one reason for attending was better sleep (75%,  $n = 30$ ), and the second most frequent reason was muscle pain (70%,  $n = 28$ ). Other reasons include diabetes ( $n = 2$ ), knee pain ( $n = 1$ ), rheumatoid arthritis ( $n = 1$ ), inflammation

( $n = 1$ ), shoulder pain ( $n = 1$ ), leg pain ( $n = 1$ ), and vertigo ( $n = 1$ ). More than 70% of participants ( $n = 28$ ) felt the CAM sessions were helpful.

Participants reported improvements in health for all Medicine Wheel domains (see Table 2). There was a significant increase in the mean scores for all measured self-reported health ratings. The greatest increase observed was for physical health ( $M = 5.32$ ,  $SD = 2.53$ ) and physical health after ( $M = 8.38$ ,  $SD = 1.60$ ), based on self-report data;  $t(78) = 6.46$ ,  $p = .0001$ . Self-reported scores also improved for the following Medicine Wheel domains: spiritual health before ( $M = 6.32$ ,  $SD = 2.50$ ) and spiritual health after ( $M = 8.54$ ,  $SD = 1.36$ );  $t(78) = 4.93$ ,  $p = .0001$ , emotional health before ( $M = 6.08$ ,  $SD = 2.27$ ) and emotional health after ( $M = 8.41$ ,  $SD = 1.46$ );  $t(78) = 5.45$ ,  $p = .0001$ , mental health before ( $M = 6.32$ ,  $SD = 2.43$ ) and mental health after ( $M = 8.39$ ,  $SD = 1.83$ );  $t(78) = 4.30$ ,  $p = .0001$ .

**Table 2**  
**Self-reported health ratings after CAM sessions ( $n = 40$ )**

Domain	Before	After	Difference	Significance*
Physical	5.32	8.38	3.06	.0001
Spiritual	6.32	8.54	2.22	.0001
Emotional	6.08	8.41	2.33	.0001
Mental	6.32	8.39	2.08	.0001

\* $p < .001$

### Self-reported CAM Impacts

CAM sessions positively impacted participants. Based on self-report data collected using the CAM instrument, 25% ( $n = 10$ ) take fewer prescription medications, 35% ( $n = 14$ ) feel like they belong, 40% ( $n = 16$ ) are more confident in their sobriety, 53% ( $n = 21$ ) feel like there are more resources in their community to help them, 70% ( $n = 28$ ) know more about alternative pain management strategies, and 83% ( $n = 33$ ) are more hopeful about their overall health and wellness. Two other participants wrote in additional responses: CAM sessions helped with my anxiety, and CAM sessions helped me become aware of physical issues that need further attention.

### Participant Suggestions

Six participants had recommendations for improvement of CAM sessions based on the open response question, “Do you have any suggestions on how to improve future acupuncture



(CAM) sessions?’. Two recommended longer session times, two asked the program to continue offering CAM sessions, one requested more flexible times for CAM sessions, and one wrote they would like beach sounds.

### **Limitations**

The evaluation findings from CAM sessions are subject to a few limitations. First, the relatively small and heterogeneous sample means that these results are not generalizable to other populations and communities. Second, social desirability bias may have influenced how individuals responded to the instrument (Larson, 2019). Third, all data were self-report and based on perceived changes from sessions. It is possible that individuals perceived the impacts more favorably than they were. Fourth, due to the small sample size, all CAM session data were combined into one overall sample for this evaluation. It is possible that the impacts and outcomes related to massage, chiropractic, and acupuncture are different when viewed as individual groups and not aggregated. Finally, this was an open study and did not have a comparison group; therefore, demonstrating the effectiveness of CAM relating to opioid use, pain management, and overall wellness is not possible. Even with these limitations, the approach demonstrated in this paper from this community provides a framework and preliminary data demonstrating that CAM strategies were perceived by participants to help promote holistic wellness, including chronic pain management and improved physical health. More importantly, it addresses the whole person and four domains of wellness (mental, physical, spiritual, and emotional), not just SUD/OD.

## **DISCUSSION**

To address extant health disparities and the opioid overdose crisis in AI/AN communities, CAM provides a promising and realistic approach. AI/AN communities may not have full access to specialty treatment providers, inpatient treatment facilities, MAT, or easy access to Western clinical models of treatment and care, but they may have access to CAM strategies like the ones outlined in this paper that heal, promote hope, and connect individuals to resources and CAM providers in the community. The CAM approach is more congruent with AI/AN values and norms. Offered in the community by members of the community familiar with the culture, traditions, language, and norms, the Healing Center provided a pathway for wellness. Participants know

where to get resources and where to refer friends and family who may be unhealed, and most importantly, healing took place over the year of CAM sessions.

The elders remind us that the answers to our challenges are within the community, within the culture, and inside us. They are not on the outside, and they do not always come from Western science, colonizing approaches, and deficit-based programs. The CAM evaluation presented here demonstrates the promising results of CAM on overall wellness and belonging. While many participants attended CAM sessions to improve sleep and relieve physical pain, the benefits of CAM sessions extended beyond the physical realms. Notably, the CAM approach implemented by the Healing Center is prevention and treatment at the same time. The largest impact was that participants felt more hopeful about their overall health and wellness.

The implications of this evaluation are far-reaching and apply to other communities, contexts, and settings. First, the community-based approach, designed by the Tribal Healing Center, was holistic, connecting, and inclusive. This was felt by participants and the Healing Center staff. Second, offering CAM in two locations improved the recruitment and retention of CAM participants. Third, data collection or documenting the value of CAM sessions can be difficult due to COVID-19, scheduling issues, retention, and distrust of evaluation and research (Kelley et al., 2013). The use of a peer support specialist and a tribal evaluation intern helped address some of the barriers to data collection.

Further evaluation is needed to explore how CAM may be implemented as a culturally centered approach to managing chronic pain often associated with OUD. The Healing Center plans to use these evaluation findings to expand CAM sessions in other settings such as schools, jails, health care facilities, community centers, and tribal offices. Additional research with a comparison group, a larger sample size, and health histories is also necessary. The need for research must be balanced by the level of community readiness and support for data collection, participation in research, and wellness efforts. CAM sessions are not just for pain. CAM is for healing what is unhealed and encouraging all relatives to walk in a journey of wellness and hope. This is what the elders and ancestors would want for our people.

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### **CONFLICT OF INTEREST**

The authors declare that they have no conflicts of interest.

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## APPENDIX

**Note:** These were the same instrument used with modifications to the type of CAM provided (acupuncture, massage, and chiropractic treatment).

### Participant Feedback

We want to know more about your experience. Please take a minute to complete this form. Information will be used to improve future alternative pain management and wellness sessions at HC. Contact the program director at 123-456-7890 for more information.

1. How many acupuncture sessions did you attend at HC? \_\_\_\_\_
2. Have you ever received acupuncture, before the sessions at HC? Yes      No
3. If HC did not offer acupuncture sessions, would you have gone to an acupuncturist on your own? Yes      No      Not Sure
4. What are the reasons that you attended acupuncture session (s) at HC? (select all that apply).
  - ☐ Alternative to taking pain medication
  - ☐ Chronic back or neck pain
  - ☐ Headache relief
  - ☐ Better sleep
  - ☐ Stress relief
  - ☐ Depression and anxiety
  - ☐ Detox
  - ☐ Blood pressure normalization
  - ☐ Other, please describe: \_\_\_\_\_
5. Were the acupuncture sessions helpful? Yes   No   Not Sure
6. Using a scale from 1 to 10, please rate your health BEFORE attending HC acupuncture sessions and AFTER.



**1 is Very Poor Health and 10 is Very Good Health**

	Health Before	Health After	N/A
<i>Example of how to select a score.</i>	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10	
Physical health	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10	
Spiritual health	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10	
Emotional health	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10	
Mental health	1 2 3 4 5 6 7 8 9 10	1 2 3 4 5 6 7 8 9 10	

7. How did participation in the acupuncture session(s) impact you? (select all that apply).
- ☐ I take fewer prescription medications
  - ☐ I know more about alternative pain management strategies
  - ☐ I am more hopeful about my overall health and wellness
  - ☐ I feel like there are more resources in my community to help me
  - ☐ I am more confident in my sobriety
  - ☐ I feel like I belong
  - ☐ Other \_\_\_\_\_
8. Do you have any suggestions on how to improve future acupuncture sessions?

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

Jessica L. Liddell, PhD, MSW/MPH, and Amy L. Stiffarm, cPhD, MPH

*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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