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A POSITIVE YOUTH DEVELOPMENT PERSPECTIVE ON MENTAL DISTRESS AMONG AMERICAN INDIAN/ALASKA NATIVE YOUTH

Ozge Ersan, MA, and Michael C. Rodriguez, PhD

Abstract: Positive youth development approaches with American Indian/ Alaska Native (AI/AN) youth have been particularly successful and promising. Utilizing a survey with 3,736 AI/AN students, we investigated the associations between risk and protective factors and significant mental distress of AI/AN youth. The protective factors were studied within the positive youth development framework, which includes positive developmental assets reflecting aspects of the Circle of Courage, a prior framework embodying core indigenous values for youth development and education to support youth at risk. Risk factors in the study included having experienced trauma, being bullied by peers, substance use, and skipping school; protective factors were social supports, out-of-school-time activity participation, healthy eating, and healthy sleeping behaviors. Through logistic regressions, we found that risk factors were associated with more mental distress, consistent with prior research. However, students who participated in out-of-school-time activities at least three times a week, were sleeping at least eight hours daily, and those reporting social supports, particularly family/community support and sense of empowerment, had lower likelihood of mental distress. In fact, the presence of these protective factors reduced the associations of risk factors and risky behaviors with mental distress.

INTRODUCTION

Although student learning, school success, and meeting state educational achievement standards are top education topics, mental health as a part of student wellness has gained substantial public awareness (e.g., EAB, 2020; National Association of Secondary School Principals, 2019; Shallowhorn, 2018). Considering the association between mental distress and educational attainment and academic achievement, mental distress is a component of educational

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disparities (Becker & Luthar, 2002; Breslau et al., 2008; DeSocio & Hootman, 2004), where researchers acknowledge that some adolescent groups suffer from more considerable mental distress, such as American Indian and Alaska Native (AI/AN) youth.

AI/AN adolescents reported the highest rates of mental health issues, including depression and anxiety, compared to their peers with different racial/ethnic backgrounds (National Institute of Mental Health [NIMH], 2019; Serafini et al., 2017). Moreover, AI/AN adolescents had the highest suicide rates relative to other races/ethnicities in the United States (Center for Disease Control and Prevention [CDC], 2020; Jiang et al., 2015). For instance, in 2012–2013, the suicide rate among young adults 18 to 24 years old was 22.5% for AI/ANs, higher than White (15.4%), Latino (8.3%), Black (8.9%), and Asian (9.4%) young adults (Jiang et al., 2015). In addition, the intentional self-harm rate was highest for AI/AN youth aged 14 to 19 (CDC, 2020). Relatedly, alcohol use, smoking, and substance use were more prevalent among AI/AN youth (Substance Abuse and Mental Health Services Administration [SAMHSA], 2017). These disparities are well documented.

Mental health status is an important part of youth social, emotional, and academic development. Nevertheless, AI/AN students have been historically underserved (Guillory & Wolverton, 2008), and research regarding their academic and developmental outcomes is limited, due to consistently small samples (Peng & Wright, 1994; Hughes et al., 2009) and the complexity of racial, ethnic, and tribal characteristics (Demmert et al., 2006; Wall et al., 2000). Therefore, knowledge and practice regarding AI/AN student experiences and contexts must be understood to better meet their needs and support thriving, including both risk factors that affect their mental health status and protective factors that support their development.

In this study, we addressed mental health status and its associations with risk[1] and protective[2] factors. Using the 2019 Minnesota Student Survey (MSS), with a large sample of AI/AN students, we examined positive youth development perspectives of AI/AN students, including developmental supports and challenges, healthy lifestyle status, and family and social contexts. In examining elements of the ecology of youth development and the occurrence of mental distress, we offer a different elucidation of the developmental journeys of AI/AN students.

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[1] Variables associated with a higher likelihood of negative outcomes (SAMHSA, 2019).

[2] Variables associated with a lower likelihood of negative outcomes or that reduce a risk factor's impact (SAMHSA, 2019).

Risk Factors Associated with Mental Distress

Described in Burnette and Figley's systematic review (2016), risk factors associated with the mental wellness of AI/AN adolescents include societal (e.g., historical oppression, discrimination), cultural (e.g., ethnic identity, spirituality, cultural connectedness), individual (e.g., self-esteem and self-worth, substance use, depression, self-care), familial (e.g., lack of family support, family income, parental mental health, family trauma and stressful life events), and community (e.g., community and school environments, peer influence and support) factors.

As a societal factor, longstanding historical trauma (e.g., negative stereotypes, microaggressions, forced relocation, and prohibition of cultural practices) has lasting impacts on the mental health and well-being of AI/AN communities and is a risk factor for mental distress (Brendtro et al., 2019; Campbell & Evans-Campbell, 2011; Evans-Campbell, 2008). Children and youth carry, as mental distress (emotional, behavioral, and mental health problems), lingering intergenerational trauma (Brokenleg, 2017). Cultural factors or assets, including cultural and ethnic identity, commitment to cultural tribal spirituality, and belonging to one's own culture and value systems, are associated with positive mental health and well-being and lower mental distress and suicide ideation (Garroutte et al., 2003; Hill, 2009; LaFromboise et al., 1993; Masotti et al., 2020).

Individual factors, such as sex, age, family socio-economic status (SES), and race/ethnicity, are strongly associated with mental distress among adolescents. For instance, females and older youth have higher risk of experiencing mental distress or depressive symptoms (Ersan et al., 2018; NIMH, 2019). Similarly, adolescents from families with low SES are more likely to experience mental health problems (Schraedley et al., 1999). Low SES is associated with mental health problems directly, as well as indirectly, through individual (e.g., low quality of nutritional intake), relational (e.g., unhealthy social relationships with family members and peers), or institutional (e.g., school, neighborhood, unstable parental employment) factors (Yoshikawa et al., 2012). Moreover, mixed-race status is associated with higher risk of general health problems and mental health and behavioral problems among youth (Ersan et al., 2018; Garcia et al., 2019; Udry et al., 2003).

Negative family environments are another risk factor. AI/AN youth receiving mental health services reveal high rates of traumatic experiences, such as witnessing domestic violence or experiencing physical, emotional, and sexual abuse at the hands of family members, or living with someone who has substance abuse problems or engages in criminal activity (Borowsky et al., 1999; Burnette & Figley, 2016; Dickerson & Johnson, 2012; Grossman et al., 1991).

Similarly, negative school environments pose community-related risk factors. AI/AN youth often face peer victimization that includes behaviors like racism, cultural insensitivity, and stereotyping that leads to feelings of isolation, low self-esteem, and hopelessness in AI/AN youth (Galliher et al., 2011; Gloppen et al., 2018; Jaramillo et al., 2016; Messias et al., 2014; Silmere & Stiffman, 2006). Youth subsequently internalize these feelings, experience depression, or engage in high-risk behaviors, such as substance use (Boyd-Ball et al., 2006; Johnson & Tomren, 1999; Whitbeck et al., 2001) and suicide attempts (Barlow et al., 2012; Yu et al., 2005). Moreover, school absenteeism is associated with higher risk of depression, suicide ideation, self-harm, social exclusion, and lack of school connectedness, and these factors negatively impact adolescents' emotional and mental health (Burton et al., 2014; Epstein et al., 2019; Gonzálves et al., 2018; Langille et al., 2015; Shochet et al., 2006).

Positive Youth Development

In this study, we promote a positive youth development framework providing an ecological and asset-based approach to AI/AN students' mental health. We also connect positive youth development through an indigenous perspective on youth development through the Circle of Courage.

Positive youth development (PYD) is a framework to bring greater attention to positive aspects of youth development through assets, relationships, and environments that support youth thriving, acknowledging youth as the focus of their own development. The framework indicates when youth participate in multiple meaningful relationships, contexts, and environments, positive development is enhanced (Benson, 1990, 2002; Benson et al., 2006; Lerner et al., 2011). Adolescents who have greater assets (e.g., high level of social supports, empowerment, social competence, positive identity) have lower risk of engaging in alcohol use, aggressive behaviors, and depression and have higher grades in school (Benson et al., 2011; Kang et al., 2018). Most notably, the role and function of developmental assets are relevant and important to youth from diverse communities, including youth from different racial and ethnic communities (Aspen Institute, 2018; Benson et al., 2006).

Family and community social supports benefit AI/AN students' social, emotional, mental, and academic well-being (Benson et al., 2006). Parental support, for instance, is a positive factor in AI/AN students' schooling (Okagaki et al., 2009), and AI/AN adolescents who have peer support are more resilient in general (Stumblingbear-Riddle & Romans, 2012). Most importantly, social supports lower depressive symptoms, promote social and emotional well-being (Cummins et al., 1999; Sherman et al., 2011), and decrease substance use (Kulis et al., 2002). Belongingness and social connectedness are critical basic human motivations (Baumeister & Leary, 1995), particularly for AI/AN youth, where belonging to community is a significant element of identity (Brendtro et al., 2019).

In addition to family and community support, feeling safe in families, schools, and neighborhoods (Côté-Lussier & Fitzpatrick, 2016; Cummins et al., 1999; Meltzer et al., 2007) and being empowered by family warmth and connectedness are additional protective factors associated with lower mental distress and depressive symptoms (Cummins et al., 1999; Whitbeck et al., 2009). Moreover, feelings of school connectedness and having a fair, trustworthy school environment play significant roles in students' mental health (Cummins et al., 1999).

From a PYD perspective, high quality out-of-school-time (OST) activity participation is associated with positive developmental outcomes. For instance, participation in school sports is positively associated with developmental skills and social supports and negatively associated with developmental challenges, including depression, anxiety, and other mental distress (Fraser-Thomas et al., 2005; Hosker et al., 2019; Mason et al., 2009; Van Boekel et al., 2016; Zhu et al., 2019). Participating in structured leisure activities, such as sports, arts, or youth organizations, has a positive impact on development of initiative that is an essential skill on the human development continuum through adulthood (Larson, 2000). For disadvantaged youth with mental health challenges, higher frequency of OST activity participation is associated with higher interpersonal strengths and lower internalizing problems (Abraczinskas et al., 2016).

Finally, maintaining a healthy lifestyle, including eating nutritional diets and getting enough sleep, is important for overall health and wellness. More specific to mental health, sleeping 8 to 10 hours a day on a regular basis, as recommended for teenagers, is associated with better mental and physical health (Hosker et al., 2019; Paruthi et al., 2016; Tarokh et al., 2016) and improved school outcomes (Wahlstrom, 2016). A healthy diet of regularly eating vegetables, fruits, proteins, and healthy grains, as well as limiting sugary drinks and fast foods, have significant, although small, positive associations with lower depression and anxiety (Jacka et al., 2011; Khalid et al., 2017; O'Neil et al., 2014) and are important in maintaining a healthy lifestyle (Hosker et al., 2019).

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The Circle of Courage

The PYD framework primarily directed our work. However, we acknowledge an earlier form of PYD relevant for AI/AN youth, the Circle of Courage, which was introduced in 1990 by Brendtro et al. (2019; third edition), predating the introduction of positive psychology by Seligman and Csikszentmihalyi in 2000. There are meaningful connections between the Circle of Courage and PYD frameworks. The Circle of Courage is formulated in indigenous sacred contexts of the four directions and the medicine wheel. The four core values embodied in the Circle of Courage include belonging, mastery, independence, and generosity.

The spirit of belonging transcends kinship (where kinship is more than biology) and encompasses the recognition of interdependence, not only among people, but all living things, the environment, and Earth. Belonging to community is a significant element of identity. Notions of belonging are similar to PYD concepts of family and community support.

The spirit of mastery is realized through meaningful and appropriate opportunities to learn, to achieve competencies, and to become a model for others. Achievement motivation is essential for positive cognitive, social, emotional, physical, and spiritual competence. In PYD, mastery is developed through supports from family, community, teachers, and schools. Many youth develop important skills through participation in OST activities, particularly those that are culturally grounded.

The spirit of independence includes not only autonomy, but self-control, self-confidence, and shared responsibility. In contrast, mainstream cultural notions of independence focus on assertiveness, competition, and individualism that may lead to a sense of powerlessness, learned helplessness, disengagement, and alienation. In PYD, the related concept of empowerment rests on a sense of safety at home, school, and community; feeling appreciated; and having responsibilities and meaningful roles in the family. Independence is developed through multiple support systems and engagement in meaningful OST activities.

The spirit of generosity is presented as the highest virtue in many indigenous legends and stories; “it is mapped in our genes” (Brendtro et al., 2019, p. 25). When adults give to others in need, children and youth participate in generosity. In PYD, generosity is exemplified through service-learning activities and community engagement, opportunities to engage in caring for others, and promoting self-worth and community-worth by serving others.

Therefore, the Circle of Courage is, in part, characterized in this study through the inclusion of indicators for tribal membership, teacher and school support, family and community support, empowerment, and participation in OST activities, as well as self-care through healthy diets and sleep, all elements of PYD.

Study Purpose

The purpose of this study was to estimate the strength of associations between mental distress and demographic characteristics, risk factors, risky behaviors, and protective factors. In addition, the effects of risk factors and risky behaviors was examined in the presence of protective factors including social support measures, OST activity participation, and healthy behaviors, from a PYD framework. Four research questions were posed:

1. To what extent are student characteristics associated with mental distress?
2. To what extent are risk factors and risky behaviors associated with mental distress (beyond demographics)?
3. To what extent are developmental supports and positive assets associated with mental distress (beyond demographics)?
4. To what extent are demographics, risk factors and risky behaviors, and developmental supports and positive assets simultaneously associated with mental distress?

METHODS

Instrument

The data were from the 2019 Minnesota Student Survey ([MSS], Minnesota Department of Education, 2019), designed by the Departments of Education, Health, Human Services, and Public Safety, administered triennially and anonymously to fifth, eighth, ninth, and eleventh grade public-school students. The purpose of the MSS is to monitor trends in students' well-being, developmental skills and supports, and positive and risky behaviors. Fifth grade students were not asked questions regarding mental health, thus were excluded.

The MSS Interagency Team provided the researchers access to the survey database for secondary data analyses, as part of a larger research program investigating the ecologies of PYD (Minnesota Youth Development Research Group, n.d.), with institutional review board approval.

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Participants

Participants included 3,736 AI/AN students in eighth (38%), ninth (38%), and eleventh (24%) grade, where 53% identified themselves as female and 34% lived in the Twin Cities metropolitan area. The mean age was 14.7 (*SD* = 1.3). About 60% of AI/AN students reported experiencing mental distress, although much higher among females (71%) than males (48%). Students could select all racial/ethnic categories to which they identified. Accordingly, 30% of the AI/AN participants reported only AI/AN identification, and 70% identified with multiple racial/ethnic groups. The most common combination included White (44%), followed by Black (4%), other (5%), or combinations of Asian, Black, White, and Latino (18%). Additionally, three options for tribal affiliation were available; students identified themselves as Anishinaabe/Ojibwe (51%) and Dakota/Lakota (17%), the two largest tribal communities in Minnesota, with the remaining in the *other tribal affiliation* category (34%).

Measures

All study variables, associated items from the MSS, and response options for each item are listed in Appendix Table A1.

Mental Distress

Mental distress was measured in the MSS (Rodriguez, 2017) as a severe form of mental distress, including having long-term mental health, behavioral, or emotional problems; having been treated for mental health, emotional, or behavioral problems; having considered or attempted suicide; or purposefully hurting or injuring oneself. The dichotomous mental distress indicator identified students who reported experiencing at least one instance of severe mental distress. AI/AN youth had the largest percentage (60%) with mental distress, followed by multiracial/ethnic students (48%), Latino students (46%), White students (40%), Black students (37%), and Asian students (34%).

Demographics

Demographic variables included age, sex (male as reference group), and participation in free/reduced priced lunch (a proxy for low SES). Racial identification was grouped into five categories with AI/AN-only as the reference group, including AI/AN-White, AI/AN-Black, AI/AN with other races/ethnicities (Asian-Pacific Islander, Latino), and AI/AN-multiple races/ethnicities (more than two). Tribal affiliation was grouped into three categories: Anishinaabe/Ojibwe, Dakota/Lakota, and other tribal affiliation (reference group).

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Risk Factors

Trauma, a dichotomous variable, indicated students who reported they had experienced at least one trauma event, consistent with the Adverse Childhood Experiences used by the CDC (2020; see Table A1 in Appendix). Being bullied was a continuous measure (based on 14 items; see Table A1 in Appendix).

Risky Behaviors

Substance use, a dichotomous variable, indicated students who reported they used alcohol, marijuana, or other drugs at least once during the last 12 months. Skipping school, a dichotomous variable, indicated students who reported they missed at least one full day of school during the last 30 days without an excuse.

Social Support

Family/community support, sense of empowerment (Empowerment from the Search Institute [2013] Developmental Asset Profile), and teacher/school support were continuous measures of social supports created based on students' self-reported responses to the relevant items (see Table A1 in Appendix).

Two primary sources of validity evidence for MSS measures included content-related evidence (documented in Benson, 1990, 2002; Benson et al., 2006; Search Institute, 2013) and construct-related evidence obtained from 2013, 2016, and 2019 MSS data (Rodriguez, 2017). To support construct-related inferences, the internal structure of the measures was evaluated through confirmatory factor analysis (CFA; using Mplus v.7; Muthén & Muthén, 2012). Overall, the fit indices, factor loadings, and correlations supported the use of these items as indicators of developmental support measures (Rodriguez, 2017). The support measures were scored using the partial credit Rasch model (Masters, 1982) in Winsteps 4.4.7 (Linacre, 2019). Each continuous measure was standardized with a minimum score of zero for analysis.

Out-of-school-time (OST) Activity Participation

Students were asked how many days in a typical week they participate in any of six categories of OST activities (see Table A1 in Appendix). The OST activity participation was an indicator of participating in one or more OST activities at least three times a week.

Nutrition and Sleep

Healthy dieter was a dichotomous indicator for students who reported to eat fruit and vegetables at least 4 times in the last 7 days. Similarly, healthy sleeper was a dichotomous indicator

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for students who reported to sleep at least 8 hours in a typical school night (based on recommendations of the American Academy of Sleep Medicine; Paruthi et al., 2016).

Statistical Analysis

We first examined frequencies and descriptive statistics of each variable (Tables 1 and 2), as well as intercorrelations among variables (Table A2 in Appendix). The study has a cross-sectional design where magnitude of associations were examined. We employed four logistic regression models to answer each of the research questions. Accordingly, in the first model, odds of having mental distress was examined as a function of student characteristics only. In Model 2, risk factors and risky behaviors, and in Model 3, protective factors (social supports, OST activity participation, and healthy behaviors), were added separately in addition to the student characteristics. Finally, all the study variables were examined in Model 4 (full model). Since the outcome measure, mental distress, was dichotomous, the logistic regression coefficient was the estimated change in the log-odds of experiencing mental distress, due to the presence of a student characteristic or one-unit change in the value of the continuous variables (Szumilas, 2010).

The exponential function of the regression coefficients correspond to the odds ratio (OR) of having experienced mental distress. ORs provide relative odds of having experienced mental distress. Accordingly, the adjusted OR equals the ratio of having experienced mental distress to not having experienced mental distress, conditioned on an explanatory variable, or when controlling others. For each logistic regression model, OR and 95% confidence intervals were reported. We presented McFadden's Pseudo-R^2 (an approximation of the proportion of variance explained by explanatory variables appropriate for logistic regression; Smith & McKenna, 2013) and Akaike Information Criterion (AIC; Bozdogan, 1987) for each model for model comparison.

RESULTS

Descriptive Statistics

The frequencies and descriptive statistics of each variable used in this study were reported in Table 1 and Table 2, by mental distress status. In addition, we reported the OR of having experienced mental distress given each explanatory variable independently (relative to the reference group). These are unadjusted ORs, examining the effect of each group characteristic or

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lowest level of each continuous variable (age, being bullied, family/community support, sense of empowerment, teacher/school support).

Table 1 shows the frequency and proportion distributions of the levels of given categorical explanatory variables. The ORs for categorical variables indicate change in OR for the remaining groups relative to the reference category. Table 2 contains continuous explanatory variables and shows their means and standard deviations. Accordingly, being bullied, family/community support, sense of empowerment, and teacher/school support were centered so that minimum value is 0 with *SD* = 1.0. The OR for age is the change in OR for each additional year of age. For being bullied, family/community support, sense of empowerment, and teacher/school support, ORs represent the change in odds of having experienced mental distress for a one *SD* increase in the measure score.

Table 1

Frequencies and Proportions of the Levels of Categorical Explanatory Variables as a Function of Mental Distress Status and Independent Bivariate Logistic Regression Results

	Not experiencing mental distress (*n* = 1503, 40%)		**Experiencing some mental distress (*n* =2233, 60%)**		**Logistic regression odd ratios**	
	n	**%**	***n***	**%**	**OR**	**95% CI**
Demographics						
Free/reduced priced lunch						
No (reference)	759	48	839	52		
Yes	744	35	1394	65	1.70***	[1.49, 1.95]
Gender						
Male (reference)	925	52	847	48		
Female	578	29	1386	71	2.62***	[2.29, 3.00]
Race						
AI/AN (reference)	472	42	638	58		
AI/AN-White	670	41	966	59	1.07	[0.91, 1.24]
AI/AN-Black	68	47	78	53	0.85	[0.60, 1.20]
AI/AN-other	77	46	91	54	0.87	[0.63, 1.21]
AI/AN-multi	216	32	460	68	1.58***	[1.29, 1.93]
Tribe						
Other (reference)	564	40	832	60		
Anishinaabe/Ojibwe	740	40	1107	60	1.02	[0.89, 1.17]
Dakota/Lakota	199	40	294	60	1.06	[0.88, 1.27]
Risk factors						
Trauma						
No (reference)	808	61	522	39		
Yes	695	29	1711	71	3.81***	[3.31, 4.39]

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Table 1 Continued

Frequencies and Proportions of the Levels of Categorical Explanatory Variables as a Function of Mental Distress Status and Independent Bivariate Logistic Regression Results

	Not experiencing mental distress (*n* = 1503, 40%)		**Experiencing some mental distress (*n* =2233, 60%)**		**Logistic regression odd ratios**	
	n	**%**	***n***	**%**	**OR**	**95% CI**
Risky behaviors						
Substance use						
No (reference)	1151	52	1045	48		
Yes	352	23	1188	77	3.72***	[3.22, 4.30]
Skip school or class						
No (reference)	629	47	711	53		
Yes	874	36	1522	64	1.54***	[1.35, 1.76]
Protective factors						
Out-of-school-time activities						
No (reference)	659	34	1252	66		
Yes	844	46	981	54	0.61***	[0.54, 0.70]
Healthy diet						
No (reference)	782	38	1292	62		
Yes	721	43	941	57	0.79***	[0.69, 0.90]
Healthy sleep						
No (reference)	916	34	1738	66		
Yes	587	54	495	46	0.44***	[0.38, 0.51]

Note. *$p < .05$. **$p < .01$. *** $p< .001$.

Table 2

Means and Standard Deviations of Continuous Explanatory Variables as a Function of Mental Distress Status and Independent Bivariate Logistic Regression Results

	Not experiencing mental distress (*n* = 1503, 40%)		**Experiencing some mental distress (*n* =2233, 60%)**		**Logistic regression odd ratios**	
	M	***SD***	***M***	***SD***	**OR**	**95% CI**
Demographics						
Age	14.6	1.27	14.7	1.26	1.06*	[1.01, 1.12]
Risk factors						
Being bullied	0.85	0.90	1.57	0.96	2.19***	[2.03, 2.36]
Protective factors						
Family/community support	3.14	0.96	2.43	0.92	0.46***	[0.42, 0.49]
Empowerment	3.81	0.97	3.04	0.89	0.42***	[0.39, 0.45]
Teacher/school support	3.24	0.97	2.76	0.97	0.60***	[0.56, 0.65]

Note. *$p < .05$. **$p < .01$. *** $p< .001$.

Logistic Regression Results

Logistic regression models in Table 3 correspond to each research question; all of the ORs in Table 3 are adjusted ORs, conditioned on the other variables within the model. Regarding demographic variables, age (*OR* = 1.09), participation in free/reduced priced lunch (OR = 1.79), and being female (*OR* = 2.60) were positively associated with higher odds of mental distress (Model 1). For example, the odds of having mental distress for females was 2.6 times greater than males, conditioned on other student characteristics in the model. Furthermore, students who identified as AI/AN-White (*OR* = 1.18) or AI/AN with multiple racial/ethnic combination (*OR* = 1.54) had higher odds of mental distress than students who identified as AI/AN only, the reference group. For other AI/AN mixed race/ethnicity groups, the odds of having mental distress were not significantly different than AI/AN-only students (possibly due to smaller group size). Regarding tribal identity, the odds of having mental distress for students who identified as Anishinaabe/Ojibwe and Dakota/Lakota were not different than those with other tribal affiliation.

For Model 2, both risk factors (experiencing trauma and being bullied) and risky behaviors (substance use and skipping school) were associated with higher odds of having mental distress, when controlling for demographic characteristics of students. According to Model 2, experiencing trauma (*OR* = 2.42) and being bullied by peers (*OR* = 1.85) were strongly associated with experiencing mental distress. In other words, according to Model 2 results, the odds of having mental distress were 2.42 times and 1.85 times greater for students who experienced trauma and were being bullied, respectively, conditioned on other variables in the models. In addition, the odds of having mental distress were 2.33 times greater for students using any substance (cigarette, alcohol, drug, etc.) compared to students not using substances, and 1.18 times greater for students who skipped school or class than ones who did not, controlling for other variables in the model.

Regarding protective factors, and specifically social supports (Model 3), family/community support (*OR* = 0.70) and sense of empowerment (*OR* = 0.57) were associated with lower ORs of mental distress. However, teacher/school support (*OR* = 1.00) was not associated with the likelihood of experiencing mental distress, when controlling for other variables in the model. Accordingly, one *SD* increase in family/community support was associated with 0.70 times the odds and one *SD* increase in sense of empowerment was associated with 0.57 times the odds of experiencing mental distress; more family/community support and sense of empowerment was associated with substantially lower likelihood of experiencing mental distress.

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Similarly, we examined the association of OST activity participation, healthy diet, and healthy sleep with mental distress. When controlling for other variables in the model, OST activity participation (*OR* = 0.82) and healthy sleep (*OR* = 0.73) were associated with lower odds of experiencing mental distress; however, healthy diet was not statistically significantly associated with mental distress. It should be noted that this does not mean eating healthy was not associated with mental distress, rather as shown in Table 1, it was associated with significantly lower odds of having mental distress (*OR* = 0.79). However, when the effects of other variables were included in the model, healthy diet no longer explained significant incremental variation in the odds of having mental distress.

In addition, we examined the proportion of explained variance as a measure of goodness of fit that shows how well the variation in dependent variable is explained approximately by the model. Accordingly, McFadden R^2 showed the increase in variance explained was about .14 when adding risk factors, or there was about .10 additional explained variance when adding protective factors above demographics. Finally, in Model 4, all variables were examined simultaneously, risk and protective factors together explain even more variance (.18) above demographics. Similarly, AIC suggested Model 4 had better model-data fit compared to other models.

Relative to the other models, in Model 4, skipping school (*OR* = 1.12) was no longer significantly associated with mental distress, and teacher/school support (*OR* = 1.15) was significantly associated with mental distress in the unexpected direction. Teacher/school support counterintuitively predicted a slightly higher likelihood of mental distress.

In Model 4, we observed slight changes in most ORs relative to Model 2, which did not include the protective factors. The negative effects of being female, being older adolescent, and having low SES were slightly smaller, and the ORs associated with risk factors and risky behaviors were smaller, especially with trauma. Without the inclusion of protective factors, the OR for mental distress associated with trauma experiences was 2.42; with protective factors the OR was 1.90. In the presence of the few protective factors included in this model, the adjusted odds of experiencing mental distress being associated with experiencing trauma was reduced by about 37% ([2.42-1.90] / [2.42-1.00]). Similarly, the adjusted odds of experiencing mental distress being associated with being bullied and substance use were reduced by about 18% and 15%, respectively, comparing Model 4 to Model 2.

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Table 3

Logistic Regression Results Predicting Mental Distress

Variables	Model 1		Model 2		Model 3		Model 4	
	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Demographics								
Age	1.09**	[1.03, 1.15]	1.09**	[1.03, 1.16]	1.06*	[1.02, 1.16]	1.08*	[1.01, 1.15]
Free/reduced priced lunch	1.79***	[1.55, 2.06]	1.49***	[1.27, 1.75]	1.49***	[1.15, 1.60]	1.32**	[1.12, 1.56]
Female	2.60***	[2.26, 2.98]	2.23***	[1.91, 2.59]	2.21***	[1.79, 2.45]	2.10***	[1.79, 2.46]
Race								
AI/AN-White	1.18*	[1.00, 1.40]	1.24*	[1.03, 1.49]	1.20*	[1.01, 1.47]	1.25*	[1.03, 1.51]
AI/AN-Black	0.72	[0.50, 1.04]	0.71	[0.47, 1.05]	0.77	[0.49, 1.11]	0.78	[0.52, 1.17]
AI/AN-other	0.74	[0.53, 1.04]	0.73	[0.50, 1.07]	0.68*	[0.47, 1.04]	0.71	[0.48, 1.05]
AI/AN-multi	1.54***	[1.24, 1.91]	1.44**	[1.14, 1.83]	1.52***	[1.16, 1.88]	1.50**	[1.17, 1.92]
Tribe								
Anishinaabe/Ojibwe	0.97	[0.84, 1.12]	0.88	[0.75, 1.03]	0.91	[0.74, 1.03]	0.87	[0.74, 1.03]
Dakota/Lakota	1.08	[0.90, 1.31]	0.98	[0.79, 1.21]	0.98	[0.77, 1.18]	0.95	[0.76, 1.18]
Risk factors/behaviors								
Trauma			2.42***	[2.06, 2.85]			1.90***	[1.61, 2.26]
Being bullied			1.85***	[1.70, 2.00]			1.70***	[1.56, 1.86]
Substance use			2.33***	[1.98, 2.75]			2.13***	[1.79, 2.53]
Skip school or class			1.18*	[1.01, 1.39]			1.12	[0.95, 1.32]
Protective factors								
Family/community support					0.70***	[0.67, 0.84]	0.77***	[0.69, 0.86]
Empowerment					0.57***	[0.57, 0.71]	0.66***	[0.59, 0.73]
Teacher/school support					1.00	[1.04, 1.26]	1.15**	[1.04, 1.26]
Out-of-school-time activities					0.82**	[0.61, 0.84]	0.71***	[0.61, 0.84]
Healthy diet					1.12	[0.93, 1.29]	1.09	[0.93, 1.29]
Healthy sleep					0.73***	[0.68, 0.96]	0.81*	[0.68, 0.96]
Model fit								
Model loglikelihood	-2369.317		-2015.542		-2100.143		-1911.440	
Null model loglikelihood	-2517.817		-2517.817		-2517.817		-2526.198	
McFadden R^2	.059		.199		.166		.241	
AIC	4758.6		4059.1		4232.3		3862.9	

Note. Age was centered so that minimum value is 0. Being bullied, Family/community support, Empowerment, and Teacher/school support were centered so that minimum value is 0 with *SD*=1.0. OR = adjusted odds ratio. **p* < .05. ***p* < .01. *** *p*< .001.

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DISCUSSION

For the first research question, we examined the associations between AI/AN students' background variables and mental distress. We found that AI/AN students who are older, lower SES, and female have higher likelihoods of mental distress. Additionally, students who identify as AI/AN-White and AI/AN with multiple racial/ethnic combinations have higher likelihoods of mental distress than students who identify as AI/AN only (reference group), although students identifying as AI/AN (regardless of other race/ethnicities) do report higher likelihoods of mental distress than students who do not identify as AI/AN. This increased likelihood of mental distress could reflect a history of trauma, colonization, and assimilation. That is, this history may impact how students perceive the extent to which they belong to their educational and social environments (Baumeister & Leary, 1995), as one example, that subsequently contributes to their likelihood of mental distress. The complexity introduced by multi-racial AI/AN students and AI/AN-White students likely indicates the struggles students with multiracial backgrounds face that may present conflicting ways of knowing or being, greater exclusion or isolation, and unique forms of discrimination (Sanchez, 2010; Shih & Sanchez, 2005). However, empirical research on multiracial AI/AN youth is sparse.

From the second research question, we found that risk factors, particularly trauma, are significantly associated with higher likelihood of mental distress. Risky behaviors, including substance use and skipping school, are also associated with higher likelihood of mental distress; simultaneously, risky behaviors are possibly the result of mental distress (bidirectional associations; Kang et al., 2018). These results were expected.

When the protective factors were added into the full model, the magnitudes of the risk factors each dropped, and skipping school was no longer statistically significant. This is the major set of findings: adding protective factors in the model of student characteristics and risk factors and behaviors reduced the likelihood of experiencing mental distress and reduced the negative accumulating effects of risk factors.

Furthermore, we observed that teacher/school support counterintuitively predicted a slightly higher likelihood of mental distress in the full model. We consider two possible explanations for this result. First, we see that the bivariate correlations for family/community support, sense of empowerment, and teacher/school support with mental distress are all negative (Table A2 in Appendix). One explanation is that the partial correlation of teacher/school support

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with mental distress, controlling for family/community support and sense of empowerment, is positive. Another possibility is that once we account for family/community support and sense of empowerment, the remaining variance could be due to students who have more mental distress and are seeking out more support from teachers and school personnel (teacher/school support). This finding is important and could serve to highlight the discrepancies between roles of various sources of social support. This deserves further study.

In this quantitative study, we aimed to contribute to AI/AN youth development and mental health programming to promote PYD practices in a way that is consistent with indigenous perspectives of youth development. The Circle of Courage provides a foundation for psychological resilience for Native youth, particularly youth at-risk (Brendtro, 2020; Werner, 2012). For instance, Werner (2012) explained that youth with disadvantaged backgrounds can gain resiliency and thrive in life in conjunction with the elements of the Circle of Courage. Accordingly, the belonging element portrays that youth with adverse life events gain resiliency and thrive in life, with help of social support from peers, extended family members, or community. Mastery element of the Circle of Courage is realized by providing opportunities to youth to feel valued, appreciated, and competent by encouraging sense of empowerment and OST activity participation that also motivates youth to have a purpose in life. Similarly, sense of empowerment, OST activity participation, and self-care through healthy lifestyle can help youth to acquire independence and self-discipline. Lastly, with feelings of belongingness through social supports and OST activity participation, sense of responsibility in a partnership with others is enhanced, reflecting the generosity element of the Circle of Courage.

Limitations

There are some limitations for this study. The first limitation is the focus on AI/AN students in Minnesota, and although the sample includes over 3,700 students, generalizability beyond Minnesota should be done cautiously. Also, in the case of multi-racial AI/AN students, sample sizes were small for some groups. For example, although the ORs were different than 1.0 with AI/AN-Black students for each model, they were not statistically significant (likely due to low power). In addition, there may be a differential threshold for students whose bi-cultural identities are both stigmatized compared to students with only one stigmatized identity, or the two cultures are in conflict. Finally, although the MSS did allow students to identify with Anishinaabe/Ojibwe

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and Dakota/Lakota tribal affiliations (the largest groups attending Minnesota schools), one-third of students selected *other tribe* with unknown affiliation.

Since the measures and variables used in the study were based on self-reported responses to the survey items, it should be noted that respondents may tend to be more biased to the items related to negative experiences. Therefore, self-report bias may mask the real magnitude of the associations (Devaux & Sassi, 2015; Krumpal, 2013; Latkin et al., 2017).

CONCLUSION

The socio-cultural and educational contexts for AI/AN students are complex and their mental health outcomes are unacceptable, which begets the need to expand on and increase research activities in this student community. Bivariate associations and correlations are insufficient and do not uncover the whole picture. Risk factors and risky behaviors are consistently associated with mental distress across AI/AN student groups. But most importantly, not only do protective factors reduce the likelihood of mental distress, they also reduce the negative effects of risk factors and behaviors. Educators, counselors, and youth workers can use this information to structure curriculum and after school programs, learning supports, therapy practices, and developmental opportunities, to better support the needs of these students, specifically through better understanding of the events and contexts that contribute to students' elevated mental distress levels. de Heer et al. (2020), and many others (McKinley et al., 2019, Shane et al., 2018), point to the value of collaborations among researchers and practitioners; this is a good place to demonstrate that recommendation.

Social supports reduce the likelihood of mental distress among AI/AN students, particularly family/community support and sense of empowerment. In fact, in the context of such supports, the negative effects of risk factors and behaviors are reduced, particularly the negative effects of experiencing trauma. These findings can equip practitioners with the knowledge to further support AI/AN students, specifically, through a better understanding of which social supports are at play and the importance of context, such as home and school environments. The Circle of Courage, as an indigenous PYD framework, is more than a philosophy; it represents core values for education and youth work in ways that are consistent with our findings. Leveraging the assets, positive supports, and elements reflected in the Circle of Courage, practitioners and policy makers can be better equipped to promote positive mental health among AI/AN students.

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interests.

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APPENDIX

Table A1

Study Variables and Associated Items in MSS 2019

Name of variable	Items used to create the variable	Variable construction method
Mental Distress	• Do you have any long-term mental health, behavioral or emotional problems? Long-term means lasting 6 months or more. • Have you ever been treated for a mental health, emotional or behavioral problem (during the last year or more than a year ago)? • During the last 12 months, how many times did you do something to purposely hurt or injure yourself without wanting to die, such as cutting, burning or bruising yourself on purpose? * not Y/N • Have you ever seriously considered attempting suicide (during the last year or more than a year ago)? • Have you ever actually attempted suicide (during the last year or more than a year ago)? Choices: *Yes, No*	dichotomous variable 1=Yes, if *Yes* item choice is selected at least for one question; 0=No, otherwise.
Trauma	• Do you live with anyone who drinks too much alcohol? • Do you live with anyone who uses illegal drugs or abuses prescription drugs? • Does a parent or other adult in your home regularly swear at you, insult you or put you down? • Has a parent or other adult in your household ever hit, beat, kicked or physically hurt you in any way? • Have your parents or other adults in your home ever slapped, hit, kicked, punched or beat each other up? • Has any older or stronger member of your family ever touched you or had you touch them sexually? • Have any of your parents or guardians ever been in jail or prison? • During the past 12 months, have you stayed in a shelter, somewhere not intended as a place to live, or someone else's home because you had no other place to stay (on your own without any adult family members or with an adult family member)? Choices: *Yes, No*	dichotomous variable 1=Yes, if *Yes* item choice is selected at least for one question; 0=No, otherwise.

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Name of variable	Items used to create the variable	Variable construction method
Being bullied (victim)	During the last 30 days, how often have other students harassed or bullied you for any of the following reasons? • Your race, ethnicity or national origin • Your religion • Your gender • Because you are gay or lesbian or because someone thought you were • A physical or mental disability • Your weight or physical appearance During the last 30 days, how often have you been bullied through e-mail, chat rooms, instant messaging, websites or texting? During the last 30 days, how often have other students at school… • pushed, shoved, slapped, hit or kicked you when they weren't kidding around? • threatened to beat you up? • spread mean rumors or lies about you? • made sexual jokes, comments or gestures towards you? • excluded you from friends, other students or activities? Choices: *never, once or twice, about once a week, several times a week, every day*	continuous variable created by partial credit Rasch model
Family/ community support	• Can you talk to your mother about problems you are having? Choices: *yes, most of the time; yes, some of the time; no, not very often; no, not at all; my mother is not around* • Your parents care about you. • Other adult relatives care about you. • Friends care about you. • Adults in your community care about you. Choices: *not at all, a little, some, quite a bit, very much*	continuous variable created by partial credit Rasch model

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Name of variable	Items used to create the variable	Variable construction method
Empowerment	• I feel safe at school. • I feel safe in my neighborhood. • I feel safe at home. Choices: *strongly disagree, disagree, agree, strongly agree* • I feel valued and appreciated by others. • I am included in family tasks and decisions. • I am given useful roles and responsibilities. Choices: *not at all or rarely, somewhat or sometimes, very of often, extremely or almost always*	continuous variable created by partial credit Rasch model
Teacher/ school support	• Overall, adults at my school treat students fairly. • Adults at my school listen to the students. • The school rules are fair. • At my school, teachers care about students. • Most teachers at my school are interested in me as a person. • Teachers/other adults at school care about you. Choices: *strongly disagree, disagree, agree, strongly agree*	continuous variable created by partial credit Rasch model
OST activity participation (at least 3 times/week)	During a typical week, how often do you participate in each of the following activities outside of the regular school day • Sports teams, such as park and rec teams, school teams, in-house teams or traveling teams • School sponsored activities or clubs that are not sports, such as drama, music, chess or science club • Leadership activities such as student government, youth councils or committees • Other community clubs such as 4-H, Scouts, Y-clubs or Community Ed? • Artistic lessons, such as music or dance • Physical activity lessons, such as tennis or karate Choices: *0 days, 1 day, 2 days, 3 to 4 days, 5 or more days*	dichotomous variable 1=Yes, if student participates in any activities a total of at least three times a week; 0=No, otherwise

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Table A2
Intercorrelations Among the Study Variables

	MD	age	low SES	sex	race	tribe	trauma	BD	subs. use	skip school	FCS	EM	TSS	OST activ.	diet
age	0.05	1.00													
low SES	0.20	-0.08	1.00												
sex	0.36	-0.02	0.08	1.00											
race	0.06	-0.02	-0.09	0.10	1.00										
tribe	0.01	0.04	0.19	0.06	-0.23	1.00									
trauma	0.48	0.02	0.35	0.15	-0.05	0.13	1.00								
BD	0.45	-0.11	0.08	0.20	0.06	-0.03	0.31	1.00							
subs. use	0.47	0.16	0.07	0.15	0.04	0.07	0.46	0.31	1.00						
skip school	0.16	0.04	0.14	0.10	-0.04	0.13	0.16	0.10	0.20	1.00					
FCS	-0.44	-0.02	-0.17	-0.17	-0.03	-0.05	-0.42	-0.32	-0.31	-0.12	1.00				
EM	-0.48	0.00	-0.18	-0.22	-0.02	-0.03	-0.41	-0.36	-0.32	-0.14	0.65	1.00			
TSS	-0.30	-0.01	-0.06	-0.19	-0.02	-0.07	-0.29	-0.31	-0.30	-0.18	0.54	0.51	1.00		
OST activ.	-0.19	-0.04	-0.24	0.00	0.04	-0.06	-0.20	0.06	-0.09	-0.12	0.24	0.23	0.13	1.00	
diet	-0.09	-0.02	-0.15	0.02	0.01	-0.08	-0.16	-0.01	-0.09	-0.06	0.20	0.23	0.14	0.25	1.00
sleep	-0.30	-0.16	-0.05	-0.15	-0.03	-0.04	-0.26	-0.16	-0.30	-0.18	0.34	0.35	0.27	0.12	0.16

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ASSESSING THE NEEDS OF URBAN AMERICAN INDIANS IN NORTH TEXAS: A COMMUNITY-BASED PARTICIPATORY RESEARCH PROJECT

Paul Conrad, PhD, and Maria Scannapieco, PhD

Abstract: This article discusses a community-based participatory research project with university researchers, an urban inter-tribal center, and other community partners to develop, administer, and deliver a community needs assessment of an urban American Indian (AI) community. In the development process, community focus groups identified major domains of inquiry for a needs assessment survey: mental health and substance abuse, medical care, and social services, including cultural programming. Results are presented and discussed in each domain. Overall, this community needs assessment contributes to a better understanding of American Indian and Alaska Native (AI/AN) urban challenges by providing information about the AI/AN population in a large southwest metropolitan area. Specifically, it highlights the relevance of local and state contexts for understanding issues facing AI/AN populations.

A growing body of research indicates that AI/AN populations demonstrate some similar challenges in terms of health, social service needs, and mental health and substance abuse needs due to shared histories of colonization and misguided or underfunded government programs, among other factors. It remains true that AI/AN communities nonetheless are each distinctive and face unique challenges and opportunities within the local, state, and regional contexts in which they reside. The process described in this paper will inform policy, practice, and research communities interested in understanding the unique realities of an urban community representing many different AI tribes.

INTRODUCTION

While the majority of American Indians (AI) and Alaska Natives (AN) live in urban areas, their social, emotional, and medical needs have received less study than communities on reservations

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or tribal lands. High poverty, unemployment, and physical and mental health disparities are well documented for the AI/AN population at large and urban AI/AN communities more specifically (Trombino, 2005). Home to more than 75,000 AI/ANs, the urban southwest metropolitan area described in this paper shares similarities with other large metro areas with significant AI/AN populations (Norris et al., 2012; UITCT, 2017). While census data combines AI/AN populations, the community in North Texas primarily identifies as AI and as members of specific AI tribal nations. Urban AI/ANs in this area—as in other places—are impacted by the long-term consequences of historical trauma due to loss of tribal lands and identity, suppression of cultural and spiritual beliefs, boarding schools, and relocation programs in the 1950s and 1960s (Fixico, 1986). These consequences include loss of cultural connectedness and a subsequent impact on overall health, education, employment, child welfare, and engagement with the criminal justice system. This is evidenced by high rates of violence, substance abuse, unresolved grief and loss, depression, and suicide (Brave Heart & Debruyn, 1998; Evans-Campbell, 2008).

While the U.S. government provides health care to members of federally recognized tribes through the Indian Health Service (IHS), resources continue to be focused mostly on reservation-based tribal nations. Moreover, the IHS reports that current congressional appropriations only meet 60% of the health needs of the AI/AN population (IHS, n.d.a). In addition, only 1% of the IHS budget is allocated for Urban Indian Health programs, with the IHS estimating that urban programs are funded at only 22% of need (Office of Urban Indian Health Programs, n.d.a). The problem of limited care providers and underfunding is exacerbated in a state like Texas, which has one of the largest uninsured populations more generally, in part due to state policies such as not participating in Medicaid expansion (Buettgens et al., 2018). A key purpose of this study was to gauge the needs of AI/ANs in North Texas based on community members' perceptions as well as the observations of people familiar with the community, such as care providers. Awareness of such needs can inform policy, practice, and research communities about the unique issues facing urban AI/AN communities.

Community Organization

Historically, urban AI/ANs have worked to address the needs of their communities by forming urban intertribal centers, churches, Powwows, and student organizations (Britten, 2017). The roots of the Urban Inter-Tribal Center of Texas (UITCT), the key partner for researchers in this study, reflect this broader history. While the Dallas-Fort Worth area was originally the territory

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of multiple Indigenous groups, including Comanche, Wichita, and Caddoan peoples, by the late-nineteenth century, few remained after years of war and displacement to tribal lands in Indian territory, later Oklahoma (Smith, 2006). It was not until the U.S. government implemented a new relocation program in the 1950s and 1960s that the AI population of North Texas grew significantly; by 1970, more than 20,000 AIs from more than 90 different tribes moved off tribal lands and into the Dallas area (UITCT, 2017). Officially, this program sought to lure AI people off tribal lands to cities with promises of employment and opportunity. In practice, people often reported arriving in cities like Dallas to face isolation and discrimination (Fixico, 1986; Britten, 2017).

The UITCT opened in 1971 to meet the needs of the growing AI/AN population (UITCT, 2017). In the present day, the UITCT is a key community organization that provides health care services to clients representing 174 federally recognized tribes. However, the UITCT has limited resources to provide health and social services to the community. Data limitations have impeded it from obtaining funding to expand services or to fully assess the social and cultural needs and interests that may exist. In fact, staff were not aware of any other needs assessments having ever been conducted.

Currently, the UITCT primary care clinic has an active user population of 4,956 who had a total of 26,297 visits in 2018. Most clients live in the Dallas/Fort Worth Metroplex: Dallas (53.2%), Fort Worth (16.4%), and surrounding suburban counties (10.5%). Three and a half percent of the patients are veterans. While clients are members of many different tribes, the following table (Table 1) represents the top ten tribes whose members make up 77.3% of the clients utilizing UITCT services.

Table 1
Tribes Represented

Tribe	%
Choctaw Nation, OK	29%
Cherokee Nation, OK	14.5%
Muscogee (Creek) Nation, OK	6.7%
Chickasaw Nation, OK	6.5%
Navajo Tribe, AZ, NM, and UT	5.6%
Comanche Indian Tribe, OK	4.3%
Mississippi Band Choctaw Indians	3.3%
Seminole Nation, OK	2.2%
Kiowa Indian Tribe, OK	1.9%
Citizen Potawatomi Nation, OK	1.7%

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Compared to some metropolitan areas with significant AI/AN populations, this North Texas metropolitan area is further characterized by limited access to health and social services, such as government-funded Indian health facilities. Because UITCT is the only Urban Indian Health Program (UIHP) clinic in the entire state, people travel long-distances from across the state to receive care. Moreover, because the services of this clinic are limited, many people also travel back to tribal communities in Oklahoma and elsewhere to see specialists or to avoid long wait times (Office of Urban Indian Health Programs, n.d.b).

RESEARCH METHODS

The researchers received University of Texas at Arlington institutional review board and human subject review approval for all stages of the project. Researchers employed a community-based participatory research design. The key principles of participatory evaluation include the direct, strategic, and inclusive involvement of stakeholder groups and the ongoing communication and use of evaluation results to guide decision making and change. With an eye towards capacity building and solution focused principles, community members were actively sought to fill data collection, analysis, and interpretation roles. This empowers the individuals and communities being studied and provides a catalyst for community-defined change.

The participatory evaluation involved a partnership between the University of Texas at Arlington evaluation team and AI community partners. Initially, key community stakeholders were engaged to discuss possibilities for projects examining the issue of AI/AN health and medicine broadly conceived. The idea for a needs assessment project came from these groups' discussions as it was not believed that an assessment had ever been conducted, and UITCT believed that the resulting data could be useful to their work. At that stage, additional university researchers with relevant expertise were brought into the project.

The participatory evaluation approach continued to be utilized going forward, including: 1) engaging stakeholders in instrument development; 2) obtaining perspectives from all relevant stakeholders; 3) providing translation and interpretation as necessary; 4) using and refining methods that consider cultural sensitivities or preferences; and 5) ensuring communication and research materials are appropriate and accessible to the range of ages represented. Participatory evaluation is also a critical approach recommended for use with AI communities (Yuan et al., 2014).

During the first phase of the design (October and November 2016), we conducted focus groups, teamed with a community member, to understand the domains of concern the community wanted to explore. Three focus groups were conducted at various times and days to accommodate participants' availability. Participants were recruited via flyers at UITCT and through snowball sampling. Each participant had to be a client of the Center or affiliated with it as an employee or community member. All the focus groups were held at UITCT and included a discussion of the purpose, and each participant signed an informed consent. Participants received a $10 stipend for their participation.

Focus group sessions ranged in participant size from 11 to 17 and lasted between 60 and 90 minutes. In total, 31 women and 10 men participated. Each session began with an open-ended question about the perceived needs of AIs living in North Texas: What general areas of needs are there for American Indians living in North Texas? Follow-up questions probed topics of concern raised by participants. At each session, similar concerns were voiced. Substance abuse treatment and mental health services were discussed in all the focus groups. The need for AI-specific programing for children and youth was another common area, including cultural education within public schools and more awareness among school counselors of scholarships for AI students. Notably, diabetes care did not emerge as a specific topic of concern in the focus groups, perhaps owing to this being an existing focus of care at UITCT. Many social service needs were discussed, such as housing, employment, and financial assistance of all kinds. The relatively limited services offered at UITCT and the need to travel to tribal nations in Oklahoma to receive specialized care also emerged as a concern.

Phase two involved the development of the needs assessment measurement tool (December 2016 and January 2017). The evaluation team, which included tribal members and UITCT staff, evaluated the focus group findings. In particular, we analyzed themes across each of the three focus group sessions to determine the domains of needs expressed by participants. The needs assessment was informed in this process. Key areas of need were mental health and substance abuse, cultural programming and education, access to specialized health care and health insurance, and social service needs such as food, clothing, and childcare. A search of the literature for other needs assessments done in urban AI communities also informed the development of the measurement items by confirming that no major categories of need identified in previous studies had been overlooked. Twenty-three areas of need were identified through the focus groups and ranged from mental health/substance abuse treatment to affordable housing and employment (see

Appendix). A few examples are Mental Health Services for Youth, Sober Living Alternative Housing for Youth, AI/AN-Specific Domestic Violence Counseling, and Availability to AI/AN Cultural Events. Additionally, there were 14 items asking about the respondents themselves (e.g., age, education, income), such as: *Are you enrolled in a federally recognized tribe?, What is your tribal affiliation?,* and *Do you have health insurance?*

During this second phase, we also conducted a pilot administration of the measurement to ensure validity of the needs assessment survey tool. The survey was found to be sound, and we did not have to make any adjustments.

The third phase of the research (February-May 2017) involved administering the survey, which included an informed consent. Participants were asked to rate identified areas of needs on a scale from 1 to 4 (4 = *critical need*, 3 = *moderate need*, 2 = *low need*, 1 = *not a need*). The survey was administered through multiple means to ensure the community was well represented. Recruitment occurred via social media, flyers at the UITCT, at community events, and through snowball sampling. Survey administration included web-based survey, paper surveys, and, when necessary, face-to-face administration if there were language or reading limitations. Surveys were collected at the UITCT clinic, and the evaluation team also participated in several community outreach events in order to reach the community, such as Powwows, American Indian Heritage Day, and Agency events. The original sample (N = 382) included non-AI/AN respondents (n = 110) who were self-identified spouses or care providers knowledgeable of AI/AN needs. AI/AN respondents (n = 272) consisted of clients of UITCT (who must be enrolled members of federally recognized tribes) and self-identified members of the urban AI community. Phase four (June 2017-December 2018) included analysis of the needs assessment and dissemination of the results to the organization and the community through sponsored face-to-face presentations of the findings. Based on reviewer feedback, we subsequently removed the non-AI/AN respondents from the sample. While our community partner, UITCT, had found it useful to understand non-AI/AN perceptions of AI/AN needs, the primary contribution of this study is in terms of the perceived needs of the AI/AN community itself.

NEEDS ASSESSMENT RESULTS

The majority of AI/AN respondents identified as female (66.8%). The mean age of respondents was 47 years of age. Most participants had some college or had completed college (71%). The majority of the sample had an income under $35,000 (56.8%), with a significant

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percent under $15,000 (23.6%). Most of the respondents had part-time or full-time employment (64.7%).

Table 2
Demographic Information

	N	f (n)	%	*M*	*SD*	Min/Max
Age	268			47.39	14.24	19 / 92
Gender	270					
Male		85	31.50%			
Female		185	68.50%			
Education	266					
Neither high school diploma, nor GED (1)		16	6.00%			
GED (2)		19	7.10%			
High school diploma (3)		42	15.80%			
Some college/Associate degree (4)		120	45.10%			
College degree or higher (5)		69	25.90%			
Income	259					
$ 0 - 14,999		61	23.60%			
$15,000 - 34,999		86	33.20%			
$35,000 and above		112	43.20%			
Employment Status	261					
Employed FT 35+ hrs/wk (1)		135	51.70%			
Employed PT (2)		34	13.00%			
Unemployed (FT student) (3)		10	3.80%			
Other ** (4)		82	31.40%			

Self-reported health was a part of the assessment survey. The majority of the respondents rated their health as excellent or very good (59%).

Table 3
Self-Reported Health

	N	f (n)	%
Self-Reported Health Rating	266		
Excellent (1)		56	15.10%
Very Good (2)		174	46.80%
Fair (3)		126	33.90%
Poor (4)		16	4.30%

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In the area of mental health and substance abuse, adult substance abuse treatment was the greatest need (*M* = 3.45), followed by adult mental health treatment (*M* = 3.44). Youth substance abuse treatment (*M* = 3.39) and youth mental health services (*M* = 3.36) were also seen as important needs.

Table 4
Mental Health/Substance Abuse

Mental Health/Substance Abuse	No need: %	Low need: %	Moderate need: %	Critical need: %	M	SD
YOUTH Mental Health Services	6.5%	7.2%	30.0%	56.3%	3.36	0.88
ADULT Mental Health Services	4.5%	5.3%	32.3%	57.9%	3.44	0.79
YOUTH SA Treatment	8.3%	6.8%	22.3%	62.5%	3.39	0.94
ADULT SA Treatment	6.4%	5.7%	24.9%	63.0%	3.45	0.86
YOUTH Sober Living Alt. Housing	6.8%	12.9%	33.8%	46.4%	3.20	0.91
ADULT Sober Living Alt. Housing	6.1%	10.2%	31.1%	52.7%	3.30	0.88

The social service areas were divided into social service 1, representing AI/AN-specific type services, and social service 2, representing tangible needs. In the social service 1 grouping, after-school programs for AI/AN children and youth was found to be the greatest need (*M* = 3.39), followed by AI/AN-specific childcare (*M* = 3.32*)*. Domestic violence shelters specific to AI/AN women was also seen as a critical need (*M* = 3.31).

In the social service 2 category, employment was ranked as highest need (*M* = 3.55), followed by affordable housing (*M* = 3.5). Financial assistance was also a stated need for both rental assistance (*M* = 3.43) and food assistance (*M* = 3.45).

In addition to social services, there were two questions on cultural activities. Availability of cultural activities (*M*=3.36) was rated most highly.

Table 5
Social Services and Cultural Activities

	No need: %	Low need: %	Moderate need: %	Critical need: %	*M*	*SD*
Social Service 1						
Domestic violence Shelter	6.1%	11.8%	27.0%	55.1%	3.31	0.90
Child Care	6.4%	8.3%	31.7%	53.6%	3.32	0.88
After School Prog. for Child/Youth	4.1%	9.4%	29.7%	56.8%	3.39	0.82
Parenting Classes	5.6%	13.5%	30.8%	50.0%	3.25	0.89

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Table 5 Continued

Social Services and Cultural Activities

	No need: %	Low need: %	Moderate need: %	Critical need: %	*M*	*SD*
Social Service 2						
Employment	3.4%	6.3%	22.0%	68.3%	3.55	0.76
Transportation	4.5%	8.3%	35.0%	52.3%	3.35	0.82
Affordable Housing	3.8%	6.8%	25.6%	63.9%	3.50	0.78
Rent Assistance	3.7%	6.7%	32.6%	56.9%	3.43	0.78
Food Assistance	3.0%	6.4%	33.3%	57.3%	3.45	0.75
Cultural Activities						
Availability to rec. activities	3.0%	16.3%	38.3%	42.4%	3.20	0.82
Availability to cultural events	3.4%	12.8%	27.9%	55.8%	3.36	0.83

The needs assessment also included some access to health and medical care questions. Access to health insurance (*M* = 3.63), medications (*M* = 3.58), and eye care (*M* = 3.58) were ranked as critical need areas. Specialized medical care was also ranked high (*M* = 3.54), as was access to eye glasses (*M* = 3.54).

Table 6

Health Care

Health Care	No need: %	Low need: %	Moderate need: %	Critical need: %	*M*	*SD*
Access Specialist – Medical reasons	2.3%	7.1%	24.8%	65.8%	3.54	0.73
Access to Eye Care	1.5%	5.2%	26.6%	66.7%	3.58	0.66
Access to Eye Glasses	1.9%	6.4%	25.5%	66.3%	3.56	0.70
Access to Medications	1.9%	5.2%	25.9%	67.0%	3.58	0.68
Access to Birth Control	6.3%	8.2%	23.9%	61.6%	3.41	0.89
Access to Health Insurance	2.6%	5.6%	18.4%	73.4%	3.63	0.71

DISCUSSION

Our study responded to a lack of prior needs assessments conducted in the urban AI community in North Texas. However, a review of the literature reveals that this lack of data is indicative of a broader paucity of urban AI/AN needs assessments. Recent studies conducted in Chicago, IL and Tulsa, OK provide a basis for comparison based on demographics, proximity to tribal communities, and state and regional context, but more work is needed (Johnson et al., 2010; West et al., 2012). The broader scholarship on AI/AN health and social services also provides a context in which to situate the perceived needs of urban AI/AN communities like the one in the Dallas-Fort Worth area. Key themes emerging in the current literature include: Health Needs (especially substance abuse and diabetes), Cultural Competency, Social Service Needs and Community Awareness, and Cultural Programming. These themes in the scholarly literature were reflected in focus groups conducted to develop the needs assessment survey tool and provide context for considering the implications of the results of our study.

Overall, the results suggest that the urban AI community in the Dallas-Fort Worth area has similarities to other urban AI/AN populations. For example, the study found that there was a critical need for mental health and substance abuse treatment programs, childcare, domestic violence shelters, and employment assistance. These findings fit with studies of urban AI/AN communities elsewhere discussed in the literature. Yet, the needs assessment also suggested certain needs shaped by the local and state context that warrant further discussion and point to the need to further research the unique circumstances of urban AI/AN communities around the country. The broader implications of our findings for key themes in the scholarly literature are discussed below.

Health Needs

The physical and psychological needs of AI/AN community members and how these relate to their overall health is a key theme in the existing literature. Substance abuse treatment and prevention has been identified as a major need especially among AI/AN youth (Dickerson & Johnson, 2011; Johnson et al., 2010; Lowe et al., 2016). Cultural interventions that utilize traditional healing practices combined with evidence-based treatments have been found to be effective treatment approaches to help treat substance abuse and address this need in AI/AN communities (Dickerson & Johnson, 2011; Lowe et al., 2016). Diabetes prevention and treatment have also been found to be a major need in these communities (Johnson et al., 2010; Parker et al., 2011). Community members believe diabetes prevention can be addressed by allowing elders, tribal leaders, and everyday people to educate the youth and the community about diabetes and diabetes treatment (Parker et al., 2011). However, community members might encounter barriers that prevent them from attaining behavioral change, such as conflicting priorities (e.g., difficulty in scheduling appointments because of school, work, and home demands), lack of support (e.g., lack of childcare to attend educational programs), or the cost and availability of healthy foods that might prevent them from improving their diets (Parker et al., 2011). When addressing health needs in AI/AN communities, health professionals must be aware of the challenges created by a lack of cultural awareness because these may influence community members from bringing about the desired change.

The fact that only 59% of AI/AN respondents in our study rated their health as good or excellent suggests that health disparities evident in other AI/AN populations are also reflected in North Texas. Yet other reported health care needs may reflect the unique concerns of urban AI/AN communities, and more specifically, the urban AI population in the Dallas-Fort Worth area. While more data on other urban AI/AN communities is needed to make direct comparisons, it is striking that the health care area rated as the most critical need by our respondents was access to health insurance. This was not the case, for example, in a recent study in Tulsa, OK (Johnson et al., 2010). This issue is likely exacerbated by two characteristics of the location of this urban AI population. First, as of 2016, Texas had both the highest total number and highest percentage of residents who are uninsured, in part because Texas elected not to expand its population eligible for Medicaid after the implementation of the Affordable Care Act in 2010. States that did elect to expand coverage have seen the largest drop in their uninsured population according to census data (Buettgens et al, 2018). Secondly, while members of federally recognized tribes may obtain health care without private insurance at Indian Health Service, Tribal, or Urban Indian Health Program facilities, such facilities are underfunded and limited in the services they offer, and there is only one such facility in the Dallas-Fort Worth area, the UITCT (IHS, n.d.b). Three other tribal health facilities in Texas serving members of federally recognized tribes are significantly distant from Dallas: Alabama-Coushatta Health Center (approximately 3.5-hour drive), Eagle Pass Kickapoo Health Center (approximately 7 hours), and Ysleta Del Sur Pueblo Health Station (approximately 9 hours).

The combination of limited access to health insurance and limited AI/AN-specific health care services in Texas may help to explain other health care access issues rated as especially critical areas of need: Access to Medications, Access to Specialists, and Access to Eye Care. In focus groups sessions, community members noted that they often travel to tribal facilities in Oklahoma to receive such care. A recent arrangement made between UITCT and Choctaw Nation facilities in Durant, OK may facilitate access to specialized care, yet this still requires travel of three hours or more roundtrip (UITCT, 2018).

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Social Service Needs/Community Awareness

Our findings support existing research that shows that while AI/AN communities vary significantly from each other, as a whole unemployment, substance abuse, mental health concerns, and violence against women, including domestic violence, remain significant concerns across the larger AI/AN population. At times, it is not a lack of services to address these needs that is a challenge for the AI/AN community, but rather a lack of awareness about the services that are offered (Dennis & Momper, 2016). Suggestions have been made about how this can come about; some suggest that health information be disseminated through the stories and teachings of elders and tribal leaders who are considered the most respected and honored members of AI/AN communities (Parker et al., 2011). Others have proposed the use of printed material, television, and culturally appropriate media (e.g., *Chickasaw Times*) to reach the community and make them aware of these services (Parker et al., 2011). Other important factors to consider in the marketing of services is the location and hours of operation of service providers. Conflicting schedules and lack of transportation have been listed as some of the challenges associated with seeking out services (Dennis & Momper, 2016; Parker et al., 2011). Communities have identified a need for weekend/evening hours, family programs, and/or easily accessible locations (Dennis & Momper, 2016; Parker et al., 2011). Optimal locations could be "community places, Chickasaw Nation program sites, and programs in schools for children" (Parker et al., p.59). These findings from prior studies show that it is not enough to offer needed services; the community must be made aware that these services exist and must make efforts to improve access to them.

While our results largely support findings in the literature, characteristics of the Dallas-Fort Worth metropolitan area nonetheless are evident. For example, while employment opportunities were rated the most critical social service need for the AI/AN community, affordable housing ranked second. This is unsurprising given the significant rise in rent and home sales prices in North Texas in recent years. A 2017 study found Dallas-Fort Worth to be ranked #5 (tied with two California metro areas) on a list of Metropolitan areas with the lowest availability of affordable rental homes (Aurand et al., 2017). Home sale prices suggest that home ownership is similarly out of reach for many, as sales prices between 2014 and 2017 rose by 33% (Dickson, 2018).

Similarly, the fact that culturally specific after school programming for children and youth was identified as an area of moderate or critical need by respondents may be influenced by the nature of this metro area. While two school districts in Dallas and Fort Worth have programs for AI students, the dispersal of the AI/AN population across these major cities and suburbs may limit access to AI/AN-specific school programming and counseling (Dallas Independent School District, 2019; Fort Worth Independent School District, 2019). At focus groups, several community members were particularly concerned about the lack of guidance counseling for AI students about resources specific to these students for funding college education.

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Cultural Programming

Compared to many of the social service and health needs assessed, availability of AI/AN cultural activities was ranked as a less critical need in our study. This is somewhat surprising, given that past studies have indicated significant community concerns about AI/AN youth's diminishing interest in engaging in traditional activities and cultural practices (Johnson et al., 2011). Members of the AI/AN community experience great pride from their tribal identity, and they want to make sure this is reinforced with AI/AN youth (Basto et al., 2012). AI/AN youth are sometimes raised by adoptive or foster parents who are not from the same culture and cannot appropriately teach and explain AI traditions and cultural values (Dennis & Momper, 2016). Therefore, the literature demonstrates a need for "cultural programming," where youth can engage in cultural activities and learn about their tribal culture and traditions (Dickerson & Johnson, 2011; Johnson et al., 2011). AI/AN people's fears that their youth may be losing their cultural pride are an important need that must be addressed, so that their cultures can be preserved and do not disappear as a result of historical oppression and discrimination. In sum, there is a protective factor for youth in cultural programming revealed in the current literature.

Our results suggest that AI/AN cultural activities are perceived as a less critical need in North Texas. This may in part be related to the existing vibrancy of events organized by community leaders, including American Indian Heritage Day, two major Powwows, a crafts fair, radio programming, active American Indian Students Associations at area universities including

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Texas Christian University and UT-Arlington, and religious organizations (Native American Student Association, n.d.; Schrader, 2015). The availability of such cultural offerings in part reflects the distance of the Dallas area from reservation communities. Because there was not existing readily accessible cultural programming within the metropolitan area, urban AI leaders established their own events and organizations to provide access locally.

Transportation Challenges

A final theme identified in the scholarly literature and evaluated in our needs assessment survey is the issue of transportation. Transportation has been identified as a major need in AI/AN communities (Dennis & Momper, 2016; Johnson et al., 2010; Parker et al., 2011). Lack of public or reliable transportation has made it difficult for individuals to attend appointments and seek services (Dennis & Momper, 2016), especially because a large percentage of AI/ANs experience poverty, unemployment, and earn less than $20,000 a year, which limits their ability to pay for things like gas and car repairs (Johnson et al., 2010). A more central location for agencies providing AI/AN-specific services or multiple locations may be one way to help address this need (Dennis & Momper, 2016). If improved transportation is not possible, extended or evening hours might help reduce some of the challenges associated with transportation, mainly challenges associated with travel time (Dennis & Momper, 2016; Parker et al., 2011). Interventions aimed at addressing the transportation need in AI communities must explore the possibilities of implementing better public transportation or selecting locations where travel (if any) will be minimal.

Somewhat surprisingly, transportation was not rated as highly as some other areas as a critical need facing the AI/AN community in North Texas. Some communities in the Dallas-Fort Worth metropolitan area lack public transportation entirely, which raises questions about why respondents would not have rated this as a more critical area of need (Limón, 2019). This may in part reflect certain limitations of our study, as community leaders and more affluent community members may have been overrepresented in the sample of respondents. Yet it may also reflect the efforts of the Urban Intertribal Center and tribal partners, such as the Choctaw Nation of Oklahoma, to ensure that community members have transportation options to access specialized health care in particular (UITCT, 2018).

CONCLUSION

A major change effort requires strong and trusting relationships—within the organization and with external partners. When there has been a challenging history between people or organizations, only time and demonstrating a different behavior will rebuild the trust. This cannot be rushed. This project demonstrated a process enabling the building of a trusting relationship among a university, urban inter-tribal center, and community.

The community-based participatory research design proved to be successful in the development and implementation of a culturally appropriate needs assessment. Involvement of multiple stakeholders led to a robust discussion of the AI/AN mental health, health, substance abuse, and other needs in an urban environment. Participants were engaged at every stage of the research process, which directed community engagement resulting in a successful project. It will be important for other urban communities to replicate this process to build on culturally relevant knowledge gained.

Overall, this research points to the need for further study of the needs of urban AI/AN communities in other metropolitan contexts. A growing body of research indicates that AI/AN populations demonstrate some similar challenges related to health and social services needs due to shared histories of colonization and misguided or underfunded government programs, among other factors. Yet, it remains true that AI/AN communities nonetheless are each distinctive and face unique challenges and opportunities within the local, state, and regional contexts in which they reside. The reported needs of the AI community in North Texas are illustrative, as the areas of most critical need reflect challenges facing the Dallas-Fort Worth metro area and the state of Texas at large.

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USING CONCEPT MAPPING TO UNDERSTAND GENDER- AND AGE-SPECIFIC FACTORS INFLUENCING HEALTH CARE ACCESS AMONG AMERICAN INDIAN ELDERS

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Abstract: Inequities in access to health care create barriers to physical and mental health treatment for the rapidly aging American Indian population in the United States. This study uses concept mapping—a participatory, mixed-methods approach to understanding complex phenomena—to examine the perceived impacts of multilevel factors influencing Elders' ability to access and use health care and how these perceptions vary according to gender and age, with the aim of identifying tailored strategies to address inequities. Using data from a purposive sample of American Indian Elders (n = 65) in two states, we compared ratings of thematic clusters and individual factors perceived to impact Elder health care across four participant subgroups: women aged 55-64, women aged 65+, men aged 55-64, and men aged 65+. Provider Issues and Relationships and Tribal/National Policy were themes perceived to have a particularly high impact on Elder health. Key variations between subgroups regarding individual health care access factors reflected unique interpersonal and accessibility challenges among older women, problems stemming from lack of familiarity with health care among younger Elders and men, and challenges navigating complex bureaucracies and tribal decision-making processes among older Elders. Findings underscore the need to address multilevel gender- and age-specific factors contributing to health disparities for Elders.

INTRODUCTION

Although members of the 567 federally recognized American Indian (AI) tribes in the United States have a treaty-guaranteed right to health care, inequities in access to and utilization of health

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care compared to other groups create persistent barriers to physical and mental health treatment for the nation's 5.2 million indigenous citizens (Adakai et al., 2018; Gone & Trimble, 2012). Among AIs, aged 55 and over, these disparities persist even among those with access to Medicare. In fact, by the time they reach old age, most AIs have experienced significant racial and social inequities over the course of their lives (Grandbois & Sanders, 2009; Smedley et al., 2003), contributing to a greater likelihood of poor health and barriers to care compared to all other aging populations in the United States (Boccuti et al., 2014; Jacobs et al., 2019). Elders encounter barriers at multiple contextual levels (i.e., personal and interpersonal; community and health care system; and tribal, state, and national policy) and may experience them differently based on their individual circumstances and life experiences, including those shaped by gender and age. The rapid growth of this population creates further urgency to understand and improve mechanisms that promote health care access and utilization to enhance both physical and mental health outcomes. This study utilizes concept mapping, a participatory mixed-methods research approach, to examine the perceived impacts of multilevel factors influencing whether AI Elders are able to access and utilize health care and how these perceptions vary among elderly women and men as they age.

The ongoing demographic shift towards an older population throughout the United States has been widely documented; however, this transformation is occurring among AIs at over twice the rate of the general U.S. population. Between 2000 and 2030, the percentage of AIs and Alaska Natives aged 65 and older is projected to increase from 5.6% to 13.4%, compared to an increase from 12.4% to 20.3% in the overall U.S. population (a relative increase of 139.3%; U.S. Census Bureau, 2000; 2012). This dramatic change means that systems that have not historically served many AI Elders must now prepare to address their complex health care needs while relying on the "patchwork" of funding sources and state and federal programs that provide health and social services to Elders (Bylander, 2018).

Tribal members can receive primary care services from the Indian Health Service (IHS) at no cost and without health insurance and can be referred elsewhere for treatments that they cannot access at an IHS facility, such as diagnostic tests and specialty care, through its Purchased/Referred Care program (PRC), formerly known as Contract Health Services. Although physical and mental health services provided through the IHS are more likely to be tailored to the needs of AIs than those obtained elsewhere, these programs are not available to Elders who do not meet tribal affiliation criteria or who live outside their tribe's IHS service area, including the majority of the approximately 70% of AIs who live in urban areas (Artiga et al., 2017; Gone & Trimble, 2012). Moreover, the IHS

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has never been adequately funded to meet the needs of AIs. In 2017, the per capita health care expenditure for IHS users was $4,078, compared to $9,726 for the general U.S. population (IHS, 2020a). Only a fraction of the IHS budget for clinical services are allocated to mental health and substance use treatment (IHS, 2020b). Many AI Elders have experienced the consequences of this underfunding throughout their lives, including health care facilities that are outdated and short-staffed, as well as limitations on the services covered by PRC, sometimes forcing them to go without recommended treatments or face major medical bills (Fox, 2011).

The 2010 Patient Protection and Affordable Care Act (ACA) updated the 1976 Indian Health Care Improvement Act to authorize the provision of long-term care, such as assisted living and community-based care; however, Congress has not dedicated funding to these vital supports for older AIs (Bylander, 2018). Although many older AIs have benefited from the ACA's expansion of Medicaid eligibility to most low-income adults (Artiga et al., 2017), Medicaid coverage of long-term care is still not available to many Elders in states that did not accept the Medicaid expansion. Others cannot get coverage for home- or community-based services because of the extremely complex and burdensome procedures required to establish their medical and financial needs.

In addition to these barriers, numerous other intersecting factors influence the ability of AI Elders to access and utilize health care. These may include low health literacy (i.e., the ability to locate, understand, and use information about health and health care) stemming from inequities in educational opportunity (Brega et al., 2012; Centers for Disease Control and Prevention, 2009), discomfort with the technology required to find and use health information (Kim & Xie, 2016), and difficulties with information processing due to cognitive, vision, or hearing impairments (Verney et al., 2008). AIs are also more likely than other populations to avoid care because they lack trust in health care providers and organizations, often because of prior experiences of discrimination and poor treatment (Simonds et al., 2014). Elders, especially women, may also prioritize the care of children or grandchildren over their own health (Haozous & Goins, 2012; Jaramillo et al., 2019). Together, these factors contribute to disproportionately higher rates among AIs compared to non-Hispanic Whites of physical health problems, including stroke, heart disease, diabetes, and obesity, and mental health concerns, such as alcohol dependence, posttraumatic stress disorder, and depression (Beals et al., 2005; Espey et al., 2014; Garrett et al., 2015; IHS, 2015; Shieb et al., 2014; Veazie et al., 2014).

Published reports repeatedly underscore these disparities, yet scholars have also noted that existing research on racial/ethnic disparities may not account for internal variation or "hidden heterogeneity" within groups (Institute of Medicine, 2002). For example, few studies to date examine how differences in gender and age among AI Elders shape their ability to access and utilize health care. In one national study of AIs and Alaska Natives aged 55 and older, women were significantly more likely than men to have at least one chronic health condition, even after controlling for other sociodemographic characteristics (Adamsen et al., 2018). Prevalence of chronic health conditions was also found to increase with age. In order to develop effective approaches to reducing the severe health disparities affecting AI Elders, it is critical to understand variations like these in Elders' health and health care needs, as well as the resources that are available to them.

In this study, we use concept mapping to compare the perspectives of younger (i.e., aged 55-64) and older (i.e., aged 65 and older) female and male Elders. Concept mapping is a community-driven, participatory approach to organizing complex, multilevel information and prioritizing areas for further study and intervention (Kelly et al., 2007; Windsor, 2013). It involves methods (i.e., listing and pile sorting) that are useful for eliciting emic perspectives on a particular phenomenon in a variety of sociocultural contexts (Bernard, 2017; Trotter & Potter, 1993). In this study, concept mapping illuminates areas of consensus and difference among sub-populations of AI Elders regarding the relative health impacts of factors affecting their health care access. A deeper understanding of these differences allows for the identification of tailored, locally relevant intervention strategies to address the problems impacting AI Elders with diverse life experiences and at different life stages.

METHODS

We conducted concept mapping between June and December 2017 as part of a larger study on access to and utilization of health care and health insurance among AI Elders in two states in the U.S. Southwest (Willging et al., 2018). One state had expanded Medicaid eligibility under the ACA, while the other had not. In keeping with community-engaged approaches to research with indigenous peoples (Brave Heart et al., 2016), we conceptualized and designed the overall study and the concept mapping activities in consultation with a group of AI Elders and allies called the Seasons of Care Community Action Board (CAB). The CAB members were distinguished for their knowledge and expertise related to AI health and Elder issues. They both initiated the planning for the larger study and supervised each aspect of this research, from reviewing data collection instruments and assisting with recruitment to strategizing efforts to promote Elder health. The Southwest Tribal Institutional Review Board approved the study design.

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Participants

We utilized a purposive sampling strategy to recruit a diverse set of AI Elders to take part in concept mapping activities. To ensure that the Elders participating in this study represented a range of knowledge, beliefs, and experiences related to health care and health insurance, recruitment efforts occurred in multiple tribal communities with targeted outreach to Elders living in urban settings. Elders were recruited through in-person outreach during regular visits to AI senior centers, health clinics, and meetings of health-focused AI groups and organizations in reservation and urban communities. Members of the research team (including the first, third, and fourth authors) presented the research study to Elders in these settings and remained available on site for several hours afterward to share information, answer questions, and conduct concept mapping activities with individuals who volunteered to participate. Research staff also provided printed copies of presentation materials featuring a toll-free number that Elders who were interested could call to be screened for eligibility at a later date. Inclusion criteria included self-identification as an AI Elder, aged 55 or over, and comfort in engaging with written English to complete the concept mapping activities. No one who volunteered to participate was deemed ineligible. Researchers were prepared to administer the MINI-COG© (2017) to test for cognitive impairment if they felt that a candidate was not able to understand or complete study procedures; however, no potential participants were identified or excluded for this reason. Informed consent was obtained from all participants, all of whom received an honorarium of $25.

Of the 65 AI Elders participating in concept mapping, 69.2% (*n* = 45) were women. The average participant age was 68.7 years with a range of 55 to 85 years old. All participants identified as AI, and approximately 10% (*n* = 6) reported that they also had Hispanic, Latino, or Spanish heritage. All were members of federally recognized tribes. For our analysis of the role of gender and age on perceptions of Elder health care access and utilization, we divided participants into four subgroups: women aged 55-64 (*n* = 14), women aged 65+ (*n* = 31), men aged 55-64 (*n* = 9), and men aged 65+ (*n* = 11). Age 65 was selected to split the sample for reasons that were both pragmatic (i.e., allowed for a reasonable number of participants across the four subgroups) and conceptual (i.e., full Medicare eligibility for these cohorts occurs by age 65, which might affect attitudes about and experiences with accessing health care).

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Concept Mapping Approach and Procedure

Concept mapping is a structured and iterative methodology involving both qualitative and quantitative data collection and analysis steps (Figure 1). Concept mapping is particularly useful when trying to obtain input from multiple stakeholders to better understand and identify areas for improvement in complex, multi-factorial domains such as health care access for AI Elders. First, we developed a focus question ("What factors make it easy or hard for AI Elders to get good health care?"), which we included in a separate series of semi-structured interviews that were conducted as part of the parent study.[1] Second, we created a list of 106 discrete factor statements derived from the interviews. Using member checking and advice from the CAB, we consolidated the list into a final set of 61 unique statements (e.g., "Not being comfortable/confident enough to ask questions") to reduce conceptual overlap/redundancy and result in a manageable number of statements for concept mapping participants to review. Third, we asked participants, along with 50 professional stakeholders (not the focus of this analysis),[2] to individually sort the statements into thematic groups or "clusters" that were meaningful to them. With each statement listed on a separate card, participants physically organized statements into groups. Participants were then asked to indicate a name to describe the general content of the statements included in each group (e.g., "Health care costs", "Accessibility of clinics"). Using worksheets, each participant was then asked to individually rate each statement (using a Likert scale) on three dimensions: impact (i.e., "How much do you think this factor affects the health of Native American Elders?;" 1 = *no effect* and 10 = *very large effect*), prevalence (i.e., "How common do you think this factor is among Native American Elders?;" 1 = *not common at all* and 10 = *very common*); and changeability (i.e., "How easy do you think it is to change this factor?;" 1 = *very difficult* to change and 10 = *very easy to change*). Sorting and rating activities were conducted in person in a setting that was deemed private and convenient by the participant (e.g., private room at a senior center).

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[1] Ninety-six Elders and 47 professional stakeholders took part in these individual interviews, which were conducted prior to the remaining concept mapping activities. Recruitment and interview procedures and content of the interview guides are described in Willging et al. (2018). Other interview findings are published elsewhere (Jaramillo et al., 2019; Jaramillo & Willging, 2021; Willging et al., 2021).

[2] Professional stakeholders included outreach workers, health care providers, tribal leaders, and administrators of health systems. Because this analysis focuses on Elders' assessments of the factors that impact their access to and use of health care, professional stakeholders' rankings are not reported here; they are published in Sommerfeld et al. (2021).

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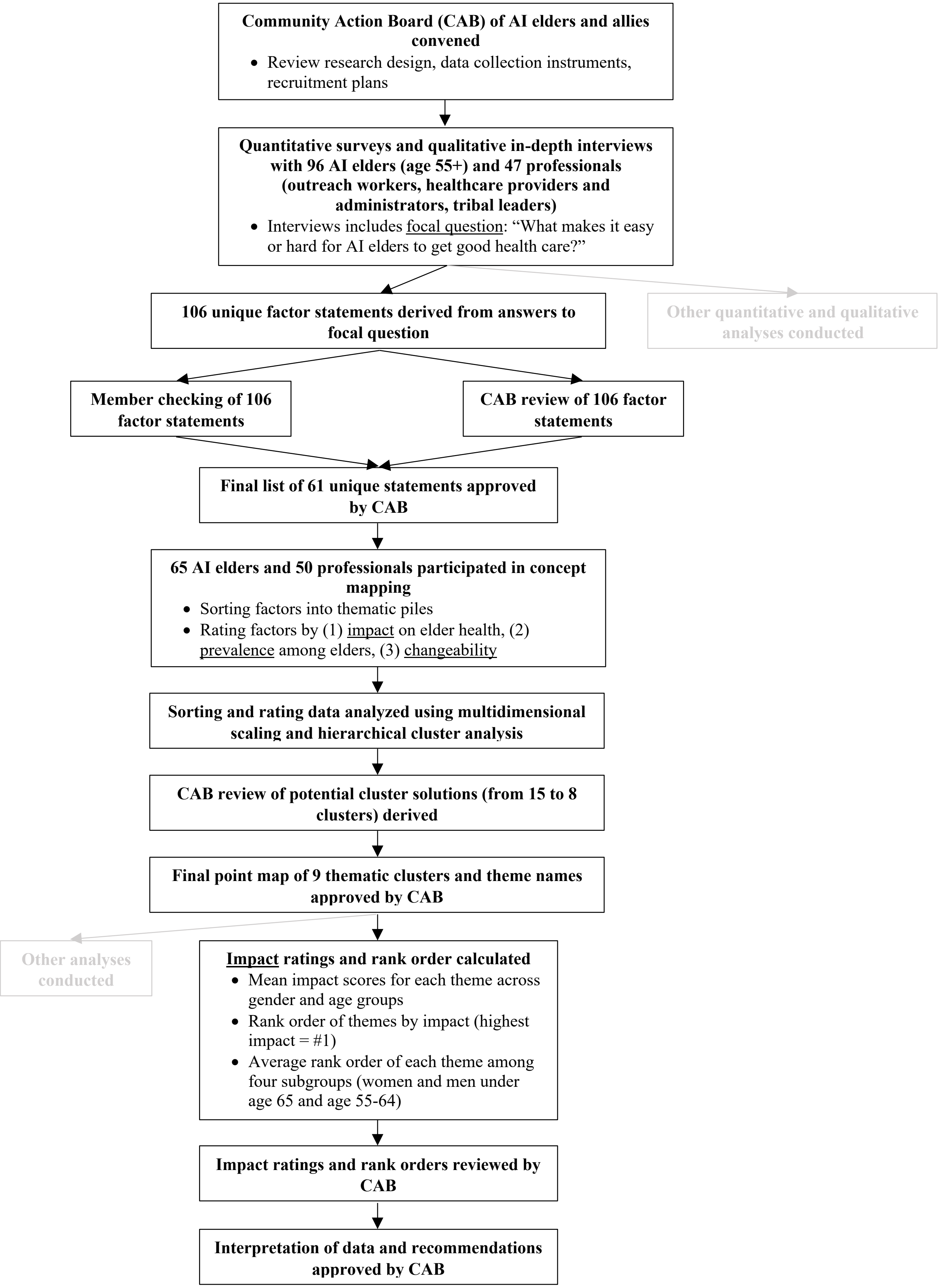
Figure 1. Concept mapping steps



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Fourth, sorting data were manually entered into Concept Systems software (Concept Systems Inc., 2018) to be analyzed using multidimensional scaling and hierarchical cluster analysis (Davison, 1983). The multidimensional scaling techniques produce a two-dimensional “point map” that provides a visual representation of how similar or dissimilar each individual factor statement is from all other factor statements based (mathematically) on how commonly the statements are grouped together by the participants. The results of the quantitative hierarchical cluster analyses identify which statements will cluster together when a fixed number of clusters is applied to the underlying point map data. Fifth, to arrive at the final cluster solution, we presented potential solutions ranging from 15 to eight clusters to the CAB members, who collaboratively settled on the nine-cluster solution as the best representation of the data without losing important distinct thematic content areas. The CAB also reviewed each cluster in this final model and ensured that the label assigned to it accurately reflected the nature of the statements that it contained. In this manner, the identification of the thematic clusters represented a truly mixed-method approach in that quantitative and qualitative steps were integrated through a specific concept mapping sequence to generate the final result.

The present analysis examines perceptions of each factor’s impact (i.e., how much each factor affects Elders’ health) among the AI Elder participants in our sample and how these perceptions varied according to gender (i.e., males vs. females) and age (i.e., “younger” vs. “older” Elders). To identify the thematic clusters that were consistently rated as having high impact on Elder health across gender and age groups, we calculated the mean “impact on health” scores for each thematic cluster by averaging the impact rating of each statement contained in the cluster. We then created an impact rank cluster order (i.e., with the cluster rated highest on the impact dimension ranked as #1, second highest as #2, etc.). Finally, we calculated the average cluster rank order across the four gender and age subgroups (i.e., women and men under age 65 and aged 65 and older) for each thematic cluster.

In addition to the analyses at the level of the thematic clusters, we examined the individual factor statements to determine which factors were identified as particularly impactful on Elder health among the gender and age subgroups. To conduct these analyses, we created *z*-scores for each individual factor by indicating how many standard deviations each subgroup’s impact rating of the factor was above or below the subgroup’s mean impact rating for all factors. We then identified the individual factor statements that were rated as having a mean impact on Elder health at least one standard deviation higher relative to the respective subgroup's overall mean impact rating for at least two of the four subgroups.

RESULTS

As reported in Sommerfeld et al. (2021), the final concept-map model comprised nine thematic clusters, each representing a key domain related to factors affecting whether Elders can obtain health care. These clusters were (in no particular order): Difficulties Obtaining and Using Insurance; Insecurity from Lack of Knowledge; Limited Availability of Services; Scheduling Challenges; Provider Issues and Relationships; Family and Emotional Challenges; Health-Related Self-Efficacy and Knowledge; Accessibility and Transportation Barriers; and Tribal/National Policy. Table 1 lists each of the nine clusters and the individual factor statements assigned to them.

Table 1

Cluster themes and factors affecting access to and utilization of health care among American Indian Elders

Cluster name	Statements included in cluster
1. Difficulties obtaining and using insurance	Uncertainty about what healthcare services/medications are covered by insurance Insurance or Indian Health Service won't cover enough healthcare costs Difficulty communicating with insurance company (including rude or unhelpful insurance representatives, understanding insurance lingo) Having to deal with billing departments and debt collectors Not knowing how to report or appeal health care/insurance decisions Needing to change insurance companies Difficulties using insurance at Indian Health Service Too many forms to fill out to get insurance Difficulties using multiple types of insurance Difficulties paying for the cost of insurance Lack of education about insurance plan choices Doctors/healthcare professionals not accepting insurance plan Insurance or Indian Health Service refusing to cover certain healthcare services or prescriptions Not having insurance/prescription card to show for services Too many forms to fill out when getting healthcare services Not being aware of Purchased Referred Care or how to use it
2. Insecurity from lack of knowledge	Not knowing where to find healthcare information Limited knowledge of computers or the Internet to obtain information about insurance Not having access to Native language interpreters/translators to help with insurance enrollment Difficulties paying for healthcare costs Getting inaccurate healthcare/insurance advice from IHS and/or Tribal services

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Table 1 Continued

Cluster themes and factors affecting access to and utilization of health care among American Indian Elders

Cluster name	Statements included in cluster
3. Limited availability of services	Not having a health facility open on weekends or after hours in or near my community Not knowing where to obtain good health care Health services/providers being shut down Not having access to Native language interpreters/translators when communicating with healthcare professionals
4. Scheduling challenges	Needing to change to a new doctor and/or healthcare facility Difficulty communicating with healthcare professionals (including rude or unhelpful providers, not understanding medical "lingo" or terminology) No same-day appointments available or walk-in access Long waits at healthcare facilities Doctors/healthcare professionals cancelling/rescheduling appointments Difficulty scheduling appointments (i.e., being told to call back at a later date when trying to schedule an appointment or having to schedule appointments more than a month in the future) Difficulties getting medication prescriptions filled/refilled
5. Provider issues and relationships	Not having a qualified/skilled doctor who can be trusted Rushed appointments with the doctor (e.g., five-minute visit) Not being able to see the desired doctor or health care professional Not having all your doctors, nurses, pharmacists, and facilities know the right information about you Not having a "regular" doctor that knows your personal health history Concerns about doctors or health care professionals not maintaining privacy/confidentiality Not knowing how to choose the right doctor Being over-prescribed too many drugs
6. Family and emotional challenges	Family being unwilling or unavailable to advocate on behalf of the Elder Difficulties dealing with emotions related to health care (e.g., feeling like a burden on family Living alone Not wanting to tell others about personal health issues Not being able to be honest with family about health care-related wants and needs Denying the need for care ("tough guy" mentality)
7. Health-related self-efficacy	Not being comfortable/confident enough to ask questions Not knowing how to advocate for own personal health care Reluctance to use services provided by Indian Health Service or Tribe Not being able to read or understand instructions for taking medicines correctly Not knowing when to go to the doctor (i.e., knowing the "warning signs")
8. Accessibility and transportation barriers	Limited availability of Elder-specific services (including home health caregivers) High cost of transportation to obtain health care Needing to travel long distances to obtain care (e.g., doctors or emergency care) Not having reliable transportation to get to health care appointments Not having access to community health programs (e.g., senior center or clinics) that provide transportation
9. Tribal/national policy	Health care is a low priority for Tribal leadership Information not shared with the community or general meetings Tribal affiliations or blood quantum restrictions make it hard to get good health care Not knowing how to influence Tribal leadership Health care is a low priority for national politicians

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Table 2 shows the average "impact on health" ratings for the nine thematic clusters and their relative rank order. The average ratings for the clusters indicate that each age and gender group perceived all domains as exerting large impacts on Elder health (i.e., all rating values were above a value of 6.5 on the 10-point scale where 1 = *no effect* and 10 = *very large effect*). Across the entire sample, impact on health ratings ranged from 6.63 (women 65+: Family and Emotional Challenges) to 8.40 (men 65+: Tribal/National Policy).

Table 2

Impact on American Indian Elder health ratings and rankings of thematic clusters by gender and age subgroups

	Women 55-64 years (*n* = 14)		**Women 65+ years (*n* = 31)**		**Men 55-64 years (*n* = 9)**		**Men 65+ years (*n* = 11)**		
Thematic Clusters of Health Care Access Factors	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Cluster "Impact" Mean**	**Average Subgroup Cluster Rank**
Provider Issues & Relationships	7.88	3	7.39	2	8.33	1	7.69	2	2.0
Tribal/National Policy	8.14	1	7.33	3	7.53	9	8.40	1	3.5
Scheduling Challenges	7.90	2	6.87	6	8.00	4	7.30	6	4.5
Insecurity from Lack of Knowledge	7.82	5	7.32	4	7.93	6	7.49	4	4.8
Limited Availability of Services	7.81	6	7.13	5	7.77	8	7.63	3	5.5
Accessibility & Transportation Barriers	7.60	8	7.40	1	7.82	7	7.22	7	5.8
Difficulties Obtaining & Using Insurance	7.53	9	6.82	7	8.06	3	7.42	5	6.0
Family & Emotional Challenges	7.83	4	6.63	9	8.00	5	6.83	8	6.5
Health-related Self-efficacy	7.66	7	6.75	8	8.27	2	6.66	9	6.5

Note: 10-point rating scale (1 = *no effect* on Elder health and 10 = *very large effect* on Elder health)

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The cluster rankings facilitated a standardized comparison of the relative perspectives among the gender and age subgroups. For example, while the average impact ratings for Limited Availability of Services were very similar for men in the 55-64 and 65+ age groups (7.77 and 7.63, respectively), this theme ranked #8 on health impact (i.e., almost the lowest rank order) for men 55-64, but #3 for men aged 65+.

An examination of the average rank score (i.e., the average of the rank order across the four subgroups) indicated that Provider Issues and Relationships was the overall highest-ranked thematic cluster for impact on health (average rank score of 2) and was ranked in the top three across all four subgroups. The second highest ranked theme was Tribal/National Policy (average rank score of 3.5). This thematic category was rated in the top three for three out of the four subgroups. However, while Tribal/National Policy was generally perceived as impactful on health, men 55-64 differed substantially by ranking this category lowest of the nine thematic categories. Additionally, the highest ranked domain among women 65+ was Accessibility and Transportation Barriers, while this category was ranked no higher than #7 among any of the other subgroups. Similarly, among men 55-64, Health-Related Self-Efficacy was ranked #2, but no higher than #7 among any of the other subgroups.

Table 3

Impact on American Indian Elder health ratings of individual health care access factor statements by gender and age subgroups[a]

		Women 55-64 years (*n* = 14)		Women 65+ years (*n* = 31)		Men 55-64 years (*n* = 9)		Men 65+ years (*n* = 11)		
Item #	**Individual Health Care Access Factor Statement**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Groups with *Z*-score >=1**
	Average impact rating for all 61 items	*7.76*	*SD=0.73*	*7.10*	*SD=0.63*	*8.02*	*SD=0.64*	*7.40*	*SD=0.86*	
1	Long waits at healthcare facilities	9.46	2.3	7.71	1.0	7.89	-	8.73	1.5	3
2	Limited knowledge of computers or the Internet to obtain online information about insurance	8.69	1.3	7.97	1.4	7.56	-	8.30	1.0	3
3	Not knowing how to report or appeal healthcare/insurance decisions	8.77	1.4	8.11	1.6	9.11	1.7	7.18	-	3

continued on next page

Table 3 Continued

Impact on American Indian Elder health ratings of individual health care access factor statements by gender and age subgroups[a]

		Women 55-64 years (*n* = 14)		Women 65+ years (*n* = 31)		Men 55-64 years (*n* = 9)		Men 65+ years (*n* = 11)		
Item #	**Individual Health Care Access Factor Statement**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Mean "Impact" rating**	***Z*-score diff. from group mean**	**Groups with *Z*-score >=1**
	Average impact rating for all 61 items	*7.76*	*SD=0.73*	*7.10*	*SD=0.63*	*8.02*	*SD=0.64*	*7.40*	*SD=0.86*	
4	Health care is a low priority for national politicians	8.77	1.4	8.41	2.1	7.33	-1.1	9.27	2.2	3
5	Not having a "regular" doctor that knows personal health history	7.85	-	7.43	-	9.38	2.1	8.30	1.0	2
6	Difficulties dealing with emotions related to health care (e.g., feeling like a burden on family)	8.77	1.4	7.82	1.1	7.44	-0.9	6.09	-1.5	2
7	Difficulty scheduling appointments	8.77	1.4	7.45	-	8.89	1.4	7.40	-	2
8	Not knowing how to influence tribal leadership	7.83	-	7.72	1.0	7.22	-1.3	8.82	1.7	2
9	Health care is a low priority for tribal leadership	8.08	-	7.73	1.0	6.89	-1.8	9.00	1.9	2
10	Not being aware of Purchased/Referred Care or how to use it	8.08	-	7.83	1.2	8.33	-	8.45	1.2	2
11	Lack of education about insurance plan choices	8.92	1.6	7.57	-	7.89	-	8.45	1.2	2
12	Information not shared with the community or general meetings	9.08	1.8	6.90	-	8.44	-	8.73	1.5	2

[a] *Z*-scores are listed only if they exceed +/- 0.75. Note: 10-point rating scale (1 = *no effect* on Elder health and 10 = *very large effect* on Elder health)

Table 3 lists the 12 (out of 61) individual factor statements that participants perceived to be particularly impactful on Elder health (i.e., having a *z*-score difference from the group mean of at least 1.0 in at least two subgroups). Four individual factors were rated as particularly impactful on health across three subgroups: "Long waits at healthcare facilities," "Limited knowledge of computers/Internet to obtain online information about insurance," "Not knowing how to report or

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appeal healthcare/insurance decisions" and "Health care is a low priority for national politicians." Eight additional factors were rated as especially impactful by two subgroups (see Table 3).

Two factor statements reflected a gendered response pattern. "Not having a 'regular' doctor," was highly rated only among men, while "Difficulties dealing with emotions related to health care," was highly rated only among women (with men highly underrating this item per the large negative *z*-scores). Similarly, there were four factors with an age-related pattern. Both women and men 55-64 identified "Difficulty scheduling appointments" as particularly impactful on health and only persons 65+ highly rated "Not knowing how to influence tribal leadership," "Health care is a low priority for tribal leadership," and "Not being aware of Purchased/Referred Care or how to use it."

Of note, as shown in Table 3, the mean ratings for the impact for all 61 factors differed across the four subgroups in a systematic manner. For example, within both women and men, the aged 55-64 overall mean impact rating was approximately 0.6 higher than the aged 65+ group mean of the respective gender. Additionally, for both age groups, the group mean for men was approximately 0.3 higher than the corresponding age group mean among women.

DISCUSSION

Concept mapping is a community-based methodology that incorporates qualitative and quantitative data on complex, multilevel phenomena—in this case, factors influencing the ability of AI Elders to effectively access health care. Use of this approach helps to identify and prioritize key areas for intervention to improve the physical and mental health of Elders in general and to extricate the unique perspectives and needs of subgroups of Elders, specifically women and men, as well as younger and older Elders. Overall, our findings emphasized several areas of agreement among Elders, particularly the perception that Provider Issues and Relationships and Tribal/National Policy have a significant impact on Elder health. Likewise, rankings of individual factor statements underscored that difficulties associated with interactions with health care organizations (i.e., "Long waits at healthcare facilities," "Not knowing how to report or appeal healthcare/insurance decisions"), unfamiliar technology (i.e., "Limited knowledge of computers or the Internet to obtain online information about insurance"), and a policy environment perceived to be indifferent to Elders' needs (i.e., "Health care is a low priority for national politicians") were broadly shared and thought to be impactful among Elders.

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The above results resonate with the findings of our larger study on health care access and utilization, which revealed shared experiences of frustration, confusion, and inadequate care resulting from program and funding shortages at IHS and tribal facilities, the bureaucratic complexities associated with health insurance, and a pervasive atmosphere of uncertainty surrounding the stability of public health insurance programs (Jaramillo & Willging, 2021). They also fit within a historical context of discrimination, abuse, and neglect against AIs within the U.S. health care system that has not been redressed. Individual and cultural memories of atrocities, such as the forced sterilization of AI women well into the latter half of the 20th century (Lawrence, 2000), as well as everyday experiences of stigma and mistreatment at the hands of medical providers, shape Elders' trust in, and engagement with, the health care system (Armenta et al., 2021; Guadagnolo et al., 2009; Simonds et al., 2014). As we argue elsewhere (Sommerfeld et al., 2021; Willging et al., 2021), our findings illuminate an urgent need to prioritize system and organizational changes to facilitate Elders' use of health care, including advocating for state and federal governments to meet their treaty obligations by securing stable and adequate funding for tribal health care facilities to provide a full range of care and devoting more resources to helping Elders navigate the health care system. Given the particular emphasis on Provider Issues and Relationships indicated across all four subgroups, this domain should be prioritized for improvement, both at the individual level (i.e., via health literacy efforts on how to navigate, understand, and build productive relationships with health care providers), and at the system level (i.e., ensuring that providers have the time and education to serve populations that have been historically marginalized and disenfranchised, such as AI Elders). In addition, the ubiquity of web-based information and communication in health and insurance systems highlights the need for increased investments in efforts to bridge the "digital divide" for the many AI communities that lack equitable access to broadband internet (Goldstein, 2018), as well as for AI Elders with limited financial and educational resources to obtain and use digital technology.

Although our data suggest that there are many commonalities among Elders in their perspectives on barriers to health care, each of the subgroups had particular areas of concern. Analysis of these differences, facilitated by discussions with our CAB members, allows us to elucidate important ways that Elders' experiences may vary according to gender and as they age. For example, women of both age groups accorded special importance to "Difficulties dealing with emotions related to health care." CAB members noted that this finding points not only to conventional expectations about women exhibiting more emotionality than men, but also to

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women's roles as caregivers (Byers, 2010; Gallant et al., 2010). They explained that women's relative difficulty dealing with their own emotions related to health care may stem from the perceived obligation to subordinate the expression of such emotions to those of others and "put on a brave face" for their children and families. Another difficult emotion that was common among elderly women was the fear of "becoming a burden" and no longer being able to care for others if they require care themselves. For example, one CAB member recounted how her cancer diagnosis made her fear that her family would treat her like "a sick person" and not like the grandmother they were used to (Jaramillo et al., 2019). Additionally, we found that the theme of Accessibility and Transportation Barriers was ranked as having the most impact on health among women over age 65, even though no other groups ranked this theme any higher than seventh. Among AIs, women have a higher life expectancy and thus make up a majority of the over-65 population (U.S. Department of Health and Human Services, 2018). Consequently, older women may not only be more likely to experience age-related accessibility barriers, such as not being able to drive or having a hard time making appointments due to hearing impairments or language differences, but also may live alone or have lost former sources of social and material support, such as a spouse who drives them. Moreover, AI women may experience emotional and financial hardships as they utilize their own limited resources to care for others (Gallant et al., 2010; Haozous & Goins, 2012; Letiecq et al., 2008). These findings underscore the influence of social relationships on the mental and physical well-being of Elder women in particular (Roh et al., 2015; Sherman et al., 2011) and the need to acknowledge Elder women's roles as caregivers. Interventions for Elder women should thus include increased opportunities to cultivate social relationships that offer both emotional and pragmatic support, especially as they get older.

In contrast, our findings suggest that Elder men have specific needs around access to and routine use of health care. The higher ranking of "Not having a 'regular' doctor that knows personal health history" among men compared to women is likely due to lower rates of health care utilization among men in general, which would allow them to establish a relationship with a regular care provider (Pinkhasov et al., 2010; Vaidya et al., 2012). A relative lack of familiarity with health care may also explain the higher ranking of Health-Related Self-Efficacy among men aged 55-64 compared to the remaining subgroups. CAB members suggested that younger Elders who were less familiar with health care might emphasize individual-level factors like the ability to self-advocate and "ask the right questions," while older Elders with more complex health care needs would highlight the difficulties of dealing with convoluted health systems, as we describe below. A similar dynamic may occur among younger Elders in general, contributing to their higher ranking of "Difficulty scheduling appointments" compared to older Elders. Moreover, younger Elders' challenges with scheduling appointments are likely to be related to variability in health insurance enrollment (Artiga et al., 2017). While Elders aged 65 and older are commonly enrolled in Medicare and are thus more likely to receive regular check-ups and follow-up visits (Boccuti et al., 2014), younger Elders may avoid making appointments because they lack health insurance or struggle with finding providers who are covered by the insurance they have. These findings suggest that efforts to improve health for younger Elders and men should focus on integrating individuals into usual sources of care. This includes ensuring that younger Elders have adequate health insurance coverage and increasing Elders' comfort with seeking care and interacting with health care providers.

Other age-related variations in our findings relate to challenges for older Elders in navigating complex bureaucracies ("Not being aware of Purchased/Referred Care and how to use it") and tribal decision-making processes ("Not knowing how to influence tribal leadership," "Health care is a low priority for tribal leadership"). Older Elders are likely to need more frequent, more complex, and potentially more expensive health care as they age (Okoro et al., 2007), necessitating those who use the IHS to increasingly rely on the PRC system to arrange and pay for specialty services. However, Elders may avoid using PRC due to experiences of rationed care and unexpected medical bills (Artiga et al., 2013). Similarly, while younger men are likely to be involved in tribal government, older Elders—particularly women—may feel unable to access tribal leaders and advocate for their own needs. This tendency is underscored by our finding that men aged 55-64 rated Tribal/National Policy as the least important theme, while all other subgroups rated it among the top three themes in importance. Consequently, efforts to support Elders should focus on helping them navigate health systems by facilitating access to understandable and effective information about resources and services to which they are entitled. For example, interventions to provide culturally congruent health navigators, who can help Elders with decision making, scheduling, transportation, and communication with health care providers, have been well-received among AIs and have been shown to increase knowledge about health and health care, improve access to care, and avoid delays in diagnosis of serious health problems (Burhansstipanov et al., 2014; Grimes et al., 2017). Additionally, tribes can work to increase accountability and responsiveness of tribal leaders—who are often young, rarely have a background in health care or insurance, and frequently are preoccupied with

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other matters of relevance to their community—by educating them about the needs of Elders (Jaramillo et al. 2019).

Overall, this study underscores the need to craft interventions that address the multilevel gender- and age-specific factors contributing to physical and mental health disparities for AI Elders. Our findings confirm that health interventions focused on health literacy and behavior (e.g., Centers for Disease Control and Prevention, 2009), particularly those that include technological and online literacy, are needed by Elders. Yet, this research also suggests that such interventions are primarily beneficial to younger Elders and men, whose health struggles are more closely linked to issues with health care utilization. Improving the health and well-being of older Elders and women will require multilevel approaches that target interpersonal and community relationships, the functioning of health care organizations, and broader social and historical factors that contribute to emotional and financial hardships. For example, health care providers should consider the “structural vulnerabilities” of their elderly women patients, meaning the upstream social structures and forces that may influence their health and ability to attend appointments or adhere to medical advice (Bourgois et al., 2017). Addressing these vulnerabilities may include modifying health care environments or procedures (e.g., the ways that appointments are scheduled) and making “prescriptions” of social and economic resources (e.g., food assistance, help with transportation; Metzl & Hansen, 2014). Finally, Elder advocates and tribal, state, and federal policymakers must step up their efforts on meeting treaty-established obligations to guarantee health care for AI people.

Limitations

To promote accurate interpretation of these data, we obtained input from the CAB and contextualized the data within the findings of our broader study, which included the perspectives of many different stakeholders. However, the sample sizes—especially of men—are relatively small and there may be biases in the sample such that these findings are not generalizable to all AI Elders, given the cultural and sociopolitical heterogeneity that characterizes Native North America. The small sample sizes also precluded the identification of issues unique to other subgroups of Elders, such as the “oldest old” (i.e., over age 75) or rural vs. urban residents, which should be prioritized in future research. In addition, individuals targeted for this study were usually fluent in English. However, Elders who were not completely comfortable with written English may have declined to participate. Although we did not identify any participants as potentially having cognitive impairment, it is possible that individuals with cognitive or other limitations (e.g., of hearing or vision) may have declined to participate.

Because concept mapping is an attention- and time-intensive process, we did not ask our elderly participants to consider separate factor statements related to physical and mental health. However, primary care is the de facto mental health system for patients of all ages (Starfield et al., 2005); consequently, we expect that themes considered here contribute to both physical and mental health disparities.

CONCLUSION

As the population of AI Elders in the United States grows, researchers and policymakers must prioritize efforts to understand and address the persistent inequities that affect their health and quality of life. Findings from this study underscore the inadequacy of broad, primarily individually focused health interventions that do not account for variations in the experiences and needs of AI women and men of different ages, nor for the multilevel challenges that they encounter (Manson, 2020). Rather, this research highlights the need to tailor physical and mental health interventions to Elders' specific life histories and circumstances. Moreover, tribal, state, and federal policymakers must engage in efforts to address the funding shortages, bureaucratic complexity, and inattention to Elders' needs that contribute to their alienation from systems of care. Finally, given the long history of abuse and neglect of AIs in the U.S. health care system, this study points to the need for future research to delve more deeply into variations in the cultural memories and experiences of Elders over the course of their lives and how those experiences influence their access to health care.

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URBAN AMERICAN INDIAN AND ALASKA NATIVE DATA SOVEREIGNTY: ETHICAL ISSUES

Emily A. Haozous, PhD, RN, FAAN, Juliet Lee, PhD, and Claradina Soto, PhD, MPH

Abstract: This paper examines the ethical issues underlying research with urban American Indians and Alaska Natives (AI/ANs) through the lens of tribal sovereignty. There are 574 federally recognized tribes within the United States. Each of those tribes is recognized by the federal government as having sovereign status, an important political designation that ensures that decisions impacting tribal peoples must be made after consultation with those nations. Most AI/AN people live away from their designated tribal lands, yet their sovereign rights are frequently only recognized when living on tribal lands. These urban AI/ANs are still considered citizens of their sovereign nations, yet they lack the protections afforded to those who live on tribal lands, including protections surrounding research with their tribal communities. We explore the Belmont Report and related documents and demonstrate their inadequacy in considering the cultural and ethical concerns specific to protecting urban AI/ANs. We also provide several solutions to help guide future institutional policies regarding research with urban AI/ANs that honors Indigenous data sovereignty, including consultation, partnership with community advisory boards, employment of data use agreements, and ensuring informed consent.

INTRODUCTION

In the United States, there are currently 574 federally recognized American Indian and Alaska Native (AI/AN) tribes in 34 states (Bureau of Indian Affairs, 2021). Federally recognized tribes are distinguished by the U.S. government as sovereign nations, a status that has historic roots stemming from early encounters with European colonizers and subsequent treaties that were negotiated with AI/ANs. Currently, U.S. and state governments are directed by multiple Supreme Court decisions, Executive Order 13175, and a January 2021 Presidential Memorandum to recognize

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tribal sovereignty through a process of participation, consultation, and accountability when considering policies that may impact tribal communities (Biden, 2021; Exec. Order No. 13,175, 2000; Wilkins & Adams, 2019).

Due to a series of historic, economic, and personal factors, as many as 70% of AI/ANs live in urban areas and away from their home tribal community, reservation, or recognized territorial lands. Despite having status as citizens of sovereign nations, AI/ANs who are not physically on tribal land are not protected by the rights of sovereignty (from this point, we will refer to this population as "urban AI/ANs," recognizing that this label encompasses a wide diversity of reservation to non-reservation living situations). Yet, unless their specific tribe retracts citizenship, AI/ANs who are members of federally recognized tribes are sovereign citizens regardless of where they live.

In health research, this can have far-reaching implications, as tribes are protective of the rights and data of their tribal members, but the extent of the protections of sovereignty for urban AI/ANs are still undefined. Furthermore, although the ethical foundations of current human subjects' protections regulations in the United States guide institutional review boards (IRBs), they do not always reflect the values of many AI/AN peoples.

The purpose of this paper is to examine the ethical issues underlying research with urban AI/ANs through the lens of Indigenous data sovereignty and governance. Through this examination, we argue that the ethical researcher will adopt additional strategies of consultation, partnership with community advisory boards, employment of data use agreements, and guaranteeing informed consent to ensure that urban AI/AN sovereign citizens' rights are recognized and protected.

Background

Sovereign Indigenous Nations have their own governance and rights over their lands, cultural knowledge, peoples, and resources. With those rights come the ownership of information, or data, that describes their peoples, activities, and all aspects of their communities (Rainie, Rodriguez-Lonebear et al., 2017; Tsosie, 2020). With ownership comes the control of how the data are used. Indigenous data governance describes the right to self-determination, controlling how tribal data are gathered, accessed, and used (Tsosie, 2020).

When tribes maintain their own data, the data are more complete and provide a better understanding of the nuances that are seen in tribal communities that would not otherwise be observed (Rainie, Schultz et al., 2017). For example, racial misclassification in cancer surveillance data is a well-established problem, and the true extent of cancer morbidity and mortality in AI/ANs

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is yet to be known (Bruegl et al., 2020; Jacobs-Wingo et al., 2016; Melkonian et al., 2020; White et al., 2014). Cancer surveillance data are improved when cancer registry data are linked with IHS and tribal enrollment records, requiring partnership with tribes and honoring of tribal data sovereignty (Weber et al., 2019). The outcome to this linkage is greatly enhanced surveillance data, which then more appropriately directs funding and cancer control efforts at the local, tribal, state, and federal levels.

Tribes who control their data also manage how samples obtained through research are used. This component of Indigenous data governance is a critical component of Indigenous data sovereignty, as it embodies exactly why these data must be protected (Tallbear, 2013). Having control over their own data allows tribes to dictate exactly how the data will be used, interpreted, and written about. In practical terms, this means tribes can control the narratives about their own people.

When a tribe practices data sovereignty through data governance, they also take immediate control over the cultural assets contained within the data that are collected by researchers. Many large, mixed-methods studies conducted with AI/ANs include extensive qualitative interviews. There is always potential for participants in these studies to share cultural information that may not be intended for publication (Tsosie, 2007). With data governance, participating tribes can engage in research activities knowing their sacred cultural information will not be exploited by researchers, and all cultural information is reviewed prior to dissemination to ensure the tribe's cultural practices are shared respectfully. Likewise, with data governance, all tribal data is reviewed prior to dissemination to protect the participating communities from inappropriate or exploitative reporting by researchers (Oetzel et al., 2015; Rainie, Schultz, et al., 2017).

A person's AI/AN enrollment is based on the eligibility of their specific Tribe, Pueblo, or Nation. Geography and proximity do not define an AI/AN identity or ability to maintain enrollment status in most tribes (Haozous et al., 2014). Ostensibly, an enrolled AI/AN member is considered a sovereign citizen of that tribe. Even so, under the current practices of tribal sovereignty in the United States, geography is the sole determining factor for protections under sovereignty. An AI/AN living on their home tribal land will maintain all protections as a member of their Nation, yet an AI/AN from that same Nation living off tribal lands likely lacks those same protections. This land-based sovereignty is made more complicated for those AI/AN Nations for whom tribal land is reduced to allotments, as is the case for certain tribes in Oklahoma (Kiel, 2019; Tsosie, 2000).

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The authors of this article (Haozous, Lee, and Toya) were part of a team that was involved in research with multiple urban AI/AN community organizations. The team included experienced AI/AN and non-AI/AN researchers who were familiar with the principles of Indigenous data sovereignty. In collaborating with urban AI/AN populations, we recognized that the protections offered through sovereignty are only within the limitations of established, federally recognized tribal communities on tribal land. This did not change the concerns regarding Indigenous data governance for urban AI/ANs, who still wanted to protect their data from the same concerns of misuse, exploitation, misrepresentation, and protection from inaccurate narratives. Recognizing this lack of protection by way of territorial sovereignty led us to investigate the ethical foundations and data governance-linked mechanisms for protecting Indigenous data.

ETHICAL FOUNDATIONS FOR PROTECTING INDIGENOUS DATA

In the United States, the Federal Policy for the Protection of Human Subjects (Protection of Human Subjects, 2018) sets the standard for all research with humans. Although not entirely so, the ethical foundation of the Common Rule is drawn from the Belmont Report (Ryan et al., 1979). The Belmont Report breaks medical bioethics into three basic concepts: justice, autonomy, and beneficence. Much of the ethical foundations of the Belmont Report are recognized as universal, but there are limitations. When considering AI/AN communities, the Belmont Report does not accommodate collective cultures, and it is based entirely on a European/Western concept of knowledge (Tsosie et al., 2019). While IRB members may receive some training on the importance of looking beyond the European, and largely Christian, values that underpin the Belmont Report, there is nothing within the Common Rule that specifically instructs an IRB or researchers to consult with community leaders, tribal members, or other cultural experts when working with AI/AN tribes (Adashi et al., 2018; Parker et al., 2019; Tsai, 2008; Williams et al., 2010).

According to Beauchamp and Childress (2001), there are four concepts that guide modern medical bioethics: justice, beneficence, nonmaleficence, and autonomy. The Belmont Report does not include nonmaleficence, instead including this with beneficence. Outside the United States, there are several guiding documents that assist in formulating a broader perspective on bioethics. These documents may assist researchers and IRB members when considering the special circumstances of AI/ANs within the United States, both reservation-based and non-reservation-based. For the purposes of this paper, the documents that we focus on are the International Ethical

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Guidelines for Health-Related Research Involving Humans, authored by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO); the Ethics of Research Related to Healthcare in Developing Countries, authored by the Nuffield Council on Bioethics; and the United Nations Declaration on the Rights of Indigenous Peoples (Calman et al., 2002; CIOMS, 2016; United Nations Declaration on the Rights of Indigenous Peoples, 2007). We are focusing on documents that center ethical issues in developing and international communities due to the power differentials between large institutional researchers and AI/AN communities, which share many qualities with those found in developing nations.

Justice

Although not explicitly classified under the same categories as Belmont or Beauchamp and Childress, all documents contain guidelines that can be clustered thematically within the same concepts of justice, autonomy, beneficence, and non-maleficence. As stated previously, domestically authored publications focus on the individual as the decision-making body. In striking contrast, those documents that consider Indigenous and developing populations consistently share a common characteristic: the firm insistence that the community in which the research is being conducted is an equal partner with all research-related decisions, from the first ideas to dissemination to data storage and ownership. This equitable partnership is seen as an issue of justice, as is described in the Nuffield guidelines in their observation that local context is critical to the safe and equitable conduct of research (Calman et al., 2002). In this report, justice and respect are synonymous, with recognition that there is always the possibility for those researchers from wealthy countries to exploit economic, political, and educational vulnerabilities, even unintentionally. For this reason, collaboration and constant consultation with community representatives are protective mechanisms to prevent this exploitation.

The Belmont Report defines justice as an equitable distribution of the benefits and burdens of research (Ryan et al., 1979). This simplistic definition is insufficient when the research endeavor includes populations with great income inequality, limited access to resources, and great distance between the researcher’s home institution and the research site. Looking at quantifiable conditions of disparity, global research in developing nations is like research in Indian Country. It is those disparities that make Indian Country so appealing as a setting for health research because AI/AN communities appear ripe for measurable change through intervention. In research with developing nations, investigators are cautioned to avoid over-representing marginalized populations in research, considering the difficulty those populations will have in naturally accessing the benefits of research in daily life (CIOMS, 2016). Likewise, issues of health care access and payment, as well as generations of disenfranchisement and the resulting mistrust, have led to a highly limited utilization of health care resources across AI/AN communities, in reservation and urban areas alike.

For AI/ANs living in urban areas, there are additional concerns that add to the Indigenous data sovereignty discussion. AI/ANs living in urban areas who utilize Urban Indian Health Programs (UIHPs; Indian Health Service, 2021) are recognized within research circles to be easily recruited and engaged to provide data without having to obtain permission from critical tribal Councils, tribal review boards, or tribal leaders (Yuan et al., 2014). Unfortunately, although UIHPs may wish to regulate data with the same principals of data sovereignty as to protect AI/ANs living on or near reservation land, they do not have the same legal protections afforded to reservation residents.

The urban AI/AN population can be difficult to locate due to conditions of economics and racial misclassification (Bird et al., 2007). Drawing from national datasets, there exist some estimates on the overall health of urban AI/AN populations, but these estimates have significant flaws, including concerns with racial misclassification contributing to undercounts of the numbers of AI/ANs overall, small sample sizes forcing AI/AN numbers to be aggregated with other small populations in the data, or concerns regarding inclusion of AI/ANs who identify with more than one race or ethnicity (Urban Indian Health Institute, 2016).

Unlike reservation-based AI/ANs, urban AI/ANs have a greater range of educational, economic, and lifestyle heterogeneity (Austin, 2013). The UIHP population is the easiest to access within urban settings, but there are concerns of data skewing when samples are drawn exclusively from UIHPs. This is a special concern for those UIHPs that serve a high number of clients without private insurance. If justice is the equal distribution of both the positive and negative effects of research, yet all data is collected through a UIHP, the ultimate result is an unequal distribution of the outcomes. Additionally, those urban AI/ANs whose data are not represented have no collaborative or consultative voice in the research process, effectively denying their sovereignty.

Autonomy

Community-based participatory research (CBPR) is the collaborative research approach suggested by the Nuffield and CIOMS guidelines. This is the approach most known in the United States and is critical in guiding researchers on important cultural insights necessary for maintaining

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autonomy in the consent process. Those insights include providing information on how best to approach the individual or collective regarding who should provide informed consent, as the person from whom data are being collected may not be considered the responsible party in all cultures. In the United States, this concept is well understood when obtaining informed consent in research with children, as it is well accepted that children cannot give independent consent, they are quite capable of giving assent. Within the domestic borders of the United States, we have Indigenous communities for whom group consent would be the best cultural model, with many variations therein. For example, tribal leaders may be the primary decision-makers, or tribal elders, or other tribal members for whom great traditional responsibilities are given, yet in the dominant culture these individuals are decision-making equals to their adult children (Smith, 2013; Tallbear, 2013). The idea of individual consent is conceptually incomprehensible (and extremely disrespectful) in many traditional AI/AN contexts (Christian, 2019; Kovach, 2021). The Nuffield Council provides excellent guidelines on obtaining consent within collective communities, suggesting that individual *consent* is sought from the research participant, but only after community consultation with *assent* obtained from the most appropriate representative of the community (Battiste, 2008; Calman et al., 2002).

Researchers engaged in the consenting process expect that the participant can make independent, goal-oriented decisions (Ryan et al., 1979). Autonomy depends on the individual to devise and act upon personal goals. Autonomy is provided with the caveat that those individuals who are deemed "vulnerable" must be protected, yet the definition of vulnerable populations is frustratingly vague. 45 CFR § 46 specifically defines vulnerable populations as children, prisoners, people with impaired decision-making ability, or economically or educationally disadvantaged persons (Protection of Human Subjects, 2018). Specifically, there is no clear definition for the subjective categories of "economically or educationally disadvantaged persons," leaving those determinations for the IRB overseeing the research. This creates potential for populations that have been marginalized through unbalanced reporting of population-based statistics to have their decisional capacity removed. Indigenous communities, whether urban or reservation-based, may rate poorly on standard measures of income and academic education, yet their cultural understandings of what consists of knowledge and worth could be substantially different (Smith, 2013). Regardless of their Indigenous definitions for economic and educational achievement, these external and often artificial measures are imposed on AI/AN communities without their consent or consultation, thus denying those communities agency in deciding whether they can consent to participate in research

(Creighton University, 2013; Kwon, 2018; Medical College of Wisconsin, 2021). Without self-determination, there is no autonomy. In IRBs where AI/ANs have a blanket determination of "vulnerable," the institution has usurped the AI/AN populations' self-determination without consultation, removing their autonomy.

In a population that has been systematically denied self-determination through generations of unjust federal and state policies, the potential for true Indigenous autonomy is rare. For this reason, tribes are exerting their sovereignty so they may govern how their data are used and shared. AI/ANs not living on or near their tribal lands do not cede their status as citizens of sovereign nations, yet they lack the protections of local sovereign governance, and thus their ethical rights as autonomous beings are at risk when engaging in biomedical research. Some may argue that the protections for vulnerable populations required within 45 CFR § 46 make research more ethical for AI/ANs, but it is our assertion that the paternalistic stance of institutional oversight is not a just replacement for community engagement and appropriate consenting processes. Indeed, denying community input by deeming specific populations vulnerable based on externally applied metrics is a clear violation of autonomy.

Beneficence

Ultimately, it is the researchers' responsibility to maximize all potential benefits in the research endeavor. The consenting process plays an important role in ensuring research informs potential participants of all possible risks, so they may weigh the risks against the possible potential benefits of the research. Frequently, consent documents will feature only the immediate personal risks and benefits such as side effects or symptoms and possibilities for data breaches, with little explanation of the long-term outcomes. Consent documents rarely state the potential collective risks and benefits which may result from the research processes and reports, including potential negative impacts as well as how the community may benefit from the program. While there may be a sentence describing publication intentions, few community participants know how their data will be used in reporting, particularly how their data can be manipulated to exploit negative narratives about their communities.

Therapeutic misconception and therapeutic optimism are also known factors that cloud participants' ability to provide true informed consent. Often, participants' judgement regarding consent is based on personal factors such as an immediate health need, or a belief that they will be randomized to the intervention group, indicating a poor understanding of clinical research and

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characteristic of therapeutic optimism (Jansen, 2011). Another characteristic of therapeutic misconception is the confusion between the overall generalizability of research results regardless of participants' personal benefit (Bhutta, 2004; Henderson et al., 2007). These two barriers to informed consent allow a poorly informed public to be unintentionally coerced into participating in research activities. In communities in which health literacy is already an issue, such as is the case with many AI/ANs (Willging et al., 2018), therapeutic misconception and therapeutic optimism at the time of consent conflict with the ethical principles of beneficence.

Applying international guidelines such as CIOMS for AI/ANs, both those on and away from tribal lands, would promote research methods that are scientifically sound and have local applicability with a clear endpoint that promotes health at the individual, community, or policy level (CIOMS, 2016). The conditions described previously can incentivize research that does not ensure the participants are fully informed of the risks and benefits to the community, an important consideration in collective cultures. Furthermore, the Nuffield guidelines describe social and cultural context as components necessary for informed consent, both of which would aid in avoiding therapeutic misconception and optimism (Calman et al., 2002).

In urban AI/AN communities, researchers may mistakenly assume the participants are more assimilated to the dominant culture, thereby lacking the same cultural tailoring of consent or other population-specific considerations they would make with a rural, reservation-based community. Although AI/ANs living in urban areas may be required to develop coping strategies that allow them to enjoy their lives in whatever settings they live, many are still strongly oriented to their worldview from an Indigenous perspective. Considerations of urban AI/ANs' cultural needs should include consideration of community-based consent and a community-oriented worldview.

Non-maleficence

Few would argue with the assertion that research should do no harm and should actively work to avoid harm through unintentional negligence (Beauchamp & Childress, 2001). This appears simple on the outset, but the art of avoiding harm by negligence is much more nuanced. Most health researchers have written a research plan they believe water-tight, only to encounter countless issues once data collection begins. This is the rub of unintentional negligence; not only addressing those complications as they occur, but meeting them with interest, recognizing that cultural norms vary, and knowing that research design can change according to the context of the location (Calman et al., 2002). The ethical researcher understands that research has a footprint in the community, and a negative experience with one researcher will leave a lasting impression for many years to come.

Although non-maleficence is appreciated as an ethical ideal, the argument that "we did not know" still allows researchers to continue with what many would consider unacceptable practices. In preparing for this paper, we found a document published by the United States National Endowment for the Humanities (NEH). This document, purporting to be a code of ethics for projects involving Native Americans, only suggests that grant recipients work in collaboration with AI/AN participants. The document fails to recognize tribal sovereignty and tribal ownership of data and has an outdated understanding of tribal hierarchical relationships and governments, going so far as to suggest that completed works be "deposited with the Native representatives of the elders and traditional leaders of the community" (NEH, 2018). While this text is well-intentioned and does not exclude urban AI/AN communities, it overlooks the highly sophisticated structures many tribes have in place for reviewing and storing tribal data, including the wide network of tribal libraries and the many tribal human subjects review boards and research review committees (Brugge & Missaghian, 2006; Hull & Wilson Dine, 2017; James et al., 2014; Morton et al., 2013). A grant recipient following these guidelines could claim ignorance to the wide body of scholarship on data sovereignty and data governance and might publish what tribal members consider sacred or protected cultural information (Holkup et al., 2004). There is precedent for the publication of sacred information across the range of academic research, and because U.S. statute protects personal property but does not consider cultural property of value, the harms caused by the release of this information are experienced without recourse (Portman & Garrett, 2006; Tsosie, 2007). These protections extend as well to urban AI/ANs.

SOLUTIONS

We propose four ethical practices that researchers adopt when conducting research with urban AI/AN communities. The first is the integration of data use agreements (DUAs) in all research that include AI/AN data as a reportable outcome. In this context, DUAs are formal documents that describe the process by which the researcher or research team intends to collect, analyze, report, and store all data, with any negotiated plans for returning data to the Tribe or urban community made explicit. Frequently, a DUA will be reviewed and signed or included in a tribal resolution or Memorandum of Understanding prior to data collection. When an AI/AN organization is included in a contractual agreement with a research organization or funder, the

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DUA can be attached as a component of the negotiated contract. If the research is a collaboration with a UIHP or urban AI/AN Community Center, the organization can require a DUA for access to their patient or client population. If there is no intermediary and the research is conducted through a university, DUAs may not be applied unless there are collaborating partners within the project, in which case the agreement is between researchers and not with the data sources. In this case, the most accountability the researcher has with the urban AI/AN is to clearly describe how the participants' data will be used in the consent form. Incidentally, all consent forms should already include a description of how the collected data will be used.

The benefit of DUAs for AI/AN communities is that Tribes or urban AI/AN organizations can define how their data are used, stored, disseminated, and destroyed prior to data collection. This process allows AI/AN groups to review dissemination products to ensure that information about their communities reflects a balanced perspective about community concerns, provides context when there are disparities that need reporting, and protects communities against having sacred or protected cultural information inadvertently released and shared to the larger public. The benefit for external research and sponsoring organizations is that the community's needs and concerns are identified and addressed well in advance of the project beginning. This process itself builds relationships between these external organizations and AI/AN communities. A well-articulated statement of benefits to the community, with risks identified and addressed, enhances buy-in and ownership of the research, which in turn can support recruitment and retention of research participants.

The Urban Indian Health Institute in Seattle, Washington has published guidelines for data collection in all AI/AN communities, including urban AI/ANs (UIHI, 2020). Included in these guidelines is the recommendation to secure tribal permission according to the conditions of a DUA when any tribal-specific data might be released. This recommendation affords protection to tribal members when working directly with specific tribes but is less applicable when working in an urban setting, where tribal representation can be diverse and seeking DUAs with all tribes represented in a research project ceases to be logistically practicable. The state of Arizona has an early childhood education initiative that includes a large data collection component. This program, titled "First Things First," created a DUA that clearly describes how data that is collected on tribal lands will be used (First Things First Institute, 2020. This DUA is comprehensive, with sections regulating data collection, analysis, communication, privacy and confidentiality, data review and publication, tribal data access, and a sample data request form. Although this agreement is intended to be used between the agency and tribes, it is a good example of the degree of information any DUA requires and is applicable for researchers wishing to work with urban AI/AN organizations.

A second solution to address the issues of data sovereignty with urban AI/ANs is community oversight via a project-specific advisory board. Without a formal tribal organization to represent this population, urban AI/ANs may have their interests overlooked in the process of research, data collection, and data usage. For this reason, the Community Advisory Board or Community Action Board (CAB) remains the gold standard for working with AI/AN data, regardless of location from which the data is obtained (Blue Bird Jernigan et al., 2020; Lewis & Boyd, 2012; Wallerstein & Duran, 2018). CABs are a foundation of community-based participatory research (CBPR) and community-engaged research (CER) and critical to any project that requires close collaboration or oversight by a community, be it urban, reservation-based, or agency-based. When partnering with a CAB, the special interests of sovereignty inherent to AI/ANs can be protected, by including a body that can provide consultation on ethical justice, ensure equitable access to research, and accurately interpret results. A trend to underutilize CABs in research lends to their role only as symbolic gatekeepers for many researchers, but for those wishing to conduct truly collaborative work with AI/ANs in urban conditions, a CAB can oversee all phases of the research to ensure maximal benefits to the community and reduce risks which may not be apparent or of concern to external agents (Oetzel et al., 2015; Wallerstein & Duran, 2006).

A CAB is not the same as a tribal government. In tribal communities, there is a nation-to-nation relationship. With that relationship comes a corresponding obligation for consultation with tribes when policy decisions are made that impact tribes. Tribal consultation between governments concerns policy making and ongoing monitoring of public programs (Wilkins & Adams, 2019). In research, a CAB functions as a consultative body but does not serve any legal function, unless specified by the terms of the research.

The role of the CAB in a research study working with urban AI/ANs has potential to guide the research through expert oversight and protection of Indigenous sovereignty, but the research team and the CAB must address certain concerns first. Membership on the CAB will require thoughtful guidance regarding knowledge and qualifications as they relate to the research. A CAB member can bring extensive knowledge and cultural guidance; it is the duty of the research team to seek out the best possible representatives from the community and then abide by their guidance. Other considerations include planning regular meeting times, meeting at locations that are convenient and culturally appropriate for the CAB members, and paying for CAB member expenses to attend meetings as needed. The CAB's involvement should consider members' qualifications, at what levels will they provide advisement, and whether they can veto decisions within the research project. Qualifications should include people with expertise germane to the research topics and methods (Lee et al., 2018; Oetzel et al., 2015). For example, a school-based intervention to improve adolescent AI/AN mental health should be overseen by CAB members with expertise in and good connections with AI/AN youth and families; such a project may also include a Youth Advisory Council for more precise insight and guidance (Lee et al., 2012). Many of these guidelines are best practice recommendations for community engagement for any population in which there is a potential power inequity with external research entities (Wallerstein & Duran, 2006, 2018). Specifically, for urban AI/AN studies, CAB membership and resourcing should address specific contours of urban AI/AN communities (e.g., include people from multiple tribes residing in community together and identify meeting spaces that are inclusive and accessible to all).

Although every project that involves AI/ANs should include a CAB, urban AI/AN-based projects will rely more heavily on a CAB for data governance purposes. For this reason, the CAB members' qualifications, role, and ability to regularly advise holds special importance for this population. A strong partnership with a CAB will enhance a project by providing clarity regarding the priorities and boundaries within a community. In the urban setting, a CAB will also help a research team identify how this population interacts and is impacted by the larger non-AI/AN community and provide necessary context to the research findings that may emerge within the AI/AN community. A CAB can also provide the necessary feedback regarding drafting and enforcing a DUA in place of a formal tribal governmental body. Without a strong CAB relationship for this feedback, data can be published that misrepresents or exploits the study population, which is ultimately an act of injustice.

CABs integrated into the research process can also provide insight into culturally congruent approaches to building consent documents that meet the specific needs of their communities. With this guidance, investigators can formulate consent documents that address cultural congruence, therapeutic misconception, and health literacy concerns as described previously in this paper. Another approach to further enhance comprehension is the inclusion of true/false statements about research goals within the consent document (Henderson et al., 2007). This strategy helps study staff charged with consenting participants identify those individuals who need additional attention

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to build understanding regarding the purpose, procedures, risks, benefits, clinician role, and general protocol of the research for which they are volunteering to participate.

Finally, projects with AI/AN communities in both reservation and urban areas may benefit greatly from consultation and training processes. Federal and state agencies have formalized tribal consultation in navigating their relationships with sovereign tribes, for example in federal rule making and budgeting and state negotiations of gaming compacts, easements, health care provision, and other revenue- and resource-sharing agreements with tribes. Consultation in the form of in-person meetings may be combined with a period of public commenting on drafts of documents of high interest to AI/AN communities, made available for review online. Increasingly, urban AI/ANs are invited to participate in these consultation proceedings along with tribal government representatives. Within an urban AI/AN community, consultation should include commonly accepted community leaders, often within the structure of an AI/AN community center or UIHC non-profit board of directors or identified through less formal word-of-mouth or social networking. Community-based consent may also consist of a series of informational meetings and a period of public consultation and comment prior to the initiation of data collection (Bhutta, 2004). Staff participating on these research studies may be unaware of Indigenous research concerns, while community leaders who have not engaged in research activities may also be unaware of basic principles and best practices in risk protection. Training all participating staff and advisors on Indigenous research ethics, for example through AI/AN-specific curricula such as Research Ethics Training for Health in Indigenous Communities (rETHICS; Parker et al., 2019), can both increase awareness and support improved research partnerships (Wallerstein et al., 2018). Through this community-focused approach, the urban AI/AN population will be more informed about the larger goals of the research and more able to endorse the research within the community at large, achieving true community-based consent.

CONCLUSION

In examining the core ethical concepts of justice, autonomy, beneficence, and non-maleficence, we present specific concerns for AI/ANs, with a focus on urban AI/AN communities. Although this population is not specifically protected by the government-to-government relationship that federally recognized tribes operate under, those individuals who are tribal deserve the same attention to their needs and rights as sovereign citizens and the same protections of their data as though they were on their tribal lands.

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Although daunting, investigators can frame this discussion as an effort to strengthen the ethical considerations of all participants while giving special thought to those issues specific to urban AI/ANs. AI/AN data are meaningful for this small population, particularly concerning allocation of resources and appreciating the size of the on-reservation and urban population of AI/ANs in the United States. This diverse population has experienced generations of misrepresentation in the lay-press and popular media, as well as by the mainstream research community, which has yet to respond at the broad institutional level (Hodge, 2012). By expressing and exerting their right to data sovereignty, AI/ANs are claiming the rights to their narratives, voicing their identities individually and as a collective. Observing the ethical principles of research as they are understood internationally will aid in appreciating and honoring Indigenous data sovereignty for all AI/ANs, regardless of physical location.

Federal research and data governance guidelines do not yet obligate research institutions, funding agencies, or IRBs to know about and ensure protection against research risks that are specific to AI/ANs. Although academic IRBs may be aware of tribal review protocols, the federal institutions that provide assurance to IRBs do not yet obligate researchers to seek out and obtain consent and oversight from tribal institutions, much less obligate researchers to ensure oversight in urban AI/AN contexts. In lieu of such policies, AI/AN communities are distinctly disadvantaged in their being assured of full protection when they participate in research programs and rely on members of the research community to inform and hold each other accountable to standards of ethics and justice due to AI/ANs wherever they reside.

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CONFLICT OF INTEREST DISCLOSURE

The authors declare they have no conflicts of interest.

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