

COVID-19 IMPACTS TO HEALTH AND WELLNESS AMONG NATIVE AMERICAN, NATIVE HAWAIIAN, ALASKA NATIVE PEOPLES, AND INDIGENOUS GROUPS THROUGHOUT THE WORLD

EDITED BY: Rene Begay, Timian Mitsue Godfrey and Jerreed Dean Ivanich
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COVID-19 IMPACTS TO HEALTH AND WELLNESS AMONG NATIVE AMERICAN, NATIVE HAWAIIAN, ALASKA NATIVE PEOPLES, AND INDIGENOUS GROUPS THROUGHOUT THE WORLD

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The art represents a Native Man and Woman in deep prayer, dance, and in teaching mode.

The identity is Native-specific versus being Tribal-specific. The two see the space around them as a safe space, their native identity, traditions, and Indigenous knowledge are protected in this space. Surrounding this safe space is the COVID-19 virus, gray and gloomy unable to affect them while in their prayer, dance, and in teaching mode.

-Walt Pourier, Creative Director/Owner Nakota Designs - Advertising Design and Graphics.

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COVID-19 in New Mexico Tribal Lands: Understanding the Role of Social Vulnerabilities and Historical Racisms

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The Coronavirus 2019 (COVID-19) pandemic has disproportionately affected Indigenous Peoples. Unfortunately, there is no accurate understanding of COVID-19's impacts on Indigenous Peoples and communities due to systematic erasure of Indigenous representation in data. Early evidence suggests that COVID-19 has been able to spread through pre-pandemic mechanisms ranging from disproportionate chronic health conditions, inadequate access to healthcare, and poor living conditions stemming from structural inequalities. Using innovative data, we comprehensively investigate the impacts of COVID-19 on Indigenous Peoples in New Mexico at the zip code level. Specifically, we expand the U.S. Centers for Disease Control and Prevention's Social Vulnerability Index (SVI) to include the measures of structural vulnerabilities from historical racisms against Indigenous Peoples. We found that historically-embedded structural vulnerabilities (e.g., Tribal land status and higher percentages of house units without telephone and complete plumbing) are critical in understanding the disproportionate burden of COVID-19 that American Indian and Alaska Native populations are experiencing. We found that historically-embedded vulnerability variables that emerged epistemologically from Indigenous knowledge had the *largest* explanatory power compared to other social vulnerability factors from SVI and COVID-19, especially Tribal land status. The findings demonstrate the critical need in public health to center Indigenous knowledge and methodologies in mitigating the deleterious impacts of COVID-19 on Indigenous Peoples and communities, specifically designing place-based mitigating strategies.

Keywords: COVID-19, Indigenous Peoples, Tribal lands, historical racisms, Social Vulnerability Index

INTRODUCTION

The Coronavirus 2019 (COVID-19) pandemic has disproportionately affected Indigenous Peoples globally and in the United States. COVID-19 has spread in Indian Country¹—general description of Native space and place in the United States, and is inclusive to the Native Nations that occupy the spaces—through pre-pandemic mechanisms ranging from disproportionate chronic health conditions, inadequate access to healthcare, and poor living conditions generated from structural inequalities. While the current pandemic has exacerbated inequalities and health inequities,

¹ See the National Congress of American Indians (NCAI) Response to Usage of the Term, "Indian Country": <https://www.ncai.org/news/articles/2019/12/27/ncai-response-to-usage-of-the-term-indian-country>.

which were already critical issues pre-pandemic, the true estimations of the magnitude of such effects continue to be challenging due to long-standing and systematic erasure of Indigenous representation in data and race misclassification (Kukutai and Taylor, 2016; Yellow Horse and Huyser, 2020). That is, despite the critical importance of reliable and accurate COVID-19 statistics in mitigating the impacts of COVID-19, public health data often completely omit Indigenous Peoples or misclassify them as “others” by aggregating Indigenous Peoples with other numerically small populations. Even as of late August 2020, roughly 6 months into the pandemic, less than half of U.S. states report race-specific COVID-19 information for American Indian and Alaska Native (AIAN, hereafter) persons (Hatcher et al., 2020). Where such data is available, it shows a small glimpse of disproportionate impacts of COVID-19 that AIAN persons are experiencing. Overall, AIAN persons are 3.5 times more likely to experience COVID-19 than non-Hispanic white individuals (Hatcher et al., 2020), but the rates of COVID-19 for AIAN persons substantially vary across the United States. For example, in New Mexico, although the AIAN population represent only 9.6% of the state’s total population, they account for nearly 50.8 and 60.3% of the state’s total confirmed COVID-19 cases and deaths, as of August 2020 (New Mexico Department of Health, 2020). Notable, the AIAN population account for the largest proportion of the state’s total confirmed COVID-19 cases, but they are also most likely to die from COVID-19 related complications.

Despite these data challenges, amplifying the experiences of Indigenous Peoples and communities during COVID-19 is critical on multiple accounts. First and foremost, stories on experiences of Indigenous Peoples and communities during the pandemic is yet another powerful testament to Indigenous resilience and the strengths of Tribal Sovereignty. Despite the magnitudes and multitudes of historical injustices Indigenous Peoples experienced from forced assimilation and separation of families through Indian boarding schools (Lomawaima, 1995), environmental contamination due to resource extraction (Hoover et al., 2012), institutional marginalization (Wilkins and Lomawaima, 2001), and violations of treaty agreements (Prucha, 1994); Indigenous Peoples are “still here” as the past, present, and future stewards of the lands. Furthermore, the experiences of Indigenous Peoples and communities during the pandemic shed light on how social inequalities are the consequences of historical racism and are central to contemporary health inequalities. Identifying racism as the fundamental cause of health inequalities and inequities for Indigenous Peoples is critical because it means that policy solutions to mitigate the effects of COVID-19 should not only focus on addressing the mechanisms but also racism itself (Link and Phelan, 1995).

SOCIAL VULNERABILITY INDEX AND COVID-19

The Social Vulnerability Index (SVI, hereafter) was first developed by a geographer as a tool for natural disaster emergencies and evacuation planning (Cutter et al., 2003),

and has been adapted and implemented by the United States’ Centers for Disease Control and Prevention (CDC, hereafter) “to help local officials identify communities that may need support in preparing for hazards; or recovering from disaster” (Flanagan et al., 2011, 2018; Centers for Disease Control and Prevention, 2018). The central idea of the SVI is to identify more socially vulnerable areas, based on multiple indicators, for the implementation of *place-based* intervention to facilitate recovery from disaster. That is, by identifying places to employ the intervention effort officials can maximize its efficiency and impacts. The CDC’s SVI is calculated by using 15 variables from Census data representing four distinct dimensions of social vulnerability (Flanagan et al., 2011, 2018): (1) Socioeconomic status vulnerability, (2) household composition and disability vulnerability, (3) minority status and language vulnerability, and (4) housing and transportation vulnerability.

Since the early phase of the pandemic, SVI has gained considerable popularity with different government entities and non-profit organizations to assess the spatial variations of disproportional impacts of COVID-19 in the United States. For example, Social Progress Imperative, a non-profit organization, launched an online platform documenting SVI and COVID-19 rates for 500 cities in the United States (Social Progress Imperative, 2020). Researchers in the United States already used the SVI to assess the impact of social vulnerability on COVID-19 outcomes nationally at the county level (Karaye and Horney, 2020; Nayak et al., 2020); and regionally at the zip code level to look at the disproportionate impacts on Black people, in particular during the early phase of the pandemic (most COVID-19 data dated April, 2020) (Amram et al., 2020; Gaynor and Wilson, 2020; Kim and Bostwick, 2020). These studies found that areas with high percentage of Black people were highly correlated with social vulnerabilities, and suggest that existing social vulnerabilities exacerbated COVID-19 outcomes for Black people (Gaynor and Wilson, 2020; Kim and Bostwick, 2020).

Despite the popularity of SVI as a potential tool for mitigating COVID-19 efforts, there are two critical questions that must be addressed. First, it is important to assess whether and how CDC’s SVI is a useful policy tool for COVID-19 mitigation efforts beyond its original intended use for natural disaster emergencies and evacuation planning. That is, SVI as a tool for identifying highly vulnerable places for natural disaster might not be sufficient in identifying highly vulnerability places for COVID-19. For example, SVI does not include factors that are directly associated with spread and treatment of infectious diseases such as population density and percent of population without access to health insurance (Hu et al., 2013). Second, even we assumed the effectiveness of SVI in COVID-19 mitigation efforts in general; whether and how SVI can help the mitigation efforts for Indigenous Peoples, places and communities remains unclear. For example, in early data analysis of Arizona and New Mexico counties that fall within the Navajo Nation compared with neighboring counties data showed that while counties on and off the Navajo Nation both have high vulnerability scores, the score alone does not provide insight into why COVID-19 spread quickly in Navajo communities (at the time of that data’s publishing) (Eisenberg, 2020). Calculation of SVI accounts for a

percent of racial and ethnic minority without specificity, it likely favors numerically large racialized and minoritized groups. Due to small population sizes of Indigenous Peoples, and “relatively low level of racial residential segregation from non-Hispanic whites” especially in larger geographic scales (Byerly, 2019), Indigenous Peoples are likely to be systematically marginalized in place-based COVID-19 mitigation efforts through becoming invisible by exclusionary population aggregation (Monmonier, 2018). Furthermore, SVI does not account for other important structural inequality factors stemming from historical injustices that are critical and specific for experiences of Indigenous Peoples and communities.

HISTORICAL RACISMS, TRIBAL LAND STATUS, AND ABANDONED URANIUM MINES

Historically-embedded structural racism is a fundamental cause of health inequities in the United States (Phelan and Link, 2015; Boyd et al., 2020); and contributes to the widening of racial health inequities through its impacts on social conditions as pre-existing risk factors (Garcia et al., 2020; Pirtle, 2020). Framing historically-embedded structural racism as the fundamental cause means that the significant relationship between racism and health outcomes would persist over time despite intervening mechanisms that appear to improve health (Phelan and Link, 2015). Explicitly considering the role of racism in understanding how COVID-19 is disproportionately affecting Indigenous Peoples and communities is also important for designing policy solutions to address the racism directly rather than its mechanisms (Hicken et al., 2018; Cogburn, 2019). By focusing on structural factors above and beyond individual characteristics is particularly important to refute the notion of “individualization of health” that solely puts the responsibility of health on the individuals by focusing individual behavior modification (e.g., frequent hand wash) (e.g., Mendenhall, 2016) without considering the structural factors that may influence individual behaviors (e.g., lack of access to safe water at home for frequent hand wash).

To successfully mitigate the disproportionate impacts of COVID-19 on Indigenous Peoples and communities where racism is a fundamental cause. It is not only critical to address public health challenges in Tribal public health such as the shortage of personal protective equipment (i.e., intervening mechanisms), but also to directly address the violations of treaties and other agreements (i.e., racism). In this light, Tribal land status, AIAN legal or statistical geographic areas, is important to explicitly consider as a proxy measure of systematic racism (Thornton, 1987). In New Mexico and for this study, Tribal lands are inclusive of the legal federally recognized American Indian reservations, off-reservation trust land, and tribal subdivisions (U.S. Census Bureau, 2002). That is, the characteristics of Tribal land is not simply an aggregation of individuals who occupy the land, but embody the lasting legacy of historically-embedded structural racism.

Tribal lands do not simply reflect choices and preferences of individuals on Tribal lands, but it reflects the lasting impacts of multiple historical racisms including racist reproductive policies to surveillance of reproductive health of Indigenous Peoples directly affecting the limited access to reproductive health services (Lawrence, 2000; Arnold, 2014; Gurr, 2014; Theobald, 2019) and environmental contamination influencing the health of Indigenous Peoples (Hoover, 2018). For example, after the passage of Family Planning Services and Population Research Act of 1970, it is estimated that nearly one in four Native American women of childbearing age were sterilized without consent until 1976 (Lawrence, 2000; Gurr, 2014). At the same time, the Hyde Amendment (first passed in 1976 then not amended until 1993) which made the use of federal funds for abortion services illegal denied Native American women's access to reproductive health services through lack of funding to Indian Health Services (Arnold, 2014). There is also substantial evidence on how residing close to abandoned uranium mines are associated with various reproductive physiological damages (Harmon et al., 2017). Tribal land status is also related to the lack of Internet access as Tribes have unique geopolitical and geophysical terrain influenced by colonization, cultural practices, sovereignty and Tribal governance (Warner, 1998; Monroe, 2002). That is, while access to information and communication technology, such as the Internet, depends on aspects of Tribal sovereignty there are other external obstacles such as federal policies, statutory and regulatory requirements, and historically overlooked and underfunded Internet infrastructure (Howard, 2019; Morris and Howard, 2020).

Furthermore, presence of abandoned uranium mines—as a legacy of environmental racism for Indigenous Peoples—is critical in understanding the disproportionate impacts of COVID-19 on Indigenous Peoples and communities. Presence of abandoned uranium mines is not only associated with environmental contamination (e.g., high rates of toxin exposure) and lack of safe water (Gilliland et al., 2000; Credo et al., 2019), but it is also closely related to structural inequalities (e.g., poor social conditions) (Deschine Parkhurst et al., 2020). That is, areas with abandoned uranium mines may also have a higher percentage of households without complete plumbing and access to safe water that are related to COVID-19 mitigating efforts. Research systematically documents the lasting deleterious effects of mining and abandoned uranium mines on health of Indigenous Peoples and communities through multiple interconnected mechanisms (Lewis et al., 2017). Whether the presence of abandoned uranium mines also have lasting indirect spillover effects on COVID-19 rates is an important question as historically-embedded structural racism affects the health of Indigenous Peoples and communities through multiple intervening mechanisms (Phelan and Link, 2015). Acknowledging the importance of the lasting legacy of abandoned uranium mines on the health of Indigenous Peoples, the National Institute of Environmental Health Sciences within the National Institute of Health awarded two Navajo scientists to examine the relationships between abandoned uranium mines and lack of access to clean water which can have implications

for the increased COVID-19 rates on Diné Bikéyah (Navajoland) (Saffron, 2020).

THE PRESENT STUDY

Confronted with challenges in data availability along and the critical need to examine the impact of the current pandemic with racism as a fundamental cause, we assemble an innovative data to comprehensively investigate the impacts of COVID-19 on Indigenous Peoples in New Mexico. New Mexico is home to 23 Native Nations including 19 Pueblos and three Apache tribes. New Mexico has the fourth largest presence of single-race AIAN peoples in the United States with 7.4% of the total AIAN population in the United States (199,896 out of 2,707,577). However, except for Alaska where the AIAN population accounts for 14.4% of the State's total population, New Mexico has the highest proportion of AIAN as the State's total population with 9.6% of the New Mexico population self-identified as AIAN (for example, the percentages are 7.5% in Oklahoma and 4.5% in Arizona, respectively) (U.S. Census, 2019). Furthermore, New Mexico has released COVID-19 related information for all their zip codes without suppressing the information for Tribal lands (in contrast, Arizona had not released any COVID-19 related information on Tribal lands). The data has shown disproportionate effects of COVID-19 on AIAN Peoples in New Mexico (New Mexico Department of Health, 2020).

Guided by Hózhó wisdom of Navajo people that emphasize the importance of interconnectedness and whole-system (Powell and Curley, 2008; Kahn-John and Koithan, 2015), we look at the relative impacts of multiple social vulnerability factors driven from the CDC's SVI (Flanagan et al., 2011, 2018) as well as the relative impacts of *historically-embedded* vulnerability factors that are important for Indigenous Peoples on the population-adjusted confirmed COVID-19 cases at the zip code-level in New Mexico. Grounded in an Indigenous research paradigm (Hart, 2010), we center Indigenous knowledge and methodologies. Particularly, we recognize the fluidity of knowledge derived from being Indigenous researchers who have lived on and in Indigenous lands in New Mexico, and we are committed to generating research that values and respects Indigenous communities (Hart, 2010; Smith, 2013). Thus, we pay distinct attention to the Tribal land status, presence of abandoned uranium mines, and lack of access to telephone, Internet and complete plumbing—to center the importance of structural inequalities stemming from historical racisms on the lands where Indigenous Peoples live and steward. Explicit inclusion of historically-embedded vulnerability factors as well as emerged epistemologically from Indigenous knowledge through stories and perpetual experiences of the authors. In addition to data availability, New Mexico is an ideal place for this case study as the lasting deleterious health effects of abandoned uranium mines have been well-documented in New Mexico (e.g., Jones, 2014). Substantial amounts of abandoned uranium mines exist on Diné Bikéyah on northwestern New Mexico, as well as throughout the states. **Figure 1** shows the map of confirmed COVID-19 cases per 1,000

population (as of August 9, 2020) and distribution of abandoned uranium mines.

MATERIALS AND METHODS

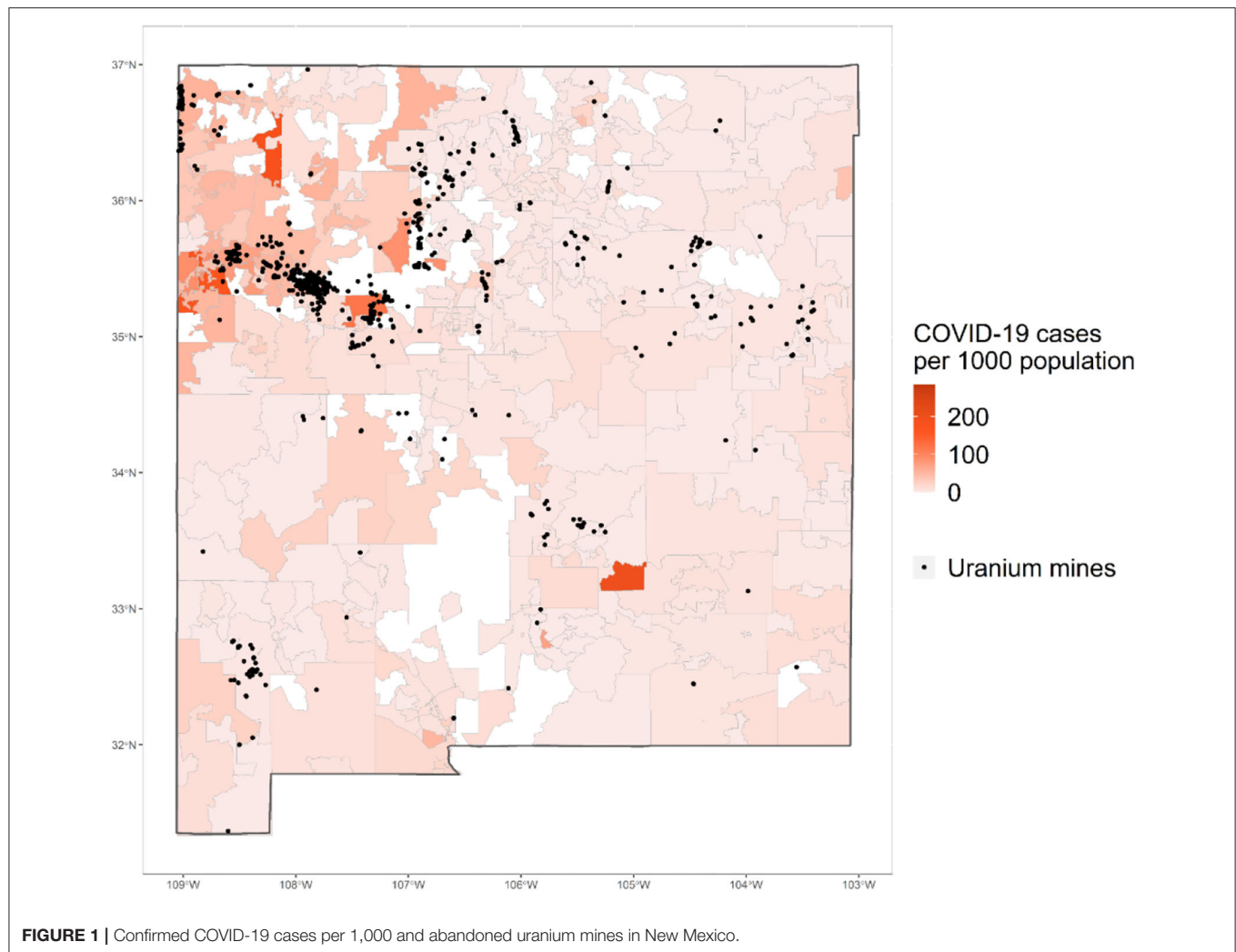
Data

To assess the relative impacts of various indicators of social vulnerability and structural inequalities from historical injustices on the confirmed COVID-19 cases in New Mexico; we assembled the unique data from multiple sources. Our dependent variable (i.e., the COVID-19 confirmed cases per 1,000 population) comes from the New Mexico Department of Health COVID-19 Dashboard (New Mexico Department of Health, 2020). Population information, indicators of social vulnerability as defined by the SVI which is widely used by the CDC (Flanagan et al., 2011, 2018), and structural inequality indicators come from the latest 5-year estimates from the American Community Survey 2014–2018 (U.S. Census, 2019). Lastly, information about the Tribal land status and presence of abandoned uranium mines come from the ESRI New Mexico Tribal lands shapefile and the New Mexico uranium mines shapefile originating from the U.S. Geological survey from the U.S. Department of the Interior (U.S. Department of the Interior, 2011). All data are linked using zip code as the common geographic identifier.

Measures

We created the dependent variable, confirmed COVID-19 cases per 1,000 population for each zip code, by dividing the cumulative counts (as of August 9, 2020) of confirmed COVID-19 cases by the zip code total population multiplied by 1,000. We log-transformed the dependent variable to meet the parametric requirement for normality, consistent with previous studies on COVID-19 (Karaye and Horney, 2020).

We included 15 variables from the four dimensions of vulnerability in the SVI used by the CDC (Flanagan et al., 2011, 2018). For the *socioeconomic status vulnerability* dimension of the SVI, we included four variables: percent of population living below poverty, percent of population who are unemployed, logged per capita income, and percent of population without a high school diploma. For the *household composition and disability vulnerability* dimension of the SVI, we included four variables: percent of children population aged under 18, percent of elder population aged 65 and older, percent of population with a disability, and percent of single-parent household. For the *minority status and language vulnerability* dimension of the SVI, we included two variables: percent of minority (i.e., who are not non-Hispanic white) and percent of population speaking English less than “well.” For the *housing and transportation vulnerability* dimension of the SVI, we included five variables: percent of housing units that are large apartment buildings (i.e., more than 10 units per structure), percent of housing units that are mobile homes, percent of crowded households (i.e., having more than one occupant per room), percent of population without a vehicle, and percent of population living in group quarters. In addition, we added two variables to capture



COVID-19 related vulnerability: logged population density and percent of population without insurance.

We included five *historically-embedded vulnerability* variables: percent of housing units without telephone, percent of housing units without Internet, percent of housing units without complete plumbing, Tribal land status, and presence of abandoned uranium mines. To create the dichotomous indicator of whether the zip code include any Tribal lands, we overlaid two shapefiles in ArcGIS software intersecting the New Mexico Tribal lands shapefile with the zip code shapefile on to create a variable indicating whether the zip code includes any Tribal lands (see **Figure 2**). If the zip code contained any Tribal lands, it is coded as 1 (coded as 0 if the zip code did not contain any Tribal lands). If the zip code shared the boundary with a Tribal land, but did not include any territory, the Tribal land status of the zip code is coded as 0. Lastly, we reverse-geocoded the locations of abandoned uranium mines from the New Mexico uranium mines shapefile originating from the U.S Geological survey from the U.S. Department of the Interior (U.S. Department of the Interior, 2011), and aggregated the numbers of abandoned uranium mines to the zip code level. Presence of abandoned uranium mines is

a dichotomous variable indicating whether or not the zip code includes any abandoned uranium mines.

Data Analysis

There were no missing values. Out of 372 standard zip codes in New Mexico (i.e., zip codes that have physical locations; excluding P.O. Box zip codes that do not contain any physical areas)², seven zip codes were excluded because there was no population. The final analytic sample included 366 zip codes. We ran three sets of ordinary least square (OLS) regressions: Model 1 includes all four dimensions of vulnerability by the SVI: socioeconomic status vulnerability, housing composition & disability vulnerability, minority status & language vulnerability, and housing and transportation vulnerability variables. Model 2 adds COVID-19 related vulnerability variables to the SVI, and the final model adds historically-embedded vulnerability

²The contextual-level characteristics of zip code *areas* derived from information from households that reside within the zip code areas, and P.O. Box zip codes do not contain any residents as they are often the addresses of physical locations where the mail boxes are located.

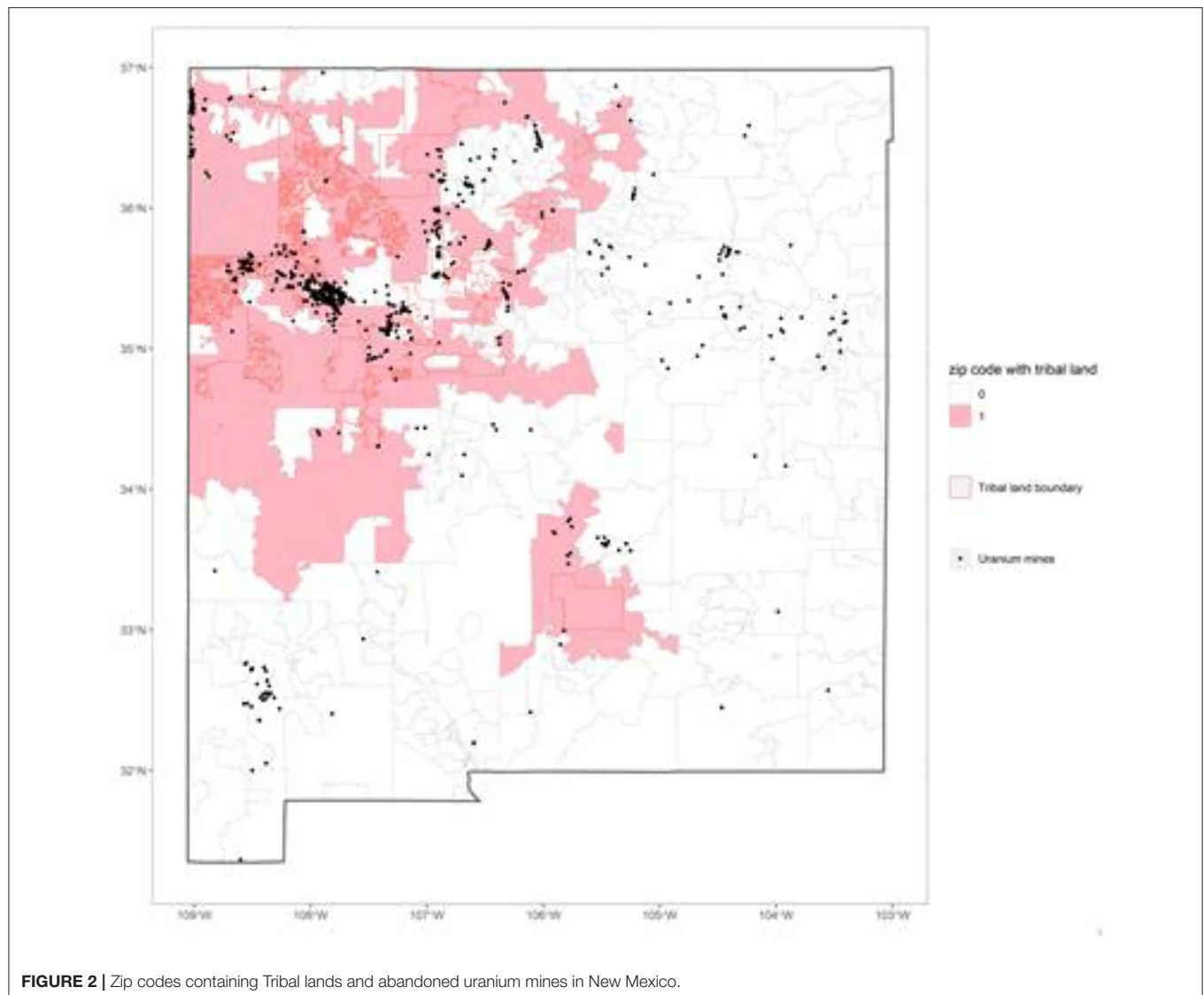


FIGURE 2 | Zip codes containing Tribal lands and abandoned uranium mines in New Mexico.

variables (Model 3). Consistent with previous research (Karaye and Horney, 2020), we exponentiated the model coefficients for ease of interpretation, except for two dichotomous variables.

RESULTS

Table 1 shows the descriptive statistics of all variables, by total and Tribal land status. Our results demonstrate that there are significant and substantial differences in the confirmed COVID-19 cases by Tribal land status at the zip code level. On average, the rate of confirmed COVID-19 cases per 1,000 population for Tribal lands was 22.33 whereas it was 5.68 for non-Tribal lands. That is, the zip codes that contain Tribal lands experience nearly 4.5 times higher rates of COVID-19 cases (see **Table 1**). Characteristics of social vulnerability differed in all dimensions in which zip codes that include Tribal lands had significantly more socioeconomic status vulnerability (i.e., higher percentages of population living below poverty and unemployed) and more

household composition & disability vulnerability (i.e., higher percentages of population under 18 and over 65, with a disability; and a higher percentage of single-parent household). Zip codes that include Tribal lands also had significantly higher percentages of race and ethnic minority population, living in crowded housing and without a vehicle. Similarly, zip codes that include Tribal lands had higher population density and percentage of population without health insurance. Lastly, the characteristics of historically-embedded vulnerability differed significantly in which zip codes that include Tribal lands had significantly higher percentages of households without telephone, Internet, and complete plumbing. For example, about 5.58% of households in zip codes including Tribal lands do not have complete plumbing compared to 1.25% of household in zip codes containing no Tribal lands.

Table 2 presents the results of OLS regression models to assess the relative impacts of various indicators of social vulnerability and structural inequalities from historical injustices

TABLE 1 | Descriptive statistics by Tribal land status.

	Total (<i>n</i> = 365)		Tribal land (<i>n</i> = 125)			Non-Tribal land (<i>n</i> = 240)	
	m/%	std	m/%	std		m/%	std
Confirmed COVID-19 cases per 1,000	11.38	27.14	22.33	38.78	***	5.68	15.69
Socioeconomic status vulnerability							
Percent below poverty	18.66	17.48	21.92	16.03	*	16.96	18.00
Percent unemployment	7.18	11.28	9.52	9.48	**	5.96	11.95
Logged per capita income	9.98	0.47	9.90	0.48	*	10.02	0.46
Percent without a high school diploma	16.56	16.65	15.90	11.21		16.90	18.89
Household composition and disability vulnerability							
Percent children under 18	19.06	11.96	21.81	8.91	***	17.63	13.06
Percent elders 65 and older	23.16	18.17	19.72	11.06	**	24.95	20.73
Percent with a disability	19.65	14.41	17.80	9.98	*	20.61	16.18
Percent of single-parent household	31.20	27.19	40.66	22.26	***	26.28	28.24
Minority status and language vulnerability							
Percent racial and ethnic minority	27.33	31.70	40.75	37.14	***	20.34	25.91
Percent speak English less than “well”	3.89	8.41	2.60	3.56	*	4.56	9.99
Housing and transportation vulnerability							
Percent large apartment buildings	1.45	4.30	1.31	4.16		1.53	4.38
Percent mobile homes	27.77	20.41	26.26	16.41		28.55	22.20
Percent crowding	4.34	8.34	6.88	7.33	***	3.02	8.54
Percent without a vehicle	5.45	8.47	6.98	6.62	**	4.65	9.20
Percent living in group quarters	2.76	11.90	2.01	9.38		3.15	13.03
COVID-19 related vulnerability							
Logged population density	2.31	2.59	3.01	1.98	***	1.95	2.79
Percent without insurance	12.04	13.73	15.74	14.62	***	10.12	12.86
Historically-embedded vulnerability							
Percent without telephone	3.98	8.01	5.42	6.46	**	3.23	8.62
Percent without Internet	37.13	24.94	41.62	26.88	**	34.79	23.59
Percent without complete plumbing	2.73	6.69	5.57	8.73	***	1.25	4.71
Tribal land status (yes or no)	0.34	0.48	1.00	0.00		0.00	0.00
Presence of abandoned uranium mines	0.25	0.43	0.34	0.48	***	0.20	0.40

p* < 0.05, *p* < 0.01, and ****p* < 0.001.

on confirmed COVID-19 cases in New Mexico. Prior to building the final saturated model, we added each set of vulnerability characteristics one at a time to examine their contribution to the exploratory power and found that the historically-embedded vulnerability dimension had the greatest explanatory power of the variations in the rates of confirmed COVID-19 cases. Model 1 includes all 15 variables from the CDC's SVI. Variables from the SVI account for explaining about 25.8% of the variance in the rates of confirmed COVID-19 cases. Of the CDC's SVI characteristics, the percentages of population without a high school diploma and racial/ethnic minorities along with percentages of housing units with crowded housing (i.e., more than one person per room) and without a vehicle were associated with higher COVID-19 rates. For example, a one percent increase in percent racial and ethnic minority is associated with a 22% increase in the confirmed COVID-19 when all other variables are held constant.

When the COVID-19 related vulnerability variables are added (Model 2), the significant associations of SVI indicators

remain constant; and percentage of population without health insurance is positively associated with the rates of confirmed cases. In the final saturated model (Model 3), once historically-embedded vulnerability variables are added, the significant associations of percentages without a high school diploma (i.e., socioeconomic status vulnerability) and without vehicle disappeared. Percentages of house units without telephone and complete plumbing were significantly associated with rates of confirmed COVID-19 cases. The presence of abandoned uranium mines is associated with a substantially higher rate of confirmed COVID-19 cases, 2.17 times higher than zip codes without abandoned uranium mines, although the relationship was not statistically significant. Accounting for all other indicators of vulnerability, Tribal land status was associated with 5.92 times higher rates of confirmed COVID-19 cases compared to zip codes that do not contain any Tribal lands. More importantly, adding indicators of historically-embedded vulnerability increased the exploratory power to 40.5% from 25.8% in Model 1.

TABLE 2 | OLS exponentiated regression results predicting confirmed COVID-19 cases per 1,000.

	Model 1		Model 2		Model 3	
Socioeconomic status vulnerability						
Percent below poverty	1.06		1.07		0.88	
Percent unemployment	0.96		1.00		0.86	
Logged per capita income	0.01		0.05		0.32	
Percent without a high school diploma	1.34	*	1.32	*	1.19	
Household composition and disability vulnerability						
Percent children under 18	1.01		1.09		1.07	
Percent elders 65 and older	1.01		1.07		1.07	
Percent with a disability	0.94		0.95		0.90	
Percent of single-parent household	0.99		0.98		0.93	
Minority status and language vulnerability						
Percent racial and ethnic minority	1.22	***	1.21	***	1.09	*
Percent speak English less than “well”	0.76		0.71		0.82	
Housing and transportation vulnerability						
Percent large apartment buildings	1.05		1.10		1.56	
Percent mobile homes	1.01		1.01		1.11	
Percent crowding	2.03	***	1.88	***	1.53	**
Percent without a vehicle	1.67	*	1.69	*	1.03	
Percent living in group quarters	0.98		1.07		1.09	
COVID-19 related vulnerability						
Logged population density			1.06		1.79	
Percent without insurance			1.38	**	1.27	*
Historically-embedded vulnerability						
Percent without telephone					1.00	
Percent without Internet					2.57	***
Percent without complete plumbing					1.04	
Percent without complete plumbing					4.23	***
Tribal land status (yes or no)					5.92	*
Presence of abandoned uranium mines					2.17	
Constant	48.07		19.92		2.52	
R-squared	0.258		0.272		0.405	

* $p < 0.05$, ** $p < 0.01$, and *** $p < 0.001$.

DISCUSSION AND CONCLUSION

Since the early phase of the pandemic, a substantial amount of attention has been paid to the disproportionate impacts of COVID-19 on Indigenous Peoples, especially those on Tribal lands (Kakol et al., 2020). However, due to long-standing and systematic erasure of Indigenous representation in data and race misclassification (Kukutai and Taylor, 2016; Yellow Horse and Huyser, 2020) of Indigenous Peoples during COVID-19; assessing the reliable and accurate impacts of COVID-19 on Indigenous Peoples and communities has been limited. While a recent study documents that the cumulative incidence of COVID-19 among AIAN Peoples were nearly 3.5 times higher compared to non-Hispanic white individuals (Hatcher et al., 2020); this estimation is based on only laboratory-confirmed COVID cases from 23 states. While it is an important study to help quantify the impacts of COVID-19 for AIAN Peoples, it

is likely a gross under-estimation. Considering the serious data challenges, public health researchers and policy makers utilized the CDC's SVI to implement place-based COVID-19 mitigation efforts (Amram et al., 2020; Gaynor and Wilson, 2020; Kim and Bostwick, 2020); yet we identified that whether and how SVI can help mitigation efforts for Indigenous Peoples and communities is unclear.

There were several key findings of the study. First, we found that only selected indicators of the SVI were significantly associated with COVID-19 cases in New Mexico: percent of population who are racial/ethnic minority and percent of housing crowded housing units. Socioeconomic status vulnerability and household composition & disability vulnerability factors were largely not significant. This finding suggests that inability to practice quarantine in one's home due to crowding may contribute to spread of COVID-19 if one family member becomes infected. Thus, providing out-of-home safe quarantine

space for those with COVID-19 can potentially prevent the spread of COVID-19. We interpret the significance of percent of population who are racial/ethnic minority as a proxy measure of systematic racism, and not as any inherent biological differences (Roberts and Rollins, 2020). Second, somewhat unsurprisingly, percent of population without health insurance was a significant factor associated with COVID-19 cases. This suggests that lack of access to health insurance should be explicitly acknowledged as a critical barrier for testing; and over-restriction should be adjusted for “critical” populations (e.g., front-line health care workers, essential workers, symptomatic patients, comorbid populations) to get tested for both viral load (virologic testing) and antibodies (serologic assessment) (Pettit et al., 2020). Third, we found that higher percentages of house units without telephone and complete plumbing were associated with higher COVID-19 rates, similar to previous findings on the importance of households with lack of plumbing (Rodriguez-Lonebear et al., 2020) as well as challenges of telemedicine implementation in Tribal communities during COVID-19 (Graves et al., 2020).

The primary implication of our findings is the critical importance of historically-embedded vulnerability variables. Guided by Hózhó wisdom of Navajo people that emphasize the importance of interconnectedness and whole-system (Powell and Curley, 2008; Kahn-John and Koithan, 2015), we moved beyond simply considering social vulnerabilities defined by the CDC’s SVI to look at factors that are important for Indigenous Peoples and communities. We found that historically-embedded vulnerability variables had the *largest* explanatory power compared to other social vulnerability factors from the SVI and COVID-19, especially Tribal land status. There are significant and substantial differences in the confirmed COVID-19 cases by Tribal lands status at the zip code level, and nearly all vulnerability characteristics varied significantly by Tribal land status. This finding illustrates that Tribal land status is a critical proxy measure of systematic racism against Indigenous Peoples that continue to have lasting implications on health of Indigenous Peoples and communities both directly and indirectly. Tribal lands signify physical manifestations of the lasting legacy of treaty violations impacting Indigenous Peoples and communities through lack of systematic funding investment in Tribal public health and household infrastructures (Rodriguez-Lonebear et al., 2020), and impact of displacement through settler colonialism. At the same time, Tribal lands are often sacred places where Indigenous resilience and healing take place. Emerging evidence suggests that non-Tribal governments’ infringement on Tribal sovereign rights during the pandemic hurt Indigenous Peoples and communities (Hoss and Tanana, 2020). It highlights the urgent need to respect Tribal sovereign legal authority to respond to the needs of their communities. For example, the funding from the Coronavirus Aid, Relief, and Economic Security (CARES) Act must lift the restrictions on how and when the funds can be used; and respect the Tribal sovereign legal authority to use the funding to address the specific needs of Indigenous communities (Hoss and Tanana, 2020).

Although presence of abandoned uranium mines was not statistically significant, it had substantial impact on COVID-19 rates in our results. We urge future studies to investigate the role

of abandoned uranium mines on health of Indigenous Peoples and communities during COVID-19 more systematically. Specifically, uncovering the mechanisms of indirect effects from abandoned uranium mines (e.g., access to safe water, levels of toxin from the abandoned uranium mines, etc.) can contribute to the literature documenting the lasting deleterious effects of environmental racism against Indigenous Peoples. This is extremely timely as President Trump’s nuclear energy plan suggested the possibility of uranium mining near the Grand Canyon (Krol, 2020), lands that are sacred to many Indigenous Peoples including the Havasupai Tribe, Hopi Tribe, Hualapai Tribe, Kaibab Band of Paiute Indians, Las Vegas band of Paiute Indians, Moapa Band of Paiute Indians, Navajo Nation, Paiute Indian Tribe of Utah, San Juan Southern Paiute Tribe, The Pueblo of Zuni, and Yavapai-Apache Nation (National Park Service, 2019).

There are several limitations of the study. First, the study is an ecological assessment at the zip code level, and the findings cannot be inferred to AIAN persons (e.g., ecological fallacy). If and when data is available at the individual level, future research must investigate the potential contextual influences of social and historically-embedded vulnerabilities on individuals. However, in New Mexico, about 73.8% of individuals residing on Tribal lands were AIAN persons (U.S. Census, 2019). Second, zip code as a unit of analysis may not reflect meaningful boundaries of Indigenous communities as zip code is designed for efficient delivery of U.S. postal mail. Future studies should assess whether and how the use of different administrative units may yield comparable results. Third, many Indigenous Peoples reside in households without a physical home address and use a P.O. Box, and omitting those who reside in households without a zip code may contribute to *underestimation* of impacts of COVID-19 as they are systemically erased from federal data through inaccurate and unreliable estimates of Indigenous Peoples (Kukutai and Taylor, 2016). Lastly, we do not capture potential inter-Tribal differences in New Mexico; and our findings may not be generalizable to other Tribal nations in different states.

Despite these limitations, our results from innovative data provide important insights for the place-based mitigating efforts and suggestions for the potential change for praxis. Specifically, our results suggest the needs for increasing out-of-home safe quarantine spaces, eliminating lack of health insurance as a barrier for testing, and explicit consideration of Tribal land status and infrastructure conditions, such as plumbing and information communication technology, in understanding the impacts of COVID-19. Furthermore, our results demonstrate the need for greater efforts to understand the experiences of Indigenous Peoples during COVID-19 from the social determinants of health framework (Kakol, Upson and Sood 2020) that explicitly incorporates historical racisms, but also from the Indigenous research framework that centers Indigenous knowledge and methodologies (Smith, 2013).

Given the disproportionately high COVID-19 confirmed cases and deaths among AIAN individuals (New Mexico Department of Health, 2020) and relatively small population size of AIAN persons at the aggregate level on non-Tribal lands; we urge public health researchers and policy makers interested in designing any place-based mitigating strategies to explicitly include percentage

of AIAN Peoples as one of the main factors of identifying vulnerable places rather than the percentage of racial and ethnic minority. This is critical, without careful attention on whom we exclude through categorization and aggregation, any mitigating efforts could further harm Indigenous Peoples and communities who are often already marginalized through inadequate and unjust representation in federal data (Taylor, 2009; Kukutai and Taylor, 2016). Any research and public health policies with AIAN Peoples that do not explicitly consider the Indigenous research framework will likely produce erroneous conclusions and/or strategies for Indigenous Peoples; and that will contribute to further harming AIAN Peoples and communities.

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DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

All authors participated in the formulation of the research questions and writing. AYH is responsible for the data analysis. All authors contributed to the article and approved the submitted version.

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Conflict of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Tino Rangatiratanga and Well-being: Māori Self Determination in the Face of Covid-19

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The New Zealand government has been globally praised for its response to Covid-19. Despite the global accolades, little attention has been given to the swift and innovative Māori response to Covid-19. This paper will detail some of this rapid Māori response to Covid-19 in Aotearoa New Zealand and argue the response can be understood as key examples of Māori exercising tino rangatiratanga (self-determination), independent of the government's measures and policies. We suggest that this exploration of tino rangatiratanga during Covid-19 demonstrates central aspects of Māori well-being that move beyond a government focus on statistics as the key measure of well-being and how tikanga Māori (Māori values) are being used to develop successful responses to the global pandemic.

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INTRODUCTION

Like many people and places around the world, 2020 has required significant changes to the way we work, socialise and carry out our day to day lives due to the ongoing impacts of Covid-19. Indigenous communities from around the world have had to make significant adaptations to cultural practices in order to protect the health and well-being of their communities. This article discusses some of the actions that Māori the Indigenous peoples in Aotearoa New Zealand have taken to protect their communities, while also maintaining and promoting tino rangatiratanga (self-determination).

In March 2020, with only 183 cases of Covid-19 the New Zealand government moved the entire country into a lockdown under level four restrictions. The decisive action taken by the New Zealand government has been heralded around the world as one of the most effective solutions to limiting the reach and impact of Covid-19. Since the reduction in alert levels, there has been a small swell in cases, but most are traced and controlled, with social distancing measures in place across the country. The measures taken by the New Zealand government has meant that the devastation that has been caused by Covid-19 throughout the world, has not been felt in the same way in our country.

A number of Māori communities throughout Aotearoa, also took swift and rapid action to the pandemic, which in many ways built on and exceeded actions taken by the New Zealand government.

This article explores those actions and the ways in which there is a cyclical and inter-dependent link between tino rangatiratanga and well-being. In this article, the authors argue that tino rangatiratanga enables positive well-being, and equally, the positive well-being of individuals and communities enables the exercise of tino rangatiratanga. In other words, despite the impacts of colonisation, Māori communities have maintained and built strong levels of tino rangatiratanga, to both protect and enable tino rangatiratanga to thrive. We suggest that an important way of understanding the actions taken by certain Māori communities, is through an analysis of

tikanga Māori (Māori values), which provide an Indigenous lens for understanding partially why and how communities responded as they have to Covid-19.

This article will begin by providing a contextual discussion of the New Zealand governments responses, before a brief on the importance of intergenerational storytelling. This is followed by a brief analysis and explanation of tino rangatiratanga, tikanga (Māori values) and hauora, before discussing five examples of Māori responses to Covid-19. Finally, we make some recommendations which we hope will provide a basis for how governments and Indigenous peoples alike can strengthen responses to Covid-19 while also supporting well-being and Indigenous self-determination. Responses to Covid-19 have not only shown the strength of Māori leadership, but more broadly Indigenous leadership, and the potential for Indigenous-led solutions, such as a values-driven holistic health approach. This could positively shape the global Covid-19 responses and impact the health of all.

Contextual Information - Overview of Covid-19 in Aotearoa (New Zealand)

The first confirmed case of Covid-19 in New Zealand was reported on the February 28, 2020, related to international travel. As the number of cases started to increase the strategy of the New Zealand government was to go hard, and go early (Jamieson, 2020). On the 19th of March 2020, for the first time in history, the government closed the country's borders to all but New Zealand citizens and permanent residents. By March 25th, the New Zealand government declared a state of emergency and the entire nation moved into Alert Level 4 Lockdown (see **Figure 1** for an Alert level summary) for a minimum of four weeks, with the exception of essential workers. Prime Minister Jacinda Ardern stated, *"We have a window of opportunity to stay home, break the chain of transmission, and save lives,"* (Strongman, 2020, p. 20, p. 20). This lockdown was extended by five days, and New Zealand moved to Alert level 3, Tuesday 28 April. As case numbers continued to remain stable and community transmission was ruled out, New Zealand moved down alert levels (New Zealand Ministry of Health, 2020). Aiding the response efforts, geographically, New Zealand is relatively isolated from the rest of the world, and New Zealand also got its first case relatively late in the outbreak - this giving us time to prepare and other responses to model off. As international travel is the main source of entry of Covid-19, New Zealand established strict government-sanctioned managed isolation facilities to quarantine those who enter the country, these still remain today.

Two days after reaching the milestone of no community transmission for 100 days, a milestone reached by very few countries, on the ninth of August, New Zealand confirmed its first Covid-19 case associated with community transmission, and there has been a resurgence located in the Auckland area. As of the 20th of September, there have been 1,464 confirmed cases of Covid-19 in New Zealand (with 351 probable cases), making the total number of confirmed and probable cases 1,815. Sadly, there have been 25 deaths related to Covid-19, with 71 active cases remaining (New Zealand Ministry of Health, 2020). Of relevance,

to date, Māori make up 10% of total Covid-19 cases, yet Māori make up approximately 16.5 percent of the New Zealand population (Statistics New Zealand, 2019). Given this context, we now discuss the Maori response to Covid-19, beginning with a discussion on tino rangatiratanga (self-determination).

Tino Rangatiratanga

Tino rangatiratanga can mean self-determination, sovereignty, independence, autonomy. The term itself is rooted in a Māori worldview, and there is no one English term which fully encapsulates its meaning. Tino rangatiratanga refers to Māori control over Māori lives, and the centrality of mātauranga Māori (Māori knowledge). While focused on a Māori worldview, tino rangatiratanga also has a close association with the challenges that have come from the loss of Māori control through colonial practices, and has been used as a framework from which Māori have continued to challenge governments for recognition of our individual and collective self-determination.

The term "rangatira" makes up the term, and is the Māori word for leader, again this English term does little to inform about the worldview through which Māori leadership is understood. The term can be broken into two parts "ranga" and "tira." Ranga derives from the term "raranga" which means to weave, and "tira" refers to a group or community. In essence, leadership from a Māori perspective, is dependent upon a leader's ability to weave a community together, while recognising the different strands which exist within a group (Mikaere, 2010). For Māori therefore, issues and acts of self-determination refer to the collective well-being of a group, for Māori these social ties include iwi (tribes), hapū (sub-tribes) and whānau (families), all of which form the main sites through which Māori tino rangatiratanga is claimed and exercised.

In some cases, actions toward tino rangatiratanga has involved overt and direct challenges to the Crown, such as protests, hīkoi (protest marches), sit ins, or utilising legal avenues, all tools through which Māori have sought to maintain and regain some level of tino rangatiratanga (Harris, 2007). However, tino rangatiratanga, and indeed indigenous self-determination can be exercised through diverse and multiple avenues. First nations scholar Jeff Corntassel (2012) for example has discussed at length how indigenous self-determination should not always be reactionary or enacted only in response to the Crown. Corntassel argues that self-determination can and is strengthened the most by indigenous peoples practicing indigenous ways of being, irrespective of a need to gain rights or recognition from the Crown. In a similar way, Māori academic Maria Bargh (2013) has argued that Māori politics occurs through "micro-oriented" practices, in which Māori practice political authority in small and diverse ways, such as establishing local, iwi gardens to support food sovereignty. These ideas relate directly to tino rangatiratanga in that Māori continue to actively promote Māori ways of being that are not only directed at reclaiming rights from the Crown.

The Māori responses to Covid-19 demonstrate numerous ways through which Māori expressed tino rangatiratanga directed at protecting and supporting local communities that happened

New Zealand COVID-19 Alert Levels Summary

Unite
against
COVID-19

- The Alert Levels are determined by the Government and specify the public health and social measures to be taken in the fight against COVID-19. Further guidance is available on the [Covid19.govt.nz](https://www.covid19.govt.nz) website.
- The measures may be updated based on new scientific knowledge about COVID-19, information about the effectiveness of control measures in New Zealand and overseas, or the application of Alert Levels at different times (e.g. the application may be different depending on if New Zealand is moving down or up Alert Levels).

- Different parts of the country may be at different Alert Levels. We can move up and down Alert Levels.
- Services including supermarkets, health services, emergency services, utilities and goods transport will continue to operate at any level. Employers in those sectors must continue to meet health and safety obligations.
- Restrictions are cumulative (e.g. at Alert Level 4, all restrictions from Alert Levels 1, 2 and 3 apply).

Updated 28 August 2020

ELIMINATION STRATEGY – New Zealand is working together to eliminate COVID-19

Alert Level	Risk Assessment	Range of Measures (can be applied locally or nationally)
Level 4 – Lockdown Likely the disease is not contained	<ul style="list-style-type: none"> Sustained and intensive community transmission is occurring. Widespread outbreaks. 	<ul style="list-style-type: none"> People instructed to stay at home in their bubble other than for essential personal movement. Safe recreational activity is allowed in local area. Travel is severely limited. All gatherings cancelled and all public venues closed. Businesses closed except for essential services (e.g. supermarkets, pharmacies, clinics, petrol stations) and lifeline utilities. Educational facilities closed. Rationing of supplies and requisitioning of facilities possible. Reprioritisation of healthcare services.
Level 3 – Restrict High risk the disease is not contained	<ul style="list-style-type: none"> Multiple cases of community transmission occurring. Multiple active clusters in multiple regions. 	<ul style="list-style-type: none"> People instructed to stay home in their bubble other than for essential personal movement – including to go to work, school if they have to, or for local recreation. Physical distancing of two metres outside home, or one metre in controlled environments like schools and workplaces. People must stay within their immediate household bubble, but can expand this to reconnect with close family/whānau, or bring in caregivers, or support isolated people. This extended bubble should remain exclusive. Schools (years 1 to 10) and Early Childhood Education centres can safely open, but will have limited capacity. Children should learn at home if possible. People must work from home unless that is not possible. Businesses cannot offer services that involve close personal contact, unless it is a supermarket, pharmacy, petrol station or hardware store providing goods to trade customers, or it is an emergency or critical situation. Other businesses can open premises, but cannot physically interact with customers. Low risk local recreation activities are allowed. Public venues are closed (e.g. libraries, museums, cinemas, food courts, gyms, pools, playgrounds, markets). Gatherings of up to 10 people are allowed but only for wedding services, funerals and tangihanga. Physical distancing and public health measures must be maintained. Healthcare services use virtual, non-contact consultations where possible. Inter-regional travel is highly limited (e.g. for critical workers, with limited exemptions for others). People at high risk of severe illness (older people and those with existing medical conditions) are encouraged to stay at home where possible, and take additional precautions when leaving home. They may choose to work.
Level 2 – Reduce The disease is contained, but the risk of community transmission remains	<ul style="list-style-type: none"> Limited community transmission could be occurring. Active clusters in more than one region. 	<ul style="list-style-type: none"> People can reconnect with friends and family, and socialise in groups of up to 100, go shopping, or travel domestically, if following public health guidance. Keep physical distancing of two metres from people you don't know when out in public or in retail stores. Keep one metre physical distancing in controlled environments like workplaces, where practicable. No more than 100 people at gatherings, including weddings, birthdays and funerals and tangihanga. Businesses can open to the public if following public health guidance including physical distancing and record keeping. Alternative ways of working encouraged where possible. Hospitality businesses must keep groups of customers separated, seated, and served by a single person. Maximum of 100 people at a time. Sport and recreation activities are allowed, subject to conditions on gatherings, record keeping, and – where practical – physical distancing. Public venues such as museums, libraries and pools can open if they comply with public health measures and ensure 1 metre physical distancing and record keeping. Event facilities, including cinemas, stadiums, concert venues and casinos can have more than 100 people at a time, provided that there are no more than 100 in a defined space, and the groups do not mix. Health and disability care services operate as normally as possible. It is safe to send your children to schools, early learning services and tertiary education. There will be appropriate measures in place. People at higher risk of severe illness from COVID-19 (e.g. those with underlying medical conditions, especially if not well-controlled, and seniors) are encouraged to take additional precautions when leaving home. They may work, if they agree with their employer that they can do so safely. Face coverings required on public transport and aircraft (but not inter-island ferries) – school buses and children under 12 are exempt along with passengers in taxis or ride share services and people with disabilities or mental health conditions.
Level 1 – Prepare The disease is contained in New Zealand	<ul style="list-style-type: none"> COVID-19 is uncontrolled overseas. Sporadic imported cases. Isolated local transmission could be occurring in New Zealand. 	<ul style="list-style-type: none"> Border entry measures to minimise risk of importing COVID-19 cases. Intensive testing for COVID-19. Rapid contact tracing of any positive case. Self-isolation and quarantine required. Schools and workplaces open, and must operate safely. No restrictions on personal movement but people are encouraged to maintain a record of where they have been. No restrictions on gatherings but organisers encouraged to maintain records to enable contact tracing. Stay home if you're sick, report flu-like symptoms. Wash and dry hands, cough into elbow, don't touch your face. No restrictions on domestic transport – avoid public transport or travel if sick. No restrictions on workplaces or services but they are encouraged to maintain records to enable contact tracing. QR codes issued by the NZ Government must be displayed in workplaces and on public transport to enable use of the NZ COVID Tracer App for contact tracing.

FIGURE 1 | New Zealand COVID-19 alert levels summary. Source: New Zealand Government (2020).

irrespective of the actions being taken by the New Zealand government. These actions show how tino rangatiratanga is enacted as independent Māori decision-making. We suggest that this independent decision-making and indeed the exercise of tino rangatiratanga was partially made possible through adherence and respect of tikanga Māori.

Tikanga Māori

Tikanga are the rules and values that are founded within a Māori worldview. According to Mead (2016) 'Tikanga Māori might be described as Māori philosophy in practice and as the practical face of Māori knowledge' (p. 15). As such, tikanga are understood to cover all aspects of life and facilitate a range of relationships between individuals and groups that extends throughout generations.

Tikanga are also often viewed as a Māori legal framework, but as Jones (2016) has discussed at length, there are some key distinctions, which in particular are about the adaptability and flexibility of tikanga in relation to the rigidity of western law. Tikanga Māori are diverse and flexible by nature. In some ways, the strength of tikanga is that they are made to adapt to differing circumstances and changes to environments and contexts. Indeed,

Māori have continued to develop tikanga for generations in order to address the changes that have occurred on our lands. However, while adaptability is a strength of tikanga, there are numerous identifiable values which provide guidance about appropriate measures and actions. In this way, tikanga provides guidance on how people should act, as well as why people should act. In other words, tikanga confirm the responsibilities that Māori have to one another as a basis for action.

While it is beyond the scope of this article to flesh out the numerous different tikanga within a Māori worldview, we suggest that part of how tino rangatiratanga was exercised during the Covid-19 response was through Māori drawing guidance and responsibilities from tikanga Māori. Some of the tikanga that we illustrate in further depth in the case studies below, include; *Mana* – this is power, authority, or prestige and can be understood also as Māori political authority and control. Both individuals and groups can exercise mana, and for an iwi and hapū to be recognised as the authority over their lands and resources, it is considered that they have mana (Smith, 2013; Mead, 2016). The examples discussed below demonstrate how iwi and hapū have maintained their mana through the political decision-making and actions that were taken.

Manaakitanga – this relates to care and respect. Essentially, if mana is to be maintained, then there need to be efforts in place which demonstrate reciprocal care between people and groups (Smith, 2013; Mead, 2016). Again, manaakitanga can be used to understand the actions taken by Māori during the Covid-19 pandemic to protect and provide for communities.

Kaitiakitanga – this is care and guardianship over the environment and relates to the genealogical connections that Māori claim to the natural environment (Smith, 2013). In essence, Māori must protect the land in return for living off the land (Mead, 2016). For some iwi, their decisions regarding community protection during the Covid-19 restrictions were influenced heavily by the need to act as kaitiaki (guardians) over their lands.

Whanaungatanga – this is relationships, both familial and non-familial. For Māori relationships between people are required in order for society to operate (Smith, 2013; Mead, 2016). Whanaungatanga requires purposeful efforts to seek out and create lasting relationships as a mechanism to support individuals and establish collective ties. For this reason, understanding the Covid-19 response as articulated through tikanga, provides context for why Māori took the actions to maintain strong community links.

This is not a finite list of tikanga by any means, nor a full explanation of the tikanga that have underpinned Māori responses to Covid-19. However, understanding Māori responses and indeed the various ways that tino rangatiratanga can be enacted through a Māori values system could provide a basis through which Māori leadership in hauora and well-being can be understood. Furthermore, using a tikanga lens to assess how tino rangatiratanga and well-being intertwine demonstrates how one of the main strengths of tikanga is the ability to rapidly adapt even in the most unprecedented circumstances.

Hauora - Māori Well-Being

Hauora refers to the holistic Māori philosophy of health and well-being. Hauora consists of two words, hau and ora. Hau translating to breath and ora meaning to be well, and together they refer to the breath of life. Heaton (2018) explains that his combination of terms has roots in Māori creation narratives where the first woman Hine-ahu-mai-i te-one was given the first breath of human life from a Māori god Tāne. Hau (wind or vital essence of life), ha (breath), ora (to be alive, healthy, to survive) and wairua (spirit) were infused into the first female, who holds the ability to create life (Heaton, 2018).

Māori are not a homogenous group, and while notions of well-being vary according to whānau, hapū and iwi, there are some common elements. A Māori worldview of health is holistic in nature and extends far beyond a biomedical model of health which focuses on purely biological factors and excludes psychological, environmental, and social influence (Durie, 1998). Whānau is the foundation of Māori society, and as a principal source of strength, support, security and identity, whānau plays a central role in the well-being of most Māori, both individually and collectively. In a Māori worldview, each whānau member, (from young children to elders), is valued and plays an integral part in contributing to the well-being of the overall whānau (New Zealand Ministry of Health, 2002).

Māori health frameworks have been created in an attempt to help articulate important aspects of hauora. Professor Mason Durie's (1998) Te Whare Tapa Wha model compares hauora to the four walls of a whare (Māori meeting house), each wall representing a different dimension of hauora: taha wairua (spiritual well-being); taha hinengaro (mental and emotional well-being); taha tinana (physical well-being); and taha whānau (family and social well-being) which includes collective aspects of well-being. In this model, each of these four dimensions of hauora influences and supports the others and are necessary for strength, symmetry and balance. In addition to these dimensions of hauora outlined by Durie, in Rangimārie Rose Pere's (1991) model of well-being - Te Wheke - Pere also identifies Mauri (life force in people and objects), Mana ake (the unique identity of individuals and family), Hā a koro ma, a kui ma (the breath of life from forbearers), and Whatumanawa (the open and healthy expression of emotion), as important contributors to whānau health. This model also highlights the important interconnectedness of all of these factors (Pere, 1991). Mauriora (cultural identity), Waiora (connection with the physical environment), Toiora (healthy lifestyles), Ngā Manukura (leadership), Te Mana Whakahaere (autonomy at a community level) and Te Oranga (participation in society) are also important aspects of Māori well-being - this outlines in the Te Pae Māhutonga public health framework (Durie, 1999). While these models do vary in how they conceptualise well-being, they all highlight that Māori understandings of well-being must be understood in a holistic, collective manner and one that includes supporting collective ties. While an analysis of these models is outside the scope of this article, we suggest that these understandings of hauora which center on holistic and collective well-being are essential parts of both why and how Māori responded to Covid-19. Furthermore, these models which are bound in a Māori worldview, relate directly to the tikanga that we have provided above.

Linking Tino Rangatiratanga and Māori Well-Being

The understanding that tino rangatiratanga and Māori well-being is linked is briefly alluded to in pre-existing literature, however in little detail (Panelli and Tipa, 2007; Cram, 2014; Jackson et al., 2018). Examining the Māori response to Covid-19 through a dual tikanga-well-being lens allows us to see how they are linked (in a real-life health context) which builds a better understanding of how this complex relationship plays out and why it is so important moving forward.

Enacting tino rangatiratanga is essential to achieve Māori individual and collective well-being. However, Māori well-being is also a foundation of Māori development (Cram, 2014) therefore, a certain level of well-being of a peoples - including their culture and language - is needed to enact tino rangatiratanga. As a result, tino rangatiratanga can be viewed as both a marker of, as well as an important contributor to well-being. And equally, well-being is an important contributor to tino rangatiratanga. The interconnected and reciprocal relationships between tino rangatiratanga and well-being can be seen during

the Covid-19 response, where the cultural values and practices, as well as the capacity of Māori people, contribute to the enacting of Tino Rangatiratanga, in turn, protected and promoted the well-being for all New Zealanders.

Māori did not just enact tino rangatiratanga in response to Covid-19. Generations of language and cultural revitalisation efforts, allowed for matauranga Māori and the use of tikanga; the capacity building of Māori academics, researchers, and health professions (as previously mentioned), over the last 30 years allowed for a swift, culturally tailored, Māori health response, as well as an acute awareness of factors that could lead disparate health outcomes (such as pre-existing health conditions, as well as documented racism in the health care system); Treaty of Waitangi claims and the organisation of hapū and iwi organisations allowed for economic self-determination and a coordinated care response. While significant struggles still exist for Māori, we have continued to reaffirm our tino rangatiratanga in diverse ways, which have helped us to respond proactively to Covid-19.

Case Studies

The following section provides five case studies of how Māori responded to Covid-19. We clearly demonstrate the link between tino rangatiratanga and well-being and how the responses were informed by tikanga Māori.

Māori Storytelling Practices Guide Covid-19 Response

Oral traditions and intergenerational storytelling practices are a fundamental part of Māori culture and communities and played an important role in the rapid Covid-19 response by Māori communities. Māori cultural practice of remembering our ancestors - their lives, experiences, characteristics, their passing - meant that Māori were acutely aware of the potentially devastating impacts that Covid-19 could have on their communities. Throughout history, epidemics and introduced diseases have had a devastating impact on Māori communities. European colonisers brought new diseases such as measles and flu to New Zealand and because Māori lacked natural immunity to these diseases, many died. From the first European contact to 1840, Māori lost an estimated 30% of our entire population, mostly to epidemics (Lange, 2011). A further 30 per cent were lost in the twenty years that followed. The influenza epidemic of 1854 killed over 5,000 Māori, and the Māori death rate from the 1918 Spanish flu, was more than eight times that for non-Māori (New Zealand Ministry for Culture and Heritage, 2020; Ngata, 2020).

Today, Māori continue to tell stories about the impact these infectious diseases had on their population, language, culture and community. Māori immortalise these stories in physical reminders, such as pictures and carved pou, to ensure they speak about and remember the devastating disproportionate impact epidemic's such as the Spanish Flu had on Māori communities. This is deliberate "We keep our ancestors close, their memories live on with us, and their lives become our lessons" (Ngata, 2020, p.1). Because of this way of remembering past events, Māori were accurately aware of the

impact previous pandemics and introduced diseases had on our communities and the potential impact Covid-19 could have. This promoted Māori to react quickly and purposely, with knowledge, innovation, insight and awareness of consequences, which built the foundation for tino rangatiratanga to take place. The foundation of the Covid-19 response was built upon this important well-being practice.

Iwi Checkpoints

Iwi checkpoints were perhaps the most well-known action undertaken by iwi throughout the country. As the Covid-19 threat became ever more present in Aotearoa, a number of iwi took it upon themselves to protect local communities by establishing monitored entry and exits from their communities. These actions complimented decisions made by the New Zealand government, who had made nationwide rules to restrict movement, however as the history of pandemic devastation in Māori communities is still being felt, this extra measure taken by Māori communities sought to provide an extra layer of protection. These checkpoints saw iwi members organising to stop travellers from entering their communities-unless they were residents- to avoid any risk of spreading Covid-19. The iwi checkpoints were essentially about protecting the well-being of entire communities, Māori and non-Māori, and represent clear sites of iwi exercising tino rangatiratanga. The communities where such checkpoints were established were towns with high Māori populations, As such, some iwi rūnanga (tribal organisations) effectively mobilised in ways that demonstrated a capacity to protect well-being due to strong systems of governance that were already in place. Iwi such as those in Te Tai Tokerau, Te Whānau a Apanui, Tūhoe and Taranaki iwi all set up various checkpoints which were guided by both a need to protect the health of communities, but also responses that were driven through tikanga. Numerous media reports covering the iwi checkpoints and interviews with iwi leaders throughout the country demonstrates the centrality of tikanga and rangatiratanga in informing the rapid responses. Co-ordinator of the Northland iwi checkpoints for example stated that their decision to close off communities was based on their position as kaitiaki (guardians) which was supported by iwi rangatiratanga; "If we have this kaitiaki status and our own rangatiratanga, we have to step up and participate in serious issues like this," (Taipari, cited in de Graaf, 2020b).

Other iwi such as Tūhoe also confirmed through media interviews that their decision to control movement in and out of their community was based on their position as kaitiaki and the obligations and responsibilities they had to protect local communities; "Our role as kaitiaki in this case means keeping people safe and ensuring this closure is respected." (Kruger cited in Williams and Biddle, 2020).

Essentially these decisions and those made in other parts of the country can be linked in through the responsibilities that iwi have and are driven through tikanga Māori. For example, these actions align succinctly with kaitiakitanga (guardianship) and the responsibility that iwi have to protect the health of their environments, which is inseparable from the health of their people. In turn, these kaitiaki responsibilities are also driven

#Protect Our Whakapapa

If you start to feel any flu like symptoms, particularly shortness of breath, sore throat or fever — call Healthline on **0800 358 5453**




Assisting whānau that need extra tautoko

All our whānau are precious to us but some need extra tautoko, so we have a responsibility to manaaki them during this time.

We need to consider **how we can care for our:**

- Kaumātua.
- Hapū mothers & pēpi.
- Our whānau who are māiui.
- Those struggling to obtain the basic needs and live in isolated rural communities.



Health & Wellbeing

If you provide physical care for someone (feeding, bed care, washing, etc), make sure you **wash your hands a lot**.

See what's needed — deliveries, planning, technology tips or just a chat.


Go outside into your yard or have a walk to get some fresh air. You are allowed to walk with the people you're in lockdown with, just stick close to home & stay well away from other people if you see them.

Mā tātau katoa e ārai atu te COVID-19

What can we do to keep them safe if they live with us?

If someone who is at greater risk from this virus is living in your whare, there are things you can do to keep them safe.

- **Prioritise** a separate sleeping space for them.
- If they get māiui they will need to stay in their own space whenever possible.
- **Deliver kai** to their door.
- **Sanitise** everything afterwards.
- If their symptoms are bad or get worse, call Healthline on **0800 358 5453**.



How can we tautoko whānau who don't live with us?

The best way to keep them safe is to **STAY AWAY**.

Make a list of your whānau who are more at risk and work out the best ways to support them.

Keep in touch by calling them regularly on the phone. Share a karakia, read a passage from their favourite book.

Don't have kaumātua look after tamariki. Tamariki with Covid-19 tend to have fewer symptoms but can pass the virus on, and some can be carriers with no symptoms at all.

Manaaki Tangata

Keeping our Kaumātua & Whānau safe


Your GP and your medications

Make sure you have contact details for GPs and other health providers.

Pharmacists are now required to limit funded medicines to one month's supply & three months for the contraceptive pill. This is to manage medicine stocks in Aotearoa.

Book your next GP appointment 3 months ahead.

Our whānau may need medication or support with their appointments. Talk to your GP or nurse about the safest way to do this.



Other medical needs

Flu vaccines are available now for those at risk, e.g. kaumātua and people with pre-existing conditions.

Any visiting health or support workers should follow strict **hygiene practices**.

Look for Covid-19 testing in your area but only get tested if you have symptoms. All District Health Boards (DHBs) have Community Based Assessment Centres (CBAC) for their areas. They are listed on your local DHB's website.




FIGURE 2 | #Protectourwhakapapa Communication Strategy. Source: #ProtectOurWhakapapa (2020).

through manaakitanga (caring, nurture) and that care for communities is essential and could be practically protected through monitoring travel in and out of communities. These

tikanga also come hand in hand with the exercise of mana (authority, power), in that iwi mana is reconfirmed through actions that are taken to support the health of a community.

These instances demonstrate the continued importance of whanaungatanga, in that social relationships are embedded in these communities as being essential to the way that iwi operate. Protecting relationships and utilising those iwi relationships to develop a planned and coordinated response was central to iwi checkpoints. Understood through a tikanga lens provides important lessons on how Aotearoa could develop well-being frameworks and structures that are underpinned by tikanga Māori. Many other Indigenous communities, such as Aboriginal Australians also identified themselves as being at risk of infection and death from COVID-19. They also enacted sovereign actions and moved quickly to keep COVID-19 out of their communities in remote regions by restricting access to both outsiders and returning Aboriginal community members (Schultz, 2020).

Iwi checkpoints provide important examples of how current iwi governance structures are in a position to mobilise in situations that require rapid responses. These are clear examples of how iwi understand their tino rangatiratanga and that an essential part of maintaining tino rangatiratanga is to protect and promote the well-being of local communities.

Kōhanga Reo

A lesser publicised example, which equally demonstrates Māori enacting tino rangatiratanga during the Covid-19 crisis, was the decision made by Te Kōhanga Reo National Trust advising all kōhanga reo (Māori language preschool's) to remain closed during alert level 3, this despite the New Zealand Government lifting restrictions and recommended early childhood programmes could go back at full capacity.

While the New Zealand Government had announced that Education providers and children could return to schools, Te Kōhanga Reo National Trust made an independent decision for children to remain at home. This decision was made as a matter of caution and protection for Māori communities beyond the national standards. Trust chief executive, Angus Hartley stated, "The Trust believes whānau should take an extra precautionary approach and not risk the health and well-being of our vulnerable pakeke (adults), kaumātua (elders) and mokopuna (grandchildren)". "Further, stating that the". The advice from the ministries of education and health is not consistent with the risk profile that exists at kōhanga reo" (Hartley, cited in Hurihanganui, 2020, p.1). This refers to the number of kaumātua that work in kōhanga reo. In enacting their own tino rangatiratanga the Trust surveyed their kōhanga reo whānau and found that over a third fall into high-risk groups and were therefore at a heightened risk to Covid-19. Furthermore, nearly 80% of those associated with kōhanga reo reported that they did not feel safe to return to mahi (work) at alert level 3 (Hurihanganui, 2020).

This extra precautionary approach demonstrates Māori decision making independent of Government and the ability to identify and manage risk unique to their own communities. As described above, in relationship to the checkpoints, these actions align with kaitiakitanga and the responsibility that Māori organisations, such as Kōhanga Reo, felt to protect the health of their whānau, employees, as well as the children they care for. In

turn, these kaitiaki responsibilities also expressed manaakitanga for their most vulnerable as well as the importance of whanaungatanga and how responses to Covid-19 require consultation with communities and those groups that connect into decisions being made. In this case study, Māori made their own decisions based on a process of observation and understanding their community, as well as the current circumstances.

Care Packages

Many hapū, iwi, Māori organisations and community groups organised and delivered care packages to members of the community. Priority was given to vulnerable members of the community, such as the elderly, low-income earners, as well as those who live rurally, or had pre-existing health conditions. While there is no official reporting of the exact number and type of resources distributed by iwi, hapū and Māori organisations, it was on the largest scale seen in recent history. For example, the iwi Ngā Puhī and Waikato Tainui distributed 8,000 and 5,000 food packages respectively (de Graaf, 2020a) and Te Pūtahitanga - the Whānau Ora commissioning agency for Te Waipounamu (South Island of New Zealand) distributed 1,734 food packages. Te Pūtahitanga also distributed 1,371 grants for home heating, 1,104 data support, 600 devices to enable digital connectivity and 25,000 hygiene packages (McMeeking and Savage, 2020).

Whānau Ora commissioning agencies were recognised as key to increasing outreach to Māori communities and ensuring equitable and holistic care. The New Zealand Ministry of Health provided \$4.3 million to the Whānau Ora commissioning agencies to support their work. A direct result of this funding was the distribution of 80,000 hygiene packages to whānau across Aotearoa, ensuring those in need had appropriate cleaning and hygiene materials. Whānau Ora also provided over 2,500 grants directly to whānau to support them, averaging over \$400 per whānau. Additionally, 7,898 whānau received Manaaki Support packages, which included food, data support, and other material means of support via Whānau Ora Navigators (New Zealand Ministry of Health, 2020). Looking globally, Native American grassroots community members demonstrated a similar response, also providing food to vulnerable community members, in one case filling the void left by canceled feeding programs, which would have disproportionately impacted the elderly and youth (Hoover, 2020).

Care packages demonstrate a holistic Māori health response which extends beyond a physical health response to ensure that Māori, in particular our vulnerable community members, were taken care of during Covid-19 lockdown, this also ensuring that existing hardships were not perpetuated during this time. The large numbers of packages provided from across agencies is significant as it demonstrated ways in which individual iwi, hapū and Māori organisations understood the key supports that were needed. This response was based on the import value of manaakitanga and also exemplifies the importance of whanaungatanga, and existing trusted relationships with Māori communities was key to successful outreach to Māori communities and ensuring equitable and holistic care.

Online Innovations

Understanding the use and development of online forums through a tikanga lens, highlights the adaptability of tikanga to maintain whanaungatanga. Relationships are central to tino rangatiratanga, in that the basis for both affirming and advocating for rangatiratanga is aimed at collective well-being as opposed to individual well-being. In lieu of face to face interactions, online tools enabled Māori to maintain whanaungatanga through the promotion of specifically Māori material. Māori online webinar series, the development of te reo Māori (Māori language) support, as well as Māori specific business pages all developed during this period which simultaneously advanced Māori knowledge as it did promote whanaungatanga in absence of physical contact. These can all be considered as actions taken to enhance tino rangatiratanga as they were aimed at essentially promoting the well-being of Māori communities through sharing Māori knowledge and Māori expertise.

For example, outside of targeted actions to protect local communities, the Covid-19 alert level restrictions and the resulting limited social interactions led to various online initiatives. Online karakia (prayer), tangihanga (funeral proceedings), research conferences, medical and psychology advice, health messaging, cultural workshops, educational resources, and pages dedicated to supporting Māori businesses through the economic downturn, are just a few of the many examples of the online innovation Māori individuals and communities showed during the lockdown. It is clear from these few examples, that Māori were not only reacting in the space but actively innovating, sharing knowledge, and supporting others.

New grassroots organisations also emerged. During the pandemic, Māori knew that Māori specific health messaging was essential to ensure effective and relevant communication of important health information to Māori communities. Therefore, a grassroots organisation started an online communication strategy and hashtag #Protectourwhakapapa (see **Figure 2** for an example) to ensure that there was health communication that was effectively conveyed and relevant to Māori families and communities (McMeeking and Savage, 2020).

Due to Covid-19 restrictions preventing gathering, some normally in-person cultural practices were moved to an online format. This included several people and organisations hosting online karakia (prayer) over Zoom and Facebook, as well as some tangihanga proceedings moving online. While we do not go into significant detail in this article about the process in which these practices were adapted, the important point here is that a significant adaptation to our cultural practices took place. Karakia and even more so tangihanga processes are not common online and indeed in many ways center on face to face interaction. However, Māori recognised the importance of both of these cultural processes for spirituality and emotional health during Covid-19 (as well as the long-term impact of these practises for well-being). Therefore, kaumātua, and those with in-depth knowledge of tikanga and mātauranga Māori, came together to adapt tikanga and create online tangihanga guidelines and also host online karakia. Again this shows the adaptive capacity of our tikanga, when we understand the

underlying mātauranga and values guiding our tikanga practices - and this in and of itself demonstrates how tino rangatiratanga and well-being are linked.

These case studies provide examples of how tino rangatiratanga can be enacted through novel and diverse measures which are underpinned by tikanga Māori. In these cases, Māori values and holistic well-being was the key motivation, as Māori responded to the physical, mental, emotional, social, spiritual and economic challenges of Covid-19, in a culturally appropriate manner.

Holistic Covid-19 Response

The holistic Covid-19 responses worked to ensure that not only were mortality rates low, but also protected wider well-being of Māori communities and in line with the World Health Organization which describes health as a “state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1995, p. 1). This value-based health approach led to a dynamic and holistic health response by iwi which included consideration of the whole person, taking into account mental, social, and cultural factors, rather than just the absence or presence of the virus.

Recommendations

The Covid-19 pandemic is still unfolding and presenting the world with unprecedented challenges and questions around how to best manage the ongoing uncertainty and response. From the actions undertaken by Māori and highlighted in this article, there are a number of key lessons that could be implemented to inform future plans. With these case study examples in mind, and in line with a Kaupapa Māori research methodology which suggests that research should lead to transformational change we suggest a number of recommendations for how Aotearoa can plan for a future that enhances both tino rangatiratanga and well-being (Smith, 2013). We offer these simply as options to consider and encourage conversations amongst indigenous and non-indigenous peoples facing this crisis together.

1. Tikanga Māori positioned at the center of decision-making across all political decision-making. Presently, while there are some policies and even fewer laws which mention tikanga Māori, there needs to be greater acceptance of tikanga Māori as key values which can benefit all of Aotearoa New Zealand. As adaptable and flexible values, tikanga have effectively informed key Māori responses to the Covid-19 pandemic.
2. Māori leadership in the responses to Covid-19 and overall health and well-being. This could take the form of an independent Māori health board at the national, regional or local levels, iwi led responses with more decision-making powers. However, whatever the structure that Māori leadership takes, it must be resourced sufficiently and given full control over how resources are used. Several governance groups have already proposed partnership with the government on Covid-19 issues such as the Māori Reference Group, Māori Monitoring Group, Iwi Chairs Forum, and Te Tumu Whakarae. The government has also eventually released a Māori Covid-19 response plan

including the formation of a Māori Touchstone Group and almost \$NZ50 million in assistance for Māori health providers (Johnsen, 2020). These are good beginnings, however control over Māori health needs to move more rapidly into Māori hands.

3. Supports the establishment of an independent Māori Health Authority which also allows capacity and space for Iwi-specific response, as seen as effective during Covid-19 (Tribunal, 2019).
4. Provide opportunity and resources for Māori to continue to explore the underlying nature of tikanga so that tikanga can continue to inform the future of Aotearoa.
5. Greater collaboration between Māori communities and police. The iwi checkpoints in particular required some level of Māori and police engagement which was largely successful. This was a result of Māori being given support by the police for Māori led initiatives. This could provide a framework for developing Māori and police relationships.
6. Finally, tino rangatiratanga needn't be considered as a threat. The Covid-19 pandemic has shown that is Māori exercising tino rangatiratanga has in fact led to greater well-being for Māori and non-Māori alike. If encouraged outside of a pandemic, the potential would be even greater.

The Covid response in New Zealand, both by the New Zealand Government and Māori, has highlighted the need for systemic change in health. The case study examples provided in this article and discussion show clearly that Māori need to be given leadership roles in health and well-being plans. While this right to have control over well-being is a central part of tino rangatiratanga, there remain significant challenges around the New Zealand government's willingness to fully accept Māori tino rangatiratanga which is often seen as a threat to governments. However, Covid-19 has and will continue to require innovative and shared responses in order to ensure that the health and well-being of all individuals and groups are protected and enhanced. Māori experience of disease coupled with our continued expressions of tino rangatiratanga, have shown that we are prepared as well as any colonial government, if not more so, to promote the well-being of our communities. Furthermore, the examples have shown how well-being for Māori has been able to thrive in both the numbers of people who contracted Covid-19, as well as well-being that has been enabled through the adaptation of our tikanga to promote social well-being and community learning.

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CONCLUSION

The New Zealand response to Covid-19 is being heralded internationally as an economic and health success (Cave, 2020). But this success cannot be viewed independently from the Māori Covid-19 response which was even harder and faster than the central government response. Not only did the Māori response likely contribute to the overall New Zealand economic and health success for all New Zealanders but it also provides an example of a more holistic health response - one that not only the New Zealand government but other governments around the world could learn from.

In analysing the Māori response to Covid-19 it is clear that Māori communities reacted with innovative, decisive, and robust decision making, that enacted tino rangatiratanga which was driven in part by tikanga Māori. Furthermore, these Māori philosophical perspectives which resulted in swift and concise actions, demonstrate the close links between tino rangatiratanga and well-being. In other words, each is necessary for the other, and that the health of our communities is dependent on the health of our tino rangatiratanga.

The response to Covid-19 to protect communities and ensure holistic well-being meant for the first time ever, Māori were not disproportionately negatively impacted by an endemic reaching the shores of Aotearoa. We echo the calls from Durie (2020) that have been made clear during this period of time that; *"I would like to see an Aotearoa moving forward, which gives more cognisance to the systems and structures that we have as Māori. What I think we require, is a system in this country which allows us, or gives us more flexibility to do things in a way in which we know work for our people"* (2020).

It is clear that there are parallels across the indigenous community lead responses, who showed strong leadership and a value-driven response to Covid-19. By examining the Covid-19 response in New Zealand, as well as that of other Indigenous peoples around the world, it is clear that Indigenous-led solutions can positively impact the Covid-19 response for all.

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CC and ATO both made an equal contribution to preparing and writing this manuscript.

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Adapting Summer Education Programs for Navajo Students: Resilient Teamwork

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In May 2020, the Navajo Native American Research Center for Health Partnership (Navajo NARCH) was scheduled to launch two summer programs: a 10 weeks-long Summer Research Enhancement Program (SREP) for undergraduate students to learn and practice health research methods and participate in a practicum experience, and a week-long Indigenous Summer Enhancement Program (ISEP) for high school students that introduces a range of health professions and develops leadership qualities. Students accepted into the programs are predominantly Navajo and live within Navajo Nation (NN) during the summer. Due to NN restrictions and CDC guidelines for physically distancing in response to the coronavirus (COVID-19) pandemic, the Navajo NARCH team organized to offer both programs entirely online via Zoom™. This paper explores the instructional teams' adaptation process to maintain a commitment to preserve the programs' supportive environment for exploring and developing strong multicultural approaches in public health and health research. In preparation for online instruction, the team developed and offered workshops for staff and instructors to address anticipated challenges. The team identified the following challenges: technological difficulties, social disconnectedness, consistent student engagement, and facilitation of a practicum research experience. Results showed that program adaptations were successful as the team applied collaborative and holistic approaches, and established social connections remotely with students to offer meaningful research and practicum experiences.

Keywords: remote learning, online engagement, public health, American Indian, Navajo, summer education program, high school student, undergraduate student

INTRODUCTION

American Indians and Alaska Natives (AI/AN) have experienced a disproportionate burden of hospitalizations (five times that of non-Hispanic Whites) and deaths related to coronavirus disease 2019 (COVID-19) (Centers for disease control [CDC], 2020; Kakol et al., 2021). In May 2020, the Navajo Nation (NN) reported the highest per-capita COVID-19 infection rate in the US with 2,304 positive cases per 100,000 citizens compared to the overall United States infection rate of 636.3 positive cases per 100,000 (Silverman et al., 2020). Although the NN population density is low, initial disease transmission was rapid. The NN consists of a 17-million-acre reservation, which extends across three states, New Mexico, Arizona, and Utah; greater than 50%, or approximately 157,000, of

the NN's more than 300,000 enrolled tribal members live within reservation boundaries (Navajo Epidemiology Center, 2013).

To address the infection surge, NN leadership established innovative methods to mitigate the spread of the virus and to communicate COVID-19 response measures and guidelines to citizens within the borders of the NN and beyond. On March 13, 2020, the NN government declared a state of emergency and closed all branches of the government and their services for the remainder of the school year (Becenti, 2020). Since March 29, 2020, the NN Office of the President and Vice President has been using Facebook Live to host weekly virtual town hall sessions, with 9,000–53,000 views per session, to inform citizens on the epidemiology of COVID-19, describe response actions, and provide culturally relevant guidelines to reduce COVID-19 spread within the NN (Nez and Lizer, 2020). On April 8, 2020, the NN President implemented a recurring 57-h weekend curfew, from Friday night through Monday morning, requiring residents to stay in their homes and refrain from large gatherings and trips to stores both on and off the NN (Lambert et al., 2020).

Setting and Partnership

Against the backdrop of the emerging pandemic, the CDC guidelines for physical distancing, and the NN's executive orders, the Navajo Native American Research Center for Health Partnership (Navajo NARCH) was preparing for the May 2020 launch of its two annual summer programs: a 10 weeks-long Summer Research Enhancement Program (SREP) for undergraduate students to learn about health research and participate in a practicum experience, and a week-long Indigenous Summer Enhancement Program (ISEP) for high school students that introduces a range of health professions and develops leadership qualities. SREP was established in 2000 and ISEP in 2018. Students accepted into the programs are predominantly Navajo and live on NN during the summer.

The Navajo NARCH is a NIH-NIGMS funded Center led by Diné College (DC) in partnership with Northern Arizona University (NAU). The overall goal of the educational component of the Navajo NARCH is to build the NN's capacity to improve the health of Navajo and other American Indian (AI) people by increasing the number of professionally trained Navajo practitioners and researchers. Both summer programs use the Diné Educational Philosophy (DEP) as a framework for the curriculum and teaching philosophy for public health education. The DEP is based on the Diné (Navajo) concept of living a long life in wellness and harmony, and being in balance with the natural world and Universe (Benally, 1992; Hughes et al., 2013; Diné College, 2020).

These institutionalized steps for mentoring Navajo students to start a career in health research and public health previously relied on a face-to-face delivery model. The Navajo NARCH instructional teams, consisting of faculty, staff, and teaching assistants, responded to the challenge by offering both programs through a remote, synchronous delivery model via Zoom™, adapting the curricula, and maintaining the reputation, academic rigor, and relational strengths the programs had built over the years. This paper describes the online adaptation process

and how the teams maintained the programs' supportive environment for exploring and developing strong multicultural approaches in public health and health research.

METHODOLOGY

Participants

Indigenous Summer Enhancement Program

Recruitment: American Indian High School Students

Recruitment of AI high school students occurred from January 2020 to May 2020. Recruitment involved radio announcements in Navajo and English, social media posts such as Facebook and Instagram, word of mouth, electronic flyers to 20 high schools both on and off the NN, and an email invitation to previous students (to return as peer mentors). Eligibility requirements included current high school enrollment (grades 9–12), parental consent and permission for the student to fully commit to the entire one-week summer program, and a brief online orientation. Fourteen high school students were accepted into the ISEP program in mid-May 2020, including seven peer mentors (previous ISEP students) and seven first time ISEP students. Of the fourteen high school students, one peer mentor and one first time student identified as male, and the other students identified as female. At the time of admission, high school status of those enrolled included: one freshman, three sophomores, seven juniors, and three seniors. All students identified as AI and resided on the NN or in Arizona.

Summer Research Enhancement Program

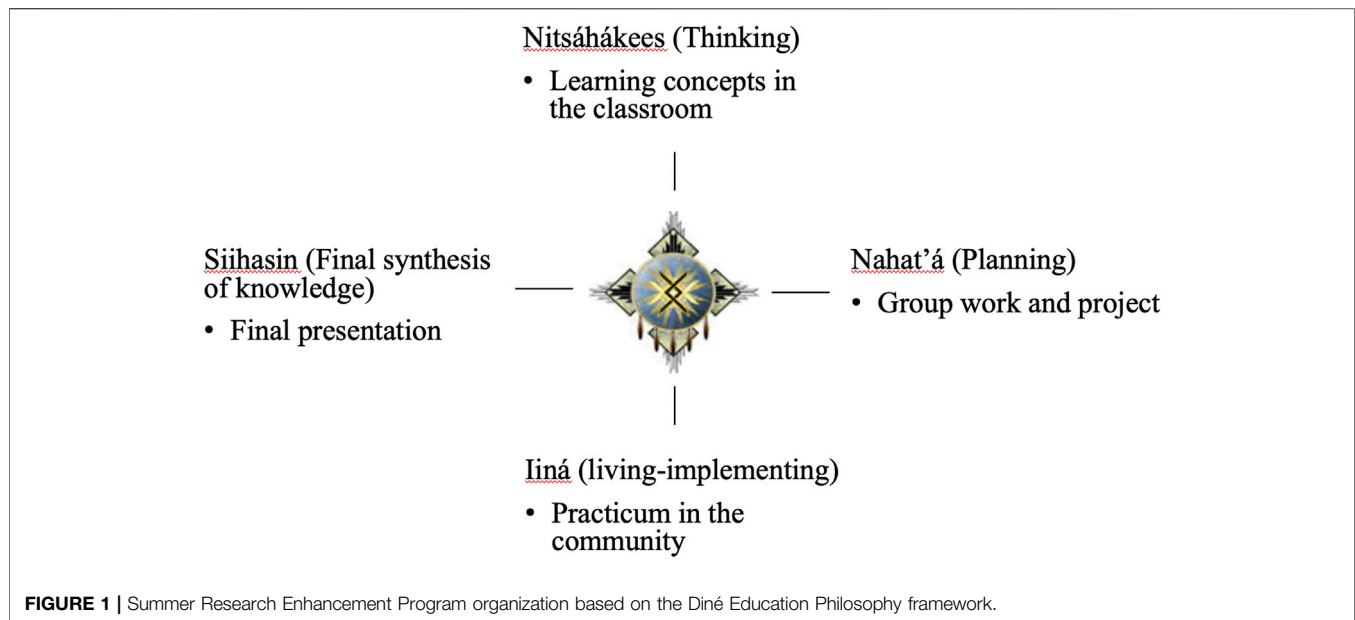
Recruitment: American Indian Undergraduate Students

AI undergraduate students were recruited from December 2019 to March 2020. Recruitment involved radio announcements in English and Navajo, applications and flyers mailed and emailed to colleges and universities, and flyers shared through Facebook and college listservs. Eligibility criteria for SREP included being an undergraduate student or a recent graduate from an undergraduate program and commitment to completing the ten-week program. Nine students were accepted into the program; one student identified as male and the other eight identified as female. At the time of admission, undergraduate status of those enrolled include: two sophomores, three juniors, and four seniors. All students identified as AI and resided on the NN or in Arizona.

Data Collection and Analysis

Indigenous Summer Enhancement Program Evaluation

ISEP students completed a 62-item evaluation questionnaire at baseline and at the conclusion of the program. In completing the online survey, students responded to the relevance and understandability of the ISEP content, interest in college preparation, public health knowledge, academic challenges and barriers, further career aspirations, education, and suggested program improvements. Thirteen students completed the baseline survey and 11 students completed the post survey. A



NARCH team member who did not mentor or instruct any student assignments administered the evaluation. ISEP evaluation analysis was conducted using Excel® and aggregate data were reported using descriptive statistics.

Summer Research Enhancement Program Evaluation

SREP students completed a 73-item evaluation at baseline, at midpoint (week 4), and at the conclusion of the program (week 10). Students responded to questions about the SREP curriculum content and delivery, program or academic challenges and barriers, practicum experience, and interactions with staff, guest speakers, mentors, and instructors. They also reported their knowledge about community health, research, and resilience, and the subjects taught i.e. statistics, program evaluation, research methods, Indigenous research models, and digital storytelling. Nine students completed the baseline and midpoint post survey, and eight students completed the final survey. A total of nine students were admitted into the SREP program; however, due to personal reasons one student did not complete the SREP practicum. A NARCH team member who did not mentor or grade any student assignments administered the evaluation. SREP evaluation analysis was conducted using Excel® and aggregate data were reported using descriptive statistics.

RESULTS

Site Description

Indigenous Summer Enhancement Program Description

The vision of ISEP at DC is to introduce AI students to careers in public health and health research in order to strengthen research capabilities of tribal colleges and universities. The program is available to high school students grades 9–12, and to returning students as peer mentors. ISEP provides a culturally supportive

atmosphere for developing a strong, multicultural approach in public health and health research. The one-week program introduces a range of health professions, teaches digital storytelling, mentorship, and develops leadership qualities with high school students. Peer mentors provide a unique type of mentorship to new ISEP students by leading presentations, activities, and advising students on their projects. Prior to the COVID-19 pandemic, ISEP students convened on the DC Tsaille, AZ campus to experience residential college life, living in dorms, participating in classes, and eating in the cafeteria. In its second year, ISEP ran concurrently with SREP, to encourage direct interactions between high school and undergraduate students.

Summer Research Enhancement Program Description

Prior to the COVID-19 pandemic, SREP for undergraduate students originally included three weeks of course work at the DC Tsaille campus, 6 weeks of site practicum placement in the students' home communities, and a final week of data analysis and presentations back at Tsaille (Bauer, 2016). **Figure 1** illustrates how SREP is organized based on the DEP framework. The course work for the original three weeks focused heavily on research and program evaluation. Digital storytelling training and guest presentations also took place during the three weeks. While at Tsaille, students were encouraged to be physically active and collected personal health data to assess any changes in their BMI or heart rate during the 10-weeks program.

The 6-weeks SREP practicum experience were held in the students' hometown communities on the NN. Students were typically placed with health programs and research organizations to work 40 h per week for a duration of 6 weeks on community health activities and projects including health fairs, walking/running events, food demonstrations, health education, community needs assessment, etc. Students worked with their site mentor and the SREP practicum coordinator.

TABLE 1 | Indigenous Summer Enhancement Program adaptations for 2020.

	2019	2020 Adaptations
Location and time	Residential program at DC tsaille campus in Arizona for 1 week	Program took place through zoom™ platform for 1 week
Instructor to instructor interaction	Face-to-face time available	Interaction through zoom™, email, text, slack; flexible
Instructional team/student interactions	Secure rapport with social connectedness	Less secure rapport with fewer times to interact; relative social connectedness
Student to student interaction	In-person opportunity to interact in the classrooms and dorms, and shared exercise hour and meal time	Interaction through slack, text, remind, phone calls, and zoom™ break out rooms
Content delivery	60 min sessions per topic. Course structure is instructor driven	30 min sessions per topic, with five 3-h morning and 3-h afternoon blocks. Uniform structure with warm up, mini- lessons, and student interaction
Content changes	Activities included morning run/walks; community resilience and asset mapping session; social determinants of health game; and indigenous determinants of health session	Begin each day with 15 min check-in, share, and reflection. Zoom™ sessions with indigenous public health leaders and impact of COVID-19 at work sites. Ended each day with 15 min check-out, share, and reflection
Final project	Community and family members invited to in-person presentations of three to 5-min digital stories	Community and family members invited to zoom™ presentations of digital stories
Team building activities	Full day of in person ropes course, canyon de chelly hike, and undergraduate/high school joint activities	Ice breakers, mindfulness, scavenger hunts, stretch breaks

Students gained hands-on experience with planning community wellness activities, administering community surveys, and assisting with program evaluations. During their practicum, students completed a data-driven research project using data collected or provided by their host site; students would most often analyze program evaluation data. The final week consisted of analyzing the site data and developing PowerPoint presentations as well as finalizing digital stories.

Instructional Team and Student Relationships for Indigenous Summer Enhancement Program and Summer Research Enhancement Program

The ISEP and SREP instructional teams and student relationships were strong due to faculty living on campus in the same dorms as students and being present each day in the classrooms. There were opportunities to connect and socialize during mealtimes, in the evenings during exercise times, and on social outings such as hiking or team building at a ropes course. Some instructors for SREP also served as site coordinators and made weekly visits to check on the students and their practicum mentors. During the courses, the instructional teams made themselves available and would often work long hours to ensure students had adequate support. Students were also placed into groups and often formed strong working relationships that fostered group experiences.

Adaptation Process Indigenous Summer Enhancement Program Adaptations

ISEP online adaptations started with the application itself, which asked students about internet access and availability of a dependable device (i.e., smartphone, tablet, iPad, laptop or desktop computer) for learning purposes. The ISEP staff began transforming the in-person rigorous 11-hour-day schedule to 2, 3-h blocks starting 9:00 am to 12:00 p.m., followed by a 1-h lunch break, and concluding 1:00 pm to 3:00 pm. The staff revised the 2019 schedule to remove the day long team-building activities (e.g., ropes course, Canyon de Chelly hike) and decided by

consensus which topics to include in the condensed ISEP schedule. Related topics were combined and converted into 30 min content sessions. New content was introduced in the morning block, while the afternoon block was dedicated for group digital storytelling work. The online version of ISEP was offered June 21 to 26, 2020. See **Table 1** for further details on ISEP 2020 adaptations.

Summer Research Enhancement Program Adaptations

SREP was modified to an online format in response to COVID-19. Since the site placements and living in the dorms at DC Tsaille campus would not be possible, the foci became strategies to build and maintain peer and instructional relationships and to shift site practicums to support students to conduct their own research on NN COVID-19 topics. In 2–3 person groups, students developed their own surveys on COVID-19. To support this shift, the coursework for the first four-weeks focused on infectious disease and emphasized data analysis. As in previous years, students were trained in digital storytelling during the five weeks and were instructed to complete their digital stories prior to returning during the last week. The last week was reserved for data analysis and preparing for presentations. The online version of SREP was delivered from May 25th to July 31st, 2020. See **Table 2** for further details on SREP 2020 adaptations.

In preparation for students to conduct their own research, the schedule provided time for students to meet with their groups to develop research methods, create surveys, and complete protocols to submit to the DC Institutional Review Board (IRB). **Table 3** describes the student projects in more detail. The protocols were approved by the IRB in week 6 and students were able to start their data collection. After week 4, students completed training for COVID-19 contact tracing and spent 20 h a week on this activity for 5 weeks.

Due to the impacts of COVID-19 with health organizations on NN, the SREP practicum was adapted to allow for students to gain public health research experience. Since traditional placement

TABLE 2 | Summer Research Enhancement Program adaptations for 2020.

	2019	2020 Adaptations
Location and time	Three-weeks at DC tsaille campus in Arizona. Six-weeks of site practicum placement in the students' home communities. Final week at tsaille campus	Online delivery, generally based at home on or off the NN.
Instructor to instructor interaction	Face-to-face content planning. Opportunity to interact in the classrooms and dorms, and exercise hour and meal time	Content planning through zoom™ and email. Primary interaction through text and cell phone
Instructional team/student interaction	Face-to-face classroom instruction. The team worked long and late hours to support student learning. Interaction in classrooms, dorms, exercise hour and meal time	Interaction through zoom™, slack, text, cell phones. The team did not often work late hours but offered office hours for extra support
Student to student interaction	Interaction in the classrooms and dorms, and during exercise hour and meal time	Interaction through zoom™, slack, google Hangout, text, cell phones
Practicum experience	Site placements at home communities with community health focus	Virtual practicum site placement focused on contact tracing
Practicum length	6-weeks	5-weeks
Final research projects	Individual applied research within community health settings. Mentors from practicum sites were assigned to students	Group research on COVID-19. The instructional team served as project mentors for students
Evaluation process	73-Item evaluation on various topics from curriculum to content delivery	Kept the 73-items but added "not Applicable" option to topics that were not administered
Content delivery	3-weeks of coursework. Classroom time started at 9:00 am and ended at 10:00 pm, with 1-h lunch break and 2-h dinner break. Most classes were 1 or more hours	4-weeks of course work. Classroom time started at 9:00 am and ended at 4:00 pm, with 1-h lunch break. Most classes ranged from 30 min to 1 h
Content changes	Content focused on research, intervention development, and program evaluation	Focused on research with emphasis on data analysis, qualitative data collection, and infectious disease. Digital storytelling training took place after the 4 weeks of coursework
Guest presentations	Topics: Food systems, indigenous determinants of health, and traditional medicine and traditional ecological knowledge	Topics: AIAN mental health, COVID-19, and disease etiology and epidemiology of COVID-19 on NN.
Team building activities	Sharing resilience shield, canyon de chelly hike, ropes course, ice breakers, evening exercise hour, just move it 5 k run/walk, and social determinants of health game	Sharing resilience shield, ice breakers, talking circles, and included an adapted online version of the social determinants of health game

sites were displaced (i.e., reassigned to new areas of their organization to address the public health crisis of COVID-19, working remotely from home or closed until further notice), the SREP director secured an alternate way for students to gain hands-on public health experience as contact tracers for the NN. This was a partnership with DC, the Navajo Department of Health (NDOH), the Navajo Epidemiology Center (NEC), and the Community Outreach and Patient Empowerment (COPE) Program. Students became certified contact tracers by completing the Johns Hopkins University COVID-19 Contact Tracing online course (Coursera, 2020), Health Insurance Portability and Accountability Act (HIPAA) training through Indian Health Services (IHS), and 10 h of live Zoom™ webinars provided by Partners in Health (PIH) prior to beginning their first shifts.

Instructional Team Training

In preparation for the online transition, the instructional teams (Table 4) attended a one-day remote training to learn and share strategies for online teaching, Zoom™, and student engagement. Instructors also got feedback on their online teaching style. A plan was put into motion for the teams to serve as mentors for students and were also placed in learning groups with their student mentees.

The instructional teams met 1-h each day during the direct instruction stage of the programs. This time was dedicated to reflecting on the day and directly applying real time adjustments in preparation for the next day's activities. Instructional teams operated on a schedule of flexibility that varied with staff schedules, student absences, changes in curriculum focus, and

new opportunities that would arise including availability of guest presenters and contact tracing training.

Supportive Environment

Since ISEP and SREP team members overlapped and ISEP began a month after SREP, the ISEP instructors were able to directly apply lessons learned from SREP. Based on these lessons learned, the ISEP team proactively held an orientation for the high school students and their parents to learn about the different platforms used for ISEP. Students learned how to reconnect to Zoom™ via phone if/when there were internet connectivity issues, use breakout rooms, chat and reactions features, share screens and conduct audio checks. ISEP staff demonstrated how to connect to and navigate Blackboard Learn™, DC's online interface, allowing high school students to experience what it would be like to participate in an online college class. Slack was introduced as a means for peer to peer, small group, and direct communication with the ISEP team outside of Zoom™ classes. The orientation concluded with tips and examples of different ways to successfully set up a student-friendly learning space for the duration of ISEP, complete with hydration and healthy snacks.

The SREP instructional team modified the 10-weeks curriculum to ensure enough course time was offered without overwhelming students with Zoom™ or other online lessons. The instructional teams gave out cell phone numbers for students to schedule meetings or ask questions. The coursework schedule was adjusted so the days started at 9:00 am and ended by 4:00 pm. One SREP instructor provided additional tutoring support for data analysis beyond the scheduled course time. The schedule shifted

TABLE 3 | Summer Research Enhancement Program student COVID-19 projects.

Group project	Purpose	Participants	Methods
Impact of COVID-19 on caregivers	To gather primary data using an online survey to understand the impacts of COVID-19 on caregiver burden, social support, and mental health	<i>N</i> = 50	Data collection <ul style="list-style-type: none"> ● online survey (survey monkey) Data analysis <ul style="list-style-type: none"> ● chi-square (OpenEpi, excel[®]) Sampling method <ul style="list-style-type: none"> ● snowball sampling ● survey posted on Pls' facebook accounts Inclusion criteria <ul style="list-style-type: none"> ● 18 years old or older ● reside on Navajo nation ● provide financial supportive care to child (ren), older adults, or person with a chronic illness/disability ● access to online survey
Impact of COVID-19 Navajo Nation policies	To gather primary data to better understand the impacts COVID-19 has on mental health, behavior, resources, and barriers	Survey <i>N</i> = 111 Focus group <i>N</i> = 5	Data collection <ul style="list-style-type: none"> ● online survey (survey monkey) ● focus group via zoom[™] Data analysis <ul style="list-style-type: none"> ● chi-square (VassarStats) ● <i>t</i>-test (excel[®]) ● grounded theory (focus group) Sampling method <ul style="list-style-type: none"> ● snowball sampling ● purposive sampling Inclusion criteria <ul style="list-style-type: none"> ● 18 years old or older ● self-identify as AI ● reside on the Navajo nation
Impact of COVID-19 on Diné College employees	To examine the impacts of COVID-19 on diné college employees, to gain knowledge and perceptions of potential barriers of job duties, and evaluate the support provided to employees	<i>N</i> = 66	Data collection <ul style="list-style-type: none"> ● online surveys (qualtrics) Data analysis <ul style="list-style-type: none"> ● chi-square and ANOVA Sampling method <ul style="list-style-type: none"> ● convenience sampling ● survey distributed via diné college employee listserv Inclusion criteria <ul style="list-style-type: none"> ● diné college employee ● access to internet ● 18 years and older

once the students started contact tracing, with some choosing to do shifts on the weekends or evenings. Students were still expected to complete homework assignments on weekends and after classes ended. The final week was a little challenging because students usually have more contact time but the online platform made it difficult for students and faculty to focus after 4:00 pm. The only exception was when students and faculty stayed online to finish practicing until 1:00 am the day the presentations took place.

Multicultural Approaches

Diné traditional knowledge and values were promoted in public health activities such as Hózhó (Kahn-John, 2015), which teaches about the importance of maintaining balance and harmony throughout life by showing respect, having self-discipline and practicing mindfulness in all daily SREP and ISEP activities. Opening and closing prayers were also offered through Zoom[™] for ISEP and SREP by a Diné hataalii (Navajo healer) to foster positive thinking and protect students and staff from unbalance and negativity that may arise from research (e.g., death and other sensitive topics). ISEP and SREP guest speakers were

invited from various public health and health profession backgrounds. One of the guest speakers for SREP and ISEP presented on the biology of the COVID-19 disease and outcomes. A protection prayer in Navajo and English was given before and after the presentation to ensure the students were not negatively impacted by the information in the presentation.

The DEP was introduced and incorporated into the presentations and activities for ISEP and SREP to teach resilience, public health, research processes, and career pathways to health professions. The incorporation of Diné traditional values helped students understand the curriculum and how to apply their cultural knowledge in public health settings. The SREP talking circles also focused on culturally based topics so students and faculty could discuss their challenges and strengths in addressing academic, professional, or personal issues. The contact tracing created some cultural and emotional issues so the faculty contact tracing coordinator offered time each Monday for students to debrief and also led a talking circle to help address cultural concerns.

TABLE 4 | Indigenous Summer Enhancement Program and Summer Research Enhancement Program instructional team members.

Institution	Teaching experience	Degree(s)	Race	Hometown/work location	Years with the program
DC	Faculty	BA, MA, PhD	White	Farmington, AZ/ Shiprock, AZ	21 with SREP
DC	Faculty	BS, MPH, DrPH	AI: Diné	Mariano Lake, NM/ Shiprock, AZ	7 with SREP 2 with ISEP
DC	Faculty	BA, MS, PhD	White	Manchester, KY/ Waterflow, NM	1 with SREP
DC	Teaching assistant	BA	AI: Diné	Shiprock, NM	3 with SREP 1 with ISEP
University of Colorado	Teaching assistant	BS, MS	AI: Diné	Salina Springs, AZ/ Aurora, CO	3 with SREP
NAU	Adjunct faculty	BA, MAT, MPH, DrPH	White	Tucson, AZ	7 with SREP 3 with ISEP
NAU	Teaching assistant	BA, MPH student	AI: Hopi and Diné	Flagstaff, AZ	1 with SREP 1 with ISEP
NAU	Adjunct faculty	BS, MPH	AI: Diné	Tuba City, AZ	5 with SREP 3 with ISEP
NAU	Teaching assistant	BS, MPH	NA: San Carlos Apache	Flagstaff, AZ	2 with SREP
NAU	Teaching assistant	BS, MPH student	AI: Santo Domingo Pueblo (Kewa) and Diné	Kewa, NM	2 with SREP
NAU	Teaching assistant	BS, MPH	AI: Diné	Pinon, AZ/ Flagstaff, AZ	3 with SREP 2 with ISEP
NAU	Teaching assistant	BS, MPH	White	Flagstaff, AZ	2 with SREP
NAU	Faculty	PhD	White	Williams, AZ/Flagstaff, AZ	15 with SREP

Challenges for Indigenous Summer Enhancement Program and Summer Research Enhancement Program

The team identified the following challenges: technological difficulties, social disconnectedness, inconsistent student engagement, and facilitation of a practicum experience. To address the need for internet access over the large rural expanse of the Navajo Nation, NARCH secured and provided laptops, iPads, and internet hotspots to select faculty and students. More importantly, to create a positive experience firmly grounded in resilience strategies and to counter potential psychological distress, the team incorporated creative techniques to keep students engaged and connected.

Technology Issues and Social Disconnectedness

The primary challenges identified by students related to technological difficulties. The majority of SREP and ISEP students lived within the NN, which has limited internet providers and unstable connectivity in many communities. During the programs, a surge of home-based internet users and challenging weather conditions (i.e., monsoons and high winds) resulted in power outages and further affected the internet connections on NN. Students experiencing compromised internet connection were not consistently able to access online resources. Other technological difficulties included software and laptop malfunctions. A student expressed her frustration with technological difficulties, “[the] software was slow and having bad internet just made it worse.”

One SREP student stated, “I had internet problems during the program, but I was able to overcome it and look for other alternative ways to stay connected.” Students reported overcoming technology

barriers by limiting the number of people in their home using the internet during SREP hours, using their phones as internet hotspots, upgrading their internet plans, utilizing the hotspot parking lots or calling into Zoom™ meetings. Calling in with a phone helped students connect but they could not see any lecture material nor fully participate in breakout rooms.

In addition to the aforementioned technological difficulties, students expressed their frustration with being socially disconnected from their peers, mentors, instructors, and community members. Students were asked to share what they liked least about the programs and a SREP student expressed disappointment in being socially disconnected from the community, “...not being able to work with community programs here in town”. One ISEP student commented, “I know that this is out of your hands, but I did not like how we had to do this program virtually.”

The technology issues may have exacerbated the social isolation, as students were not able to connect with peers and staff on a more personal level. An ISEP student remarked, “I did not like that it was virtual. I would have loved to physically be in Tsale at the campus with my peers and teachers. Overall, going virtual was the best option due to our current situation.” One SREP student shared, “Part of me wishes we were able to have an in-person SREP because of the strong bonds we were able to create as a peer group. I can’t imagine what it must be like in person.”

Student Engagement

Students felt that the SREP and ISEP instructional teams were effective in making the program engaging despite being held virtually. A student expressed her appreciation of the strategies and activities the staff employed to connect with the students, “The ice breakers were fun, the talking circle was another great component of the program because it allowed us to get to know one another.”

TABLE 5 | Evaluation results for 2020 Summer Research Enhancement Program practicum experience.

Evaluation statement	2019 Response (N = 13)	2020 Response (N = 8)
This practicum provided me basic hands-on experience in research and/evaluation methods in the field	77% strongly agree (10/13) 23% agree (3/8)	88% strongly agree (7/8) 12% agree (1/8)
During this practicum, I was able to learn about important recent findings regarding community-based public health or chronic disease research, with an emphasis on research pertinent to native American populations of the United States	77% strongly agree (10/13) 23% agree (3/13)	62% strongly agree (5/8) 38% agree (3/8)
The practicum provided me the opportunity to network with other professionals in the organization and/or in other organizations	85% strongly agree (11/13) 15% agree (2/13)	88% strongly agree (7/8) 12% agree (1/8)
This practicum provided sufficient opportunity for students to receive feedback on training and research needs	85% strongly agree (11/13) 15% agree (2/13)	88% strongly agree (7/8) 12% agree (1/8)
The SREP practicum met my expectations	77% strongly agree (10/13) 15% agree (2/13) 8% neutral (1/13)	100% strongly agree (8/8)

Another student stated, “[there was] strong team building among the mentors and students.” Another student felt the activities and social bonding was supportive in the SREP program, “I love the support from the students and instructors.”

ISEP students expressed appreciation for meeting other like-minded high school students in an online format during the summer, while they had limited in-person interactions with their peers. One ISEP student commented on the best part of the program, “I loved the staff and how open everyone was. I like this because the program can be perfectly planned, but it is the people who make it enjoyable. Furthermore, I liked how everyone learned how to work together and the icebreakers.”

Summer Research Enhancement Program Practicum Experience

Despite the changes to the SREP practicum this year, students felt that the practicum experience was valuable. Although the practicum experience was significantly different this year, there was little change in the practicum evaluation responses (Table 5). However, meeting the students’ practicum expectations improved. The entire 2020 SREP cohort strongly agreed that “The SREP practicum met my expectations” in comparison to the 2019 SREP cohort (only 77% respondents strongly agreed to the aforementioned statement).

When students were asked to share their perspectives on the practicum, students felt that the practicum was an important component to battling COVID-19, meaningful to patients’ lives, and emotionally challenging for the program staff and patients. One student expressed, “[I learned to] give empathy to COVID-19 positive patients...to advocate for my patients...I learned critical thinking skills and being able to have more confidence in myself.” Another student said, “Contact tracing was an experience I’ll never forget and taught me how to deal with emotional situations.”

Resilience in Indigenous Summer Enhancement Program and Summer Research Enhancement Program Indigenous Summer Enhancement Program Resilience Strategies

In the virtual environment, the ISEP program created direct connections between high school students and Indigenous public health leaders, who presented and discussed public

health’s role in the COVID-19 pandemic. A member of the Lumbee tribe from North Carolina and faculty member in the Department of Integrative Biology at the University of Colorado Denver presented on the biology of the COVID-19 virus. A Diné leader in the field of genetics presented on conducting ethical and culturally competent genetics research in AI communities. She also discussed her leadership role in her education and research on rural AI veteran suicide prevention. Two other Diné presenters discussed their work in trauma-informed dental care and shared their leadership qualities, including finding purpose in different spaces, speaking up, and being fearless.

Digital storytelling skills served as a collaborative learning tool for students’ final presentations. Students learned about the ethics around digital storytelling, informed consent from people in media, copyright issues in regards to music and images from secondary sources, and citing research sources appropriately. Then staff placed students in small groups, based on interest in a public health discipline, to develop a three to 5 min script that became the narrative soundtrack for the digital stories. Staff provided students with guiding questions to assist in their research of the public health discipline. Students learned and developed digital storytelling technology skills as they recorded the scripts, embedded images, and inserted interviews with Indigenous public health role models to collaborate in real time with their peers to make progress on the final projects. One ISEP student commented, “I loved meeting new role models and hearing their stories. I would love to meet more in the future.”

ISEP students shared the following comments on resilience in their evaluations:

“We are resilient in our own ways . . .”

“The main thing I learned in ISEP is to always be resilient. I learned this year that I have the capabilities to be a good mentor. This program made me love the public health field even more and I am very grateful to be able to have people and a field that continues to keep me interested and excited to learn.”

“I liked that everyone involved played an amazing role in this program. I got to know a lot of people and make good connections. I believe these connections will last a

TABLE 6 | Evaluation results for 2019 and 2020 Indigenous Summer Enhancement Program resilience categories.

	2019 (N = 14)	2020 (N = 11)
Resilience evaluation		
I Can overcome many challenges, I am resilient	100% strongly Agree/Agree	100% strongly Agree/Agree
I Know of leaders in the Navajo nation who have helped improve the health of the Navajo people	100% strongly Agree/Agree	100% strongly Agree/Agree
This program provided me basic hands-on experience in health-related research	100% strongly Agree/Agree	80% strongly Agree/Agree
During the program, I was able to learn about ways I can advocate for the health of my community	100% strongly Agree/Agree	100% strongly Agree/Agree
During the program, I was able to learn about and consider various careers in the health field	100% strongly Agree/Agree	100% strongly Agree/Agree
This week-long experience of the summer enhancement program (SEP) met my expectations	100% strongly Agree/Agree	100% strongly Agree/Agree
Multicultural evaluation		
I feel knowledgeable about my own culture	89% strongly Agree/Agree	90% strongly Agree/Agree
I strongly identify with my cultural heritage	89% strongly Agree/Agree	100% strongly Agree/Agree
I feel knowledgeable about modern medicine and public health	89% strongly Agree/Agree	100% strongly Agree/Agree
Public health and traditional medicine and the incorporation of the two is important to me	100% strongly Agree/Agree	100% strongly Agree/Agree

lifetime and help me better my life and education in the future.”

Table 6 displays the evaluation results for resilience among high school students who participated in ISEP.

Summer Research Enhancement Program Resilience Strategies

Resilience was demonstrated by the SREP students in their ability to complete the program and effectively learn despite the challenges in completing an online program. Evaluation results from the 2020 cohort compared to the 2019 cohort indicate no difference in knowledge gained, ratings of facilitators and course content, or overall satisfaction in the program. Overall, the majority of students agreed or strongly agreed that the program in 2020 fulfilled these key areas. In addition, a higher proportion of students in 2020 were not intimidated by statistics by the end of the program than students in 2019. In the final evaluation, all eight SREP students agreed that they were resilient and could overcome many challenges.

Both SREP and ISEP students were asked to reflect on the most important thing they learned during the program. Students responded:

“The most important thing I learned so far is that everyone is resilient.”

“Anything is possible with motivation, education, and the best people to give you advice and support . . .”

“SREP was able to motivate me to continue pursuing my education. SREP also reignited the passion I have for public health.”

“I have learned to be resilient. Being in a 10-week program [held] virtual[ly] with loads of work to finish is challenging but it is do-able . . .”

DISCUSSION

ISEP and SREP adapted to deliver culturally relevant learning environments for students to explore public health research and

future careers, and establish mentor/mentee relationships with staff. The adaptations for ISEP align with changes made in a few other programs offered during the COVID-19 pandemic in terms of shortening the daily time frame and offering more selective content. Of nine regional programs identified for high school students, only four transitioned to an online format during the COVID-19 pandemic. The University of New Mexico’s Health Careers Opportunity Health Career Academy, typically a 10-weeks, all-day program shortened to 3 h a day for four weeks and provided laptops to students on an as-needed basis (A. Greene, personal communication, May 11, 2020). Dream Keepers, based at New Mexico State University for 10th, 11th and 12th grade students, migrated to a six-week virtual program. The online schedule took place 1 h each weekday, and consisted of two education sessions, personal development, a small group session, and a social hour (Acosta, 2020). The Native Education Forum, a six-day summer program, and Mathematics and Science for Minorities, a three-summer program, also moved to virtual sessions; however, no details were provided for both programs (Andover, 2020; Colorado States University, 2020).

The SREP framework utilizes strategies that are embedded in other pre-COVID-19 research training programs, including internship placements, mentoring, enhancing professional networks, and emphasizing cultural strengths (Salerno et al., 2017; Lee et al., 2018; Taylor et al., 2019). The majority of SREP students indicated in the 2019 post-evaluation they had a positive site practicum experience and gained a tremendous amount of skills and knowledge. In addition, they noted the important role their site mentors played in helping them transition and feel connected. Students also received mentoring from the SREP instructional team. Mentoring not only builds research relationships but also provides for mental and emotional needs, academic support, and career guidance (Salerno et al., 2017; Lee et al., 2018). In addition to promoting mentoring relationships, SREP also builds students’ research networks through sharing final projects with the college community, and offering select students a chance to attend or present at conferences. These research networks help support career development, future research opportunities, and encouragement to continue within the field (Salerno et al.,

2017; Lee et al., 2018; Taylor et al., 2019). Students' cultural strengths are utilized and fostered throughout SREP, particularly by using the DEP framework to guide research and helping students explore topics of resilience and indigenous public health. They often reflected on their identity as indigenous scholars when creating digital stories about individual or community resilience. Helping AI students understand that they can successfully use and create multifaceted identities supports their ability to face new challenges that come from taking on new roles as researchers and scientists (Lee et al., 2018).

The COVID-19 pandemic drastically changed how undergraduate education was delivered in the United States and across the globe (Sandhu and de Wolf, 2020). New and innovative ways of teachings have been applied, with a particular reliance on webinars, Zoom™, and the application of open book exams (Sandhu and de Wolf, 2020). SREP and ISEP students and instructional team members faced numerous challenges to create a summer online program, including grappling with technological difficulties, and supporting the psychological and emotional needs of students that greatly influenced their levels of connection and engagement. The greatest challenge was to adjust the curriculum from 2019 to fit the objectives of the programs while understanding the needs, strengths, and limitations of the students. One major change was the research focus for SREP students to conduct group research projects on COVID-19 through online surveys. A recommended educational strategy to support learning during this crisis is adjusting educational curriculum to fit students' interest and engage them in applying their knowledge to understanding COVID-19 (Daniel, 2020).

To address technological difficulties, ISEP and SREP instructional teams underwent training to navigate Zoom™, become confident to lead online lectures, and develop a plan to communicate collectively. Institutional programs are encouraged to make necessary adjustments for remote learning, including utilizing asynchronous learning, blogs, and video lessons (Daniel, 2020). Both programs used a modified version to allow a mixture of synchronous and asynchronous learning by using Zoom™ lectures, video recorded lectures, and allowing ample group time in breakout rooms. Zoom™ lectures were also recorded if students indicated they would be missing class (es) for a day or more so they could keep up with the coursework.

The psychological and emotional health of the students were considered when planning the curriculum and delivery methods. The instructional teams understood the mental, emotional, and spiritual strains that the pandemic would have on the programs and participants. A recommendation is for institutional programs to understand that not all home environments are supportive and conducive for study and should focus on providing strong reassurance to students (Daniel, 2020). One study in the US reported undergraduate students were facing increased levels of depression, stress, and anxiety due to COVID-19 (Son et al., 2020). Students reported feeling challenged with social isolation, academic performance, falling behind in research or class projects, and transitioning to online classes (Son et al., 2020). Further, since the NN was hit particularly hard, some SREP students experienced the impacts of COVID-19 on a personal

level, grieving the loss of family members from COVID-19; thus, it is critically important to be attentive and understanding to serving students during a crisis. The teams were unable to completely address social disconnection, student engagement, and emotional support, but many efforts were put into play to help alleviate these burdens.

Lessons Learned

The quick transition to an online platform created unexpected challenges for ISEP and SREP. Some key lessons learned from the summer programs indicate programmatic needs were met through important adaptations and adjustments, and through the cohesive support from the instructional teams. The need for flexibility was evident as the team members reviewed the course curriculum and developed the summer schedule for the programs. Team members stressed the need to manage online engagement to prevent computer strain and stress from prolonged time on computers. At the end of SREP, students and team members noted that more content could have been removed from the curriculum to enable more focused time on key topics and less time on topics that seemed to overload the daily schedule. To address this concern during ISEP, the instructional team employed a strategy to use real time adjustments and do daily check-ins with students to see what worked and did not work so necessary adjustments could be made for the next day's schedule. Lessons learned for future programmatic needs are to modify the schedules to ensure class time is aligned with key learning objectives and offers flexibility for online or in-person engagement based on students' feedback during daily check-ins.

The limitations of online engagement increased feelings of social disconnectedness, which the team attempted to offset through innovative methods of interactive activities. Overall, some team members expressed burnout from the online format, which suggests that future programs should include additional team members to divide up content and/or create content teams. Another suggestion is for team members to rotate duties more frequently, which may include getting additional training before the program to take on more roles and responsibilities. One of the challenges with SREP was the program structure where more team members were available the first four weeks, but due to budget constraints only a few stayed on from weeks 5-9, and all team members returned for the final week.

Another adjustment to the longer SREP program was providing more flexibility for students who needed time off or extra support. Some students needed days off to take care of personal and family emergencies more often than would occur in pre-COVID-19 program days. In addition, some of the SREP students were parents and did not always have childcare and faced challenges of being online the full day while watching over their child during the day. Overall, being understanding and patient with life circumstances that occurred due to COVID-19 was key to students' feeling supported. Lessons learned to support unexpected circumstances for students include creating program structure and guidelines that help students catch up with missed classes and working with students to develop a childcare plan with family members to support their efforts to attend classes during the designated times.

The instructional teams purposefully addressed the emotional, mental, and spiritual issues surrounding COVID-19 while delivering the programs and supporting students. At times, the team admittedly did not feel fully prepared to address the psychosocial needs of the students who needed additional mental health support. Lessons learned for future programs are to involve a team counselor throughout the programs and work with existing college support networks to connect students with mental health resources. Mentors checked in with students daily and the teams utilized cultural-based strategies such as prayer and mindfulness to help alleviate stress. One of the team members also shared resources for bereavement, and guest presenters who specialized in AI mental health were invited to present and share their strategies for promoting mental health during COVID-19. Overall, the primary support for providing flexibility and innovative solutions came from the cohesiveness of the teams and the existing collaborative teamwork dynamics. Lessons learned to support team member dynamics include encouraging positive mindsets, acknowledge students' needs, and work together to problem solve while maintaining open communication through different platforms.

Recommendations for Future Program Adaptations

The adaptation process offers implications for future program adaptation to an online environment. First, adaptation needs to be team oriented and approached as collective problem solving that anticipates students' psychological and physical needs from the onset, as illustrated by the staff and instructor training. Integrating cultural grounded curriculum is supported and recommended in future adaptations from in-person to online summer programs. ISEP and SREP programs are both grounded in the DEP and integrated cultural aspects, such as talking circles and protection prayers that bolstered students' resilience. An overall supportive environment is recommended to foster a safe learning space that preemptively plans for technology difficulties and social disconnectedness.

CONCLUSION

ISEP and SREP succeeded in negotiating the transition to a virtual environment during the COVID-19 pandemic through the use of key resilience strategies that relied on relationships, holistic approaches, and collaboration. First, the online adaptations of the programs emphasized the importance of relationships in Diné culture to build connection between students and between

students and the instructional teams, thus overcoming physical distancing by reinforcing social connections. Secondly, the adapted programs used a holistic approach by employing activities that recognized students' needs to be playful, exercise, pray, and learn. Lastly, the programs applied collaborative team strategies by holding frequent meetings and using consensus decision making. Overall, the online versions of ISEP and SREP can be used as model pipeline support programs to increase the number of AI students who attend college and enter the public health workforce.

DATA AVAILABILITY STATEMENT

The datasets presented in this article are not readily available because the data belongs to the Navajo Nation, according to the Navajo Research Act and longstanding IRB policy, so any data sharing would have to be specifically approved by them, not by the authors. The datasets are small and include details that could potentially reveal the identity of individual subjects. Requests to access the datasets should be directed to Nicolette Teufel-Shone at Nicky.Teufel@nau.edu.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by Navajo Nation Human Research Review Board. Participants who were 18 years old or older provided their own consent. Anyone under 18 years old provided written informed consent and consent was also provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

All authors contributed to writing, editing, and approving the article for publication.

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Our Collective Needs and Strengths: Urban AI/ANs and the COVID-19 Pandemic

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The COVID-19 pandemic has raised national consciousness about health inequities that disproportionately impact American Indian/Alaska Native (AI/AN) communities, yet urban AI/AN communities continue to remain a blind spot for health leaders and policymakers. While all United States cities have been the traditional homelands of AI/AN peoples since time immemorial, urban AI/ANs are consistently excluded in local and national health assessments, including recent reports pertaining to COVID-19. Today the majority of AI/ANs (71%) live in urban areas, and many cities have strong Urban Indian Health Programs (UIHPs) that provide space for medical care, community gatherings, cultural activities, and traditional healing. Many of these UIHPs are currently scrambling to meet the needs of their AI/AN service communities during the pandemic. While the COVID-19 pandemic brought new sources of funding to UIHPs, the lack of local AI/AN data and arbitrary funding restrictions precluded some UIHPs from addressing their communities' most immediate challenges such as food and economic insecurities. Despite these challenges, urban AI/AN communities carry the historical resilience of their ancestors as they weave strong community networks, establish contemporary traditions, and innovate to meet community needs. This article focuses on the experiences of one UIHP in Baltimore City during the COVID-19 pandemic to illustrate present-day challenges and strengths, as well as illuminate the urgency for tailored, local data-driven public health approaches to urban AI/AN health.

Keywords: American Indian/Alaska Native, Indigenous, COVID-19, urban Indian, urban Indian health organization, coronavirus

INTRODUCTION

All United States cities are located on ancestral and contemporary Indigenous homelands and bear complex histories regarding American Indian/Alaska Native (AI/AN) peoples and settler colonialism (Furlan, 2017). While some cities have made strides toward acknowledging harmful colonial histories, few adequately recognize the enduring presence and needs of urban AI/ANs in their cities (Furlan, 2017). Although many AI/ANs have lived in urban areas since long before the 1950s, the relocation period of the 1950s marked an important population shift, as well as a shift in perceptions of American Indian identities (Furlan, 2017). As a result of federal relocation programs enacted in the 1950s and inadequate economic and educational opportunities in their home communities, many AI/AN families have lived in urban areas for generations (Venables, 2004; Rhoades et al., 2005). In the World War II

era, approximately 40,000 AI/ANs moved to urban areas to find jobs in the then booming war industries (Weaver, 2012). In 1956, the United States federal government passed the Indian Relocation Act to encourage AI/ANs to move to urban areas with the goal of assimilating them into the general population and reducing the federal government's trust responsibilities to Native peoples (Madigan, 1956). These trust responsibilities included honoring treaty rights to healthcare and education in perpetuity in exchange for land (Madigan, 1956). The former Commissioner of Indian Affairs claimed that the goal of relocation was harmonious with the federal Indian termination policies aimed to assimilate AI/ANs into the United States (Fixico, 2000). While this policy was effective in moving AI/ANs to urban areas, promises for housing, and employment made by the Bureau of Indian Affairs were never fulfilled (Furlan, 2017). In the words of one Bureau of Indian Affairs official, they were purposely given a "one-way ticket" from reservation to urban poverty (Furlan 2017; Nesterak 2019).

The urban relocation policies of the 1950s had harmful effects that ultimately resulted in risks to AI/AN health and well-being stemming from social determinants exacerbated by relocation (Burt, 1986).

Poverty

When gainful employment was not realized, many AI/ANs who relocated fell into poverty and some, into homelessness (Fixico, 2000). Today, poverty is a major concern for urban AI/ANs, with approximately half of all non-elderly AI/ANs living with incomes at or below the federal poverty level (Urban Indian Health Commission, 2007).

Food Insecurity

Although residing in an urban area is associated with greater food security for other races, national data show that urban AI/ANs are 1.5 times more likely to be food insecure than rural AI/ANs

(Morton and Blanchard, 2007; Bustillos et al., 2009; Jernigan et al., 2017). As shown in **Table 1**, Urban Indian Health Programs (UIHPs), and their clients are ineligible for many federally supported food and health related programs offered to primarily reservation based federally recognized tribes and tribal organizations. Some programs are available for Tribal citizens to apply for, but require a local organization to house the program, which is not always possible. The United States Department of Agriculture, 2016 resource guide for AI/ANs makes no mention of urban AI/AN-specific nutrition, agriculture, or housing supports (United States Department of Agriculture, 2016).

Access to Healthcare

Over the last century, federal legislation has guaranteed healthcare for citizens of federally recognized AI/AN tribes (Snyder Act, 1921; Urban Indian Health Commission, 2007). Yet, these rights are not fully realized by AI/ANs who move to urban areas, as most Indian Health Service full ambulatory clinics and hospitals are located on reservation lands (Urban Indian Health Commission, 2007). To meet the needs of urban AI/ANs, the Indian Health Service (IHS) provides contracts and grants to 41 Urban Indian Health programs (UIHPs) (Indian Health Service, 2018). Despite the efforts of these programs, the Urban Indian Health Institute (UIHI) had documented that lack of adequate health services are a serious problem for most urban AI/AN families (Urban Indian Health Institute, 2004). On average, UIHPs receive approximately half of their funding from IHS while the remainder of their funding is composed of federal health grants, state contracts, and foundation grants (National Council of Urban Indian Health, n.d.-a). Urban AI/ANs experience the same health issues as AI/ANs nationwide, but these problems are exacerbated due to reduced access to Native-specific resources for health, social support, and cultural

TABLE 1 | Examples of social support programs highlighted in the United States Department of Agriculture, 2016 Resource Guide for American Indians and Alaska Natives (2016).

	Health programs and supports	Agency	Eligibility	UIHP eligibility
<i>Agriculture Programs</i>	Local food promotion program	Agricultural marketing service	Tribes; tribal organizations	UIHPs ineligible
	Microloans (for direct farm ownership and direct operating loans)	Farm service agency	Tribal citizens; tribal organizations	UIHPs clients may be eligible to apply UIHPs ineligible UIHPs ineligible
	Farmers market promotion program	Agricultural marketing service	Tribes; tribal organizations	UIHP clients ineligible UIHPs ineligible UIHP clients may be eligible for state specific CSFP UIHPs ineligible UIHPs ineligible
<i>Food Access Programs</i>	The food distribution program on Indian reservations	Food and nutrition service	Income-eligible tribal citizens that reside on a reservation, on designated areas near reservations, or in Oklahoma	UIHP clients ineligible UIHPs ineligible
	Commodity supplemental food program (CSFP)	Food and nutrition service	Tribal elders at least 60 years of age (mostly offered on reservations) and residing in one of the states or on one of the Indian reservations that participate in CSFP	UIHP clients may be eligible for state specific CSFP UIHPs ineligible UIHPs ineligible
	Senior farmers' market nutrition program (SFMNP)	Food and nutrition service	Tribes	UIHP clients ineligible UIHPs ineligible
<i>Housing</i>	Housing preservation and revitalization demonstration loans and grant	Rural development	Rural areas only Tribes; tribal organizations	UIHPs ineligible
	Single family housing rent assistance	Rural development	Rural areas only Tribal citizens	UIHP clients ineligible UIHPs ineligible

activities (Urban Indian Health Commission, 2007; Norris et al., 2012; Indian Health Service, 2018).

COVID-19

Given the intersection of poor access to adequate healthcare, food insecurity, and poverty, urban AI/ANs were severely disadvantaged when COVID-19 hit. The Centers for Disease Control and Prevention (CDC) has reported that certain underlying medical conditions, including obesity, type 2 diabetes, and heart disease, put individuals at higher risk for severe illness from COVID-19 (Center for Disease Control and Prevention, 2020a). Nationally AI/ANs are disproportionately affected by these conditions (Cobb et al., 2014; Hutchinson and Shin, 2014; Indian Health Service, 2019). CDC data show that AI/ANs are 3.5 times more likely to contract COVID-19 and to be hospitalized than non-Hispanic Whites in the United States (Center for Disease Control and Prevention, 2020b; Center for Disease Control and Prevention, 2020c; Center for Disease Control and Prevention, 2020d; Hatcher et al., 2020). Additionally, the age adjusted mortality rate for COVID-19 was 1.8 times higher in AI/ANs than in non-Hispanic Whites (Arrazola et al., 2020). As with all races, COVID-19 mortality rates appear to be increasing with age for AI/AN peoples, but the largest mortality disparity between AI/ANs and non-Hispanic whites is in the age group of 20–49 years (Arrazola et al., 2020). COVID-19 mortality rates by both sexes for AI/ANs are 1.8 times that of non-Hispanic Whites of the respective sex (Arrazola et al., 2020). Additional considerations for AI/ANs that may increase risk for COVID-19 include; historical medical mistreatment that may make AI/AN individuals reluctant to seek care, high levels of perceived discrimination in healthcare, and that nationally nearly one-third of AI/ANs under 65 years of age do not have health insurance (Burgess et al., 2008; Findling et al., 2019; Center for Disease Control and Prevention, 2020e). When combined with high levels of poverty, multigenerational and crowded housing, and inadequate funding of UIHPs, the risk of contracting COVID-19 intensified for urban AI/ANs (Moore et al., 2020).

Additional pandemic complications, such as mass lay-offs and food and sanitary supply shortages, exacerbated conditions. In the early stages of the pandemic, many people (especially people of color) lost their jobs and were left without the financial means to afford housing bills (Kantamneni, 2020; Watson et al., 2020). While many UIHPs received COVID-19 federal funding, restrictions on how the funding could be spent (i.e., restrictions on direct support for food, housing or utility assistance) precluded UIHPs from meeting community members' most immediate needs for food, rent and utility assistance. The disconnect between the policies that created these restrictions and the community members' survival needs signify the importance of critically examining whose interests these restrictions serve: the federal government's or AI/AN peoples?

PERSPECTIVES FROM AN EAST COAST URBAN NATIVE COMMUNITY

The remainder of this article focuses on one east coast urban Native community's experiences and innovations during the COVID-19

pandemic as a case example to inform improved public health response to urban AI/AN needs and human rights. Despite failed government policies and inadequate health and social services, Native peoples have found each other in cities and built strong communities—often with added identity beyond tribal citizenship which includes proudly adding “urban Indian” to one's tribal identity (Fixico, 2000). Since time immemorial, Baltimore City and the surrounding areas have been the ancestral lands of the Piscataway and Susquehannock peoples (Maryland State Archives, n.d.). Due to relocation policies and growing urbanization, Baltimore City and the six surrounding counties are now home to a strong community of over 25,000 urban AI/ANs, representing many tribal affiliations, with a notable presence from the Lumbee Tribe of North Carolina (Urban Indian Health Institute, 2018; Minner, 2019). Native American LifeLines (NAL) is a leading urban AI/AN health service center, established in 2000 as a 501c3 non-profit organization and Title V IHS contracted UIHP that serves Baltimore and surrounding counties (Native American LifeLines, n.d.-a). NAL employs seven staff representing six tribes and two allies who provide behavioral health and substance use counseling, medical case management and referrals, dental care, health promotion, and cultural programming to AI/AN community members (Native American Lifelines, n.d.-b).

Needs Assessment: Health and Social Concerns

In the first few months of the pandemic, NAL staff contacted over 700 AI/AN clients in two rounds of phone calls to provide health education regarding COVID-19, assess community members' needs during the pandemic, and determine what health information resources community members found to be acceptable. Several main themes emerged from this outreach including needs for nutritious foods, hygiene and cleaning supplies, financial assistance with rent and utilities, and need for reliable access to health information.

NAL staff created innovative plans to meet community members' needs for food, cultural activities, and health information. NAL applied for emergency COVID-19 funding from the CDC (distributed through the National Council of Urban Indian Health) with the goal of creating holistic wellness boxes to mail to homes or distribute through pick up locations in Baltimore City, as well as to provide rent and utility assistance to community members in need. These boxes were to include traditional, cultural, and prepackaged foods, as well as fresh produce, cultural craft kits, hand sanitizer, face masks and COVID-19 educational materials specific to AI/ANs. They also made plans to assist with financial shortfalls for rent and utilities. However, when funds were awarded, restrictions were announced that altered these plans. Funding could not be spent on food, any property that would outlive the funding cycle, or direct housing/rent assistance (Hawk Lessard, email, September 24, 2020).

The inability of NAL to provide foods as the first line of COVID-19 support is particularly concerning. Without access to the Food Distribution Program on Indian Reservations (FDPIR) or the Commodity Supplemental Food Program, urban AI/ANs

have limited emergency food relief options (United States Department of Agriculture, 2016). Many AI/AN Baltimoreans live in disadvantaged areas where primarily nutrient poor, calorically dense foods are accessible at local convenience stores. Many do not own vehicles or have funds to utilize private ride sharing options to travel to grocery stores outside of their neighborhoods. Thus, during the pandemic, Baltimore AI/ANs are faced with a lesser-of-two-evils dilemma: to access poor quality foods through corner or dollar stores in their immediate neighborhoods or risk contracting COVID-19 by using public transportation to travel to grocery stores.

Despite funding restrictions, NAL exercised creativity and determination to meet community needs. NAL partnered with another community organization to distribute fresh produce to community members most in need of food. They were able to use the CDC funding distributed through the National Council of Urban Indian Health to successfully produce wellness boxes that incorporated hand soaps, handmade cloth masks, hand sanitizer, health information, cultural activities, traditional recipes and nutrition education materials. Since NAL was unable to directly provide foods in their wellness boxes, they provided nutrition education handouts, can openers, and strainers along with education (e.g., rinse canned fruits and vegetables to reduce excess sodium and sugar). NAL is also offering community events and talking circles via video conference and is helping to improve broadband access for community members by dedicating office space for community members to access internet. NAL is also partnering with local churches to arrange future “drive-through” and walk-up distributions for school supplies, flu vaccinations, and other wellness materials.

FUNDING CHALLENGES

The Indian Health Service (IHS) was founded in the 1950s to provide healthcare for Native peoples, but it was not until 1976 that their budget included urban AI/AN health services (Rhoades et al., 2005). Today, a single line item totaling less than 1% of the IHS budget is available to UIHPs (Joseph et al., 2017). The smallest percentage of funding is directed to serve the largest number of Native peoples (those living in urban areas)—a funding injustice that perpetuates health inequities and violates treaty rights of tribal citizens.

The Indian Health Service designates UIHPs as full ambulatory, limited ambulatory, or outreach and referral services, classifications which relate to funding for programs and scope of community health work (Tuomi, 2017). NAL is classified as an outreach and referral service and as such they do not employ their own physicians, nurses, or provide direct healthcare to community members, except for direct behavioral health and dental services. Given limited staff and funding, there are several issues that reflect the lack of capacity that small UIHPs, like NAL hold. For example, NAL rents their office and as such does not have a commercial kitchen, commercial refrigerators or have adequate space for cultural activities, like sweat lodges or medicine gardens. Several organizations offered to donate food to NAL, but without a way to store or quickly distribute food, they were unable to accept these donations.

While urban AI/AN health is extremely underfunded, the pandemic brought a rush of new funding to UIHPs from a variety of sources—including the CARES act and the Families First Coronavirus Response Act. These new funding sources, while much needed, were overwhelming to small UIHPs that are now tasked with even greater administrative burdens (Hawk Lessard, personal conversation, September 3, 2020). The new rush of funding was crisis-oriented; it could be used for sanitary supplies, health education materials, and COVID-19 testing but could not be used to fund permanent staff positions, buy property (including delivery vehicles or commercial refrigeration), or serve community members’ priority needs (i.e., food, utility, and rent assistance).

While funding restrictions were a temporary set-back, NAL redirected their focus to how the funding could be used to improve community health. NAL plans to purchase at home diagnostic COVID-19 tests for community members and have been able to reimburse for purchased and referred care due to COVID-19 concerns (including COVID-19 tests administered outside of NAL). Although NAL was unable to use funds to create permanent staff positions, they temporarily contracted community health workers to create and distribute wellness boxes. For community members who lost employment and therefore health insurance, NAL was able to cover co-pays, medical care, and prescription costs. NAL continues to provide health education through social media, the community’s preferred medium for health education.

Invisibility of Urban AI/ANs Living in the Baltimore Area

Mainstream data collection practices by federal, state, and local health departments frequently misclassify or completely omit AI/AN data, resulting in significant undercounting of AI/ANs and their attendant needs (Urban Indian Health Institute, 2020). Racial misclassification contributes to the “invisibility” of urban Indians and hinders UIHPs’ ability to respond to and reduce health inequities, including those exacerbated by the COVID-19 pandemic. Further, fighting against racial misclassification adds to UIHPs’ already full workloads.

Since 2015, NAL has advocated for disaggregating Native data to uncover urgent issues for their community including HIV/AIDS infection and testing rates, and opioid related overdose and fatality data. Despite their persistent activism, the Baltimore AI/AN community’s concerns were not initially reflected in reporting mechanisms for COVID-19. For the first months of the pandemic, Baltimore City COVID-19 data was completely unavailable by race and was later classified as Black, White, Asian or Other (Miller, 2020; Richman, 2020). NAL staff contacted the Baltimore City Health Department to ask for disaggregation of AI/AN data lumped into the “Other” category and received no response.

Amid the pandemic, protests against police brutality, and calls for racial justice, a prominent Christopher Columbus statue was thrown into Baltimore’s Inner Harbor. The sudden media attention around this action drew the attention of the district’s City Councilman, who had a prior relationship with NAL. This

councilman met with a local Indigenous activist group (including NAL staff) to ask how he could support the local AI/AN community during the pandemic. The Indigenous activist group cited lack of health data as a critical issue for Baltimore AI/AN. As a result of this meeting, the Councilman wrote a letter to the Baltimore City Health Department requesting they update COVID-19 racial classification categories to include AI/AN. Since then, the City has started to “report” AI/AN data, although it is unclear if the Baltimore City Health Department is now reporting the data for AI/AN peoples from the beginning of the pandemic or if the current available AI/AN only represents testing and cases since updating the racial categories for COVID-19 data. This lack of clarity is concerning as NAL is unable to discern if there has been a spike in AI/AN testing and cases, or if delayed testing numbers are just now being reported. Nonetheless, in the earliest stages of the pandemic, NAL was left without the proper data to document the rates of COVID-19 testing and infection of their service population and was forced to rely on anecdotal evidence to justify needs to funders and policymakers. Accurate, real-time data are vital for UIHPs to respond to local needs with programs and interventions that match community priorities.

DISCUSSION AND RECOMMENDATIONS

NAL has faced challenges during the pandemic, but successfully navigated partnerships with other community organizations—including a Black-led food sovereignty movement within Baltimore City—to serve the AI/AN community. In this paper, we discussed three main issues spotlighted by COVID-19: restrictions around funding, meeting the immediate needs of the service community, and inadequate data due largely to racial misclassification.

The inadequate funding of UIHPs is a violation of the federal government’s trust responsibility to AI/AN peoples that perpetuates health inequities (Crevier, 2020). There is a need to examine the funding structures of UIHPs and how they impact the health and well-being of urban AI/ANs, especially during the current pandemic. The challenges urban AI/ANs face deserve specific and immediate attention from Indian Country’s leaders and policymakers.

While small UIHPs are advocating at the local level, there are also national advocacy organizations, such as the National Council of Urban Indian Health (National Council of Urban Indian Health, n.d.-b), who works to support and develop healthcare programs for urban AI/ANs. Further, the Urban Indian Health Institute (UIHI) is the only tribal epidemiology center that specifically represents urban AI/ANs; they work to build capacity and promote urban AI/AN health (Urban Indian Health Institute, n.d.). These organizations provide support to urban AI/AN communities and would benefit greatly from additional resources.

Regarding racial misclassification, federal, local, and state health departments should move beyond simple consultation with local UIHPs and instead form meaningful collaborations to provide data and resources to UIHPs. This will enhance UIHPs’ ability to serve their urban communities. It is also imperative that mainstream health departments and entities

recognize that their views of health equity are built on Western epistemologies (Echo-Hawk, 2019). Indigenous peoples remain particularly invisible in urban landscapes and the unique intergenerational effects of previous pandemics, forced relocation, historical trauma, and cultural genocide that they have experienced are largely ignored (Brave Heart and DeBruyn, 1998; Duran et al., 1998; Brave Heart et al., 2011). One of the most essential ways mainstream health entities can support UIHPs to achieve Indigenous health equity is by critically evaluating and revising their data collection practices in true partnership with local UIHPs. The UIHI offers concrete recommendations for revising data collection measures and analyzing data in a way that honors tribal data sovereignty (Urban Indian Health Institute, 2020). An important initial step includes creating and enforcing mandates for collection of race and ethnicity in health data that utilize local, state, and federal funds (Urban Indian Health Institute, 2020). Data collection and analyses should consider allowing for multi-racial identities, as AI/AN peoples are one of the largest growing multi-racial groups in the United States (Norris et al., 2012). This can be achieved by defining AI/AN populations as inclusively as possible during analyses by using AI/AN in combination with one or more races (Urban Indian Health Institute, 2020). Weighted sampling and oversampling of AI/AN populations should be utilized to ensure that “invisible” populations are still counted, and their data is available (Urban Indian Health Institute, 2020). When reporting data, it is recommended to avoid using “multi-racial” or “other” as categories, instead consider breaking into AI/AN alone, and AI/AN in combination with one or more races (Urban Indian Health Institute, 2020). Using categories like “other” or “multi-racial” rarely yield meaningful results, for example, Baltimore City COVID-19 data was originally reported as African American, White, Asian, and Other (Miller, 2020). This sort of categorization led to confusion about whether or not AI/AN data was being collected at all, if AI/AN data was lumped into the other category, or what happened to the data of those who identified as multi-racial. Lastly, reporting strengths-based and positive outcomes helps to highlight the many successful health initiatives and innovations of AI/AN communities (Urban Indian Health Institute, 2020). While these general recommendations serve as a starting point, they do not replace direct and meaningful collaboration with local UIHPs. Each urban AI/AN community holds unique health challenges and strengths, and data priorities vary greatly from community to community.

Urban AI/AN individuals, families, and communities find themselves in cities and regions where they came for desperately needed job opportunities or have lived for many generations, in some cases due to federal policies of relocation. Despite the challenges urban AI/ANs have faced, their narrative is one of survivance and resilience driven by their reclamation of space, and creation of communities and traditions that reflect the collective strengths of the many tribal nations represented in their cities. Though they may be near or far from their traditional homelands, they share the strengths of their relatives and ancestors while forging a new collective urban Native identity. We need to honor the strengths of urban AI/AN communities and care for their health and well-being through prioritizing funding,

appropriate data collection and analysis, and ensuring urban AI/AN needs are met during the COVID-19 pandemic and beyond.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

TM drafted the manuscript. All other authors (KL, JD, KA, AB, and VO) provided feedback to manuscript drafts. All authors have contributed to the manuscript with relevant perspectives

through critical revisions and additions. All authors read and approved the final manuscript and are accountable for all aspects of this manuscript.

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Cultural Sources of Strength and Resilience: A Case Study of Holistic Wellness Boxes for COVID-19 Response in Indigenous Communities

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The COVID-19 pandemic has had disproportionately severe impacts on Indigenous peoples in the United States compared to non-Indigenous populations. In addition to the threat of viral infection, COVID-19 poses increased risk for psychosocial stress that may widen already existing physical, mental, and behavioral health inequities experienced by Indigenous communities. In recognition of the impact of COVID-19 related psychosocial stressors on our tribal community partners, the Johns Hopkins Center for American Indian Health Great Lakes Hub began sending holistic wellness boxes to our community partners in 11 tribal communities in the Midwestern United States and Canada in summer of 2020. Designed specifically to draw on culturally relevant sources of strength and resilience, these boxes contained a variety of items to support mental, emotional, cultural, and physical wellbeing. Feedback from recipients suggest that these wellness boxes provided a unique form of COVID-19 relief. Additional Johns Hopkins Center for American Indian Health offices have begun to adapt wellness boxes for the cultural context of their regions. This case study describes the conceptualization, creation, and contents of these wellness boxes and orients this intervention within a reflection on foundations of community-based participatory research, holistic relief, and drawing on cultural strengths in responding to COVID-19.

Keywords: Indigenous peoples, community-based participatory research, relief work, pandemics, COVID-19, coronavirus, holistic health

INTRODUCTION

American Indian and Alaska Native peoples, hereafter referred to as Indigenous peoples, have long experienced poorer mental and physical health outcomes than non-Indigenous Americans, including high rates of suicide, type 2 diabetes, cardiovascular disease, liver disease, and a variety of infectious diseases (Indian Health Service, 2019). From the biological warfare of smallpox brought by colonizers to Indigenous peoples in the 1790s to the modern day COVID-19 pandemic, infectious diseases continue to be a significant and disproportionate cause of morbidity and mortality in Indigenous communities (Indian Health Service, 2019; Hatcher et al., 2020). Health inequities are rooted in social determinants of health such as colonization, systemic racism, higher

rates of poverty, and unequal access to education, and these health inequities contribute to higher incidence rates of COVID-19 among Indigenous people in the United States (King et al., 2009; Walls and Whitbeck, 2012; Bombay et al., 2014). Exclusion of Indigenous communities in public health surveillance and inaccuracies in existing data mean that the full impacts of COVID-19 in these communities are unknown (U.S. Commission on Civil Rights, 2018). Even with these limitations in mind, existing data reveal that Indigenous communities are experiencing the highest documented rates of COVID-19 disease and death in the United States (Indian Health Service, 2020).

COVID-19 in Indigenous communities also elevates psychosocial stressors and exacerbates health inequities. Psychosocial stress is an etiological contributor to behavioral, mental, and physical health problems (Pearlin and Bierman, 2013). Prior research demonstrates that marginalized groups experience more frequent and severe psychosocial stressors (Turner et al., 1995), and the concentration and accumulation of stress leads to poorer health outcomes and impedes treatment for existing health issues (Dedert et al., 2009; DiMaggio et al., 2009). Historical and contemporary inequities result in greater burdens of stress for Indigenous peoples (Tiedt and Brown, 2014). A recent survey of Indigenous peoples in Canada found that six in 10 participants reported worse mental health since pandemic restrictions began; worsening mental health related to COVID-19 was reported at disproportionate rates among Indigenous compared to non-Indigenous participants (Canada Statistics, 2020).

CONTEXT

The Johns Hopkins Center for American Indian Health (CAIH) partners with Indigenous communities across North America to promote health, health leadership, and self-sufficiency. Founded in 1991, the CAIH works collaboratively with tribal partners in the areas of infectious disease prevention and treatment, behavioral health promotion, and training of Indigenous health professionals. In August of 2019, the authorship team of the current manuscript joined the CAIH as the CAIH Great Lakes Hub (GLH). The GLH research team includes over 100 tribal members across 11 Indigenous communities in the upper Midwestern United States and Canada. Our team is engaged in numerous health-related studies and intervention projects, primarily on reservation/reserve lands. All GLH studies and projects are co-led by university-based investigators and Community Research Councils comprised of tribal community members. Many of our team members have worked in partnership for nearly 20 years. All of our projects are rooted in community-based participatory research (CBPR), an approach to research that recognizes communities as necessary and equal partners in the creation of knowledge and in its application (Israel et al., 1998). The approaches of CBPR have been compared to those of social movement paradigms due to a number of shared characteristics (Tremblay et al., 2017; Tremblay et al., 2018). Underpinning social movements is collective framing of, and

actions to remedy, the underlying causes of societal ills that lead to poor outcomes among particular populations (Masters and Osborn, 2010). Such shared framing and action can be developed and mobilized through CBPR (Tremblay et al., 2018; Masters and Osborn, 2010) and has enabled our team to work together on a variety of relief efforts during the COVID-19 pandemic. In this manuscript, we explore a case study of the conception, creation, and contents of holistic wellness boxes for psychosocial support during COVID-19 and place this intervention within the context of nearly two decades of CBPR practice.

As the COVID-19 pandemic progressed, our research team temporarily paused projects, regrouped, and adapted to web and phone-based modalities. Tribally-based team members persisted in their work even as communities closed key operations and schools, caregiving roles were amplified, and financial, health, and race-related stressors peaked. Yet, the strains of social isolation and accumulating pressures were palpable among our team, particularly as the pandemic contributed to disconnection from seasonal cultural activities, ceremonies, and social gatherings—all known protective factors for health in Indigenous communities (Oré et al., 2016).

DESCRIPTION OF KEY ELEMENTS

In March of 2020, the CAIH moved quickly to dedicate resources to respond to the COVID-19 pandemic. Deep seated relationships, existing team structures, and momentum of our CBPR team enabled us to shift efforts rapidly to address the pandemic. One response effort by the GLH was the creation of holistic wellness boxes, which is the focus of the current manuscript. In April of 2020, both U.S. states within which our research team operates were granted disaster declarations by the federal government (The Office of the Governor, State of Wisconsin, 2020; The White House, 2020). In recognizing the potential value of literature related to disasters and emergencies to the local reality of COVID-19, we used existing guidance for disaster response, and feedback from community partners, to guide initial relief efforts (Sphere, 2018). Our team compiled example response approaches into a brief, online needs assessment that was distributed to existing community partners. The needs assessment asked community partners to identify the top three most pressing needs in their communities related to the COVID-19 pandemic and which potential relief approaches could best meet these needs. We considered several factors to decide which COVID-19 response activities were included in the needs assessment. These factors included: 1) relevance to the local reality of the COVID-19 pandemic; 2) support in existing literature on disaster response; 3) feasibility within the resources and capacity of the CAIH GLH and; 4) compatibility with strengths of existing community partnerships. Additionally, community partners were invited to participate in regular video calls to discuss community needs. These calls were held two times per month from April to June 2020. Feedback from community partners led us to focus initial COVID-19 response efforts on the distribution of food, household goods,

and personal protective equipment in partnership with tribal agencies and clinics.

As the pandemic persisted and our team continued regular video calls, community-based research team members voiced an increasing need for a more holistic COVID-19 response approach that would address not only physical health, but also cultural, spiritual, emotional, and mental health. Years of collaborative work on issues of Indigenous health equity allowed our team to draw on a shared understanding of culture as a source of strength and healing that can strengthen efforts to address modern day health inequities—including the disproportionate impact of COVID-19 on Indigenous peoples. Thus, to meet the need for culturally relevant psychosocial support, we designed and distributed holistic wellness boxes and aimed for box contents to be: 1) evidence-based; 2) responsive to the needs voiced by community partners; 3) culturally relevant and; 4) logistically feasible. We also gave attention to sourcing box supplies from local and Indigenous retailers as much as possible.

Holistic Wellness Box Contents

Gifts to Bring Calm, Relieve Stress, and Strengthen Cultural Connection

Supplementary Table 1 includes a full list of holistic box contents. Traditional cultural and spiritual practices have been shown to be protective for mental and physical health among Indigenous populations (Brockie et al., 2018). Thus, strengthening cultural connection during the time of COVID-19 is one approach to building mental and emotional resilience. To foster cultural connection, the boxes included sage to be used for smudging—a traditional practice of many Indigenous communities. The boxes also included cards with teachings shared by Ojibwe Elder and cultural advisor, Lee “Obizaan” Staples, (who gave permission for the teachings to be recorded and printed) on topics such as dealing with stress, taking care of oneself, and dealing with challenging emotions. Elders play an important role in many tribal communities as stewards of cultural knowledge and history and the cross-generational sharing of knowledge fosters resilience and promotes health (Cwik et al., 2019). The boxes also included ribbons featuring Ojibwe floral designs for use in making traditional crafts and resources for practicing mindfulness. Mindfulness practices have been shown to correlate with lower stress levels, “better self-regulation, less mind wandering and decreased suicidal thoughts” (Thao and Gobert, 2013, p. 12). As an aid for mindfulness and relaxation, the boxes also included lavender essential oil, which a number of studies have found to lessen anxiety symptoms and improve sleep quality (Conrad and Adams, 2012; Karadag et al., 2015).

Gifts to Nourish Body and Spirit

Wild rice is a culturally, spiritually, and historically significant food for Ojibwe communities. Several studies have confirmed that a diet based in traditional foods is protective against diet-related diseases among Indigenous populations (McLaughlin, 2010; Satterfield et al., 2016). Traditional foods are not only protective for physical health, however. During the 2018 Native Nutrition Conference, a participant shared the following insight.

Traditional Indigenous foods are highly nutritious. They're healing, spiritual and comforting. They are home to our people. When we provide traditional foods to our people, we are healing as well. (Terra Somma and Ladywithafan Designs, 2018, p. 3)

Informed by these understandings, our team included wild rice and recipes using traditional foods in the wellness boxes. Our goal was to promote nutritional health in a time when many are facing increased risk of food insecurity due to COVID-19 induced economic vulnerability, and to strengthen connection to culture as a means to support mental and emotional wellbeing.

Gifts to Support the Mental and Physical Health of Children

To support the social and emotional wellbeing of the youngest members of our partner communities, the boxes included educational and engaging story and activity books for children, many of whom were schooling from home for the first time and experiencing heightened stress due to the pandemic. Of particular note was the inclusion of the story book published by the CAIH, *Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19* (Allison-Burbank et al., 2020; Johns Hopkins Center for American Indian Health, 2020). This story book utilizes Indigenous storytelling while providing public health education and cultural strengths-based messages for children in the kindergarten to fifth grade age group. The story provides a hopeful and empowering narrative to promote the mental health and resilience of Indigenous children and families coping with the COVID-19 pandemic. This book was culturally adapted from the story *My Hero is You: How Kids Can Fight COVID-19!* developed by the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support (Inter-Agency Standing Committee, 2020; Johns Hopkins Center for American Indian Health, 2020). The adaption process was led by a team of Indigenous and non-Indigenous allied experts in child development, mental health, and health communication as well as public health professionals and an Indigenous youth artist who created the book illustrations (O'Keefe et al., 2020). This book is freely available online alongside downloadable coloring pages, children's activities, and parent resources.

The boxes also included *Minwanjige Mino-bimaadizi* activity books, published by the University of Minnesota Medical School, which integrate Ojibwe language and culture to educate children about healthy eating (Dietz-Castel, 2020; Kosobuski et al., 2020). Also included in the boxes were crayons for children to use to complete activities and coloring pages.

Resources to Prevent the Spread of COVID-19

To prevent transmission of the COVID-19 virus, the boxes included cloth face masks and hand soap and/or bottles of hand sanitizer. We included these items to encourage healthy behaviors such as hand washing and wearing face coverings, behaviors that are in line with current recommendations to slow the spread of the COVID-19 coronavirus (National Center for Immunization and Respiratory Diseases, 2020).

Holistic Wellness Box Construction and Distribution

The holistic wellness boxes were prepared by CAIH GLH team members in our office in Duluth, MN. Our team distributed roughly 110 holistic wellness boxes by mail to community-based research team members and other community partners. Mailing of the boxes happened over the course of several weeks and each box was tracked to ensure it was delivered. Our team sent the boxes in batches by community, so that all recipients within a specific community would receive their boxes at roughly the same time. When each batch of boxes was mailed, the CAIH GLH Study Coordinator sent an email to box recipients letting them know to look for the arrival of a package. Additional CAIH offices in the southwestern United States are currently adapting the holistic wellness boxes for distribution in their region.

DISCUSSION

Response from wellness box recipients was incredibly positive. Several themes emerged in the responses to the wellness boxes by recipients. One such theme was that the boxes provided a much needed source of upliftment, with one recipient sharing that receiving the box, “lit up my world.” Another theme that emerged was appreciation for culturally specific items. Several recipients, in voicing thanks for receiving their box, specifically mentioned the culturally significant elements of the boxes. One participant shared that, in response to receiving a wellness box, they would heed our message to “focus on self-care.” In the following sections of this manuscript, we will reflect on three areas that may have contributed to the boxes receiving such positive response: 1) a foundation of CBPR; 2) a holistic approach to relief and; 3) fostering resilience and wellbeing by drawing on cultural strengths.

Building on a Foundation of Community-Based Participatory Research

Fundamental to our COVID-19 response approach and the creation of the wellness boxes was communication and engagement with community partners built on a foundation of many years of partnership and collaboration. As mentioned above, all of the work of our team operates within a framework of CBPR. CBPR involves equal partnership between communities and academic institutions in the generation and application of knowledge (Israel et al., 1998). Defining characteristics of work rooted in CBPR include an iterative approach, multi-directional co-learning, and a strengths-based process that recognizes the unique contributions of all parties (Israel et al., 1998). Both a necessity and biproduct of longstanding CBPR partnerships with tribal communities is a foundation of respect and trust (Elm and Handeland, 2020). During COVID-19 response efforts, our team was able to draw on this foundation, as well as on nearly two decades of CBPR which has yielded considerable development in the key components of social movements as outlined by Masters and Osborn (2010). **Building a base and**

alliances. Our research team includes over 100 individuals from 11 tribal nations, many of whom are members of tribal government or who represent tribal agencies or clinics. **Leadership.** Each partner community is represented in our CBPR efforts by a Community Research Council, the members of whom share leadership with university based researchers. **Ideas and vision.** As already discussed, many years of partnership in working toward Indigenous health equity has enabled our team to reach a unified understanding of historically rooted social determinants as the underlying cause of modern day health inequities and of the capacity of culture to promote health. **Infrastructure for advocacy.** Through networks and relationships forged over decades with individuals, organizations, and tribal governments, the research of our team has led to the implementation of a number of evidence-based, culturally relevant interventions in partnership with tribal communities. During COVID-19, established patterns of communication and collaboration with community partners allowed us to understand what needs were most urgent, quickly adapt to changing priorities, tailor the wellness boxes to address contextually specific stressors, and draw on community specific strengths.

Holistic Relief

The COVID-19 pandemic is disproportionately affecting the physical and psychosocial health of Indigenous communities (Canada Statistic, 2020; Indian Health Service, 2020). Disasters often have an inequitable impact on the mental health of historically marginalized populations as new disaster-induced stressors are layered on existing social, political, and economic disenfranchisement (Marsella and Christopher, 2004). Thus, it is paramount that COVID-19 response in Indigenous communities address health holistically with attention to physical, spiritual, emotional, cultural, and mental factors. The National Voluntary Organizations Active in Disaster recommends that, among many other components, spiritual care and promotion of self-care be integrated into early psychological interventions in disaster settings (Everly et al., 2008). Similarly, fostering appropriate cultural and spiritual healing practices is encouraged by the Inter-Agency Standing Committee Reference Group for Mental Health and Psychosocial Support in Emergency Settings to promote psychosocial wellbeing (Inter-Agency Standing Committee Reference Group for Mental and Psychosocial Support in Emergency Settings, 2010). Through integration of culturally relevant supplies to promote physical and psychosocial health, our team strove to support holistic wellbeing and draw on existing sources of resilience already embedded within Indigenous individuals and communities.

Fostering Resilience and Wellbeing Through Drawing on Cultural Strengths

A foundational element of CBPR is building on the strengths that already exist within communities (Israel et al., 1998). Similarly, fostering “natural recovery mechanisms” is recommended in early mental health interventions following disaster events (National Institute of Mental Health, 2002; Everly et al., 2008, p. 409). Cultural connection and practices have been shown to be

protective for physical and psychosocial health in Indigenous communities (Brockie et al., 2018). Indigenous peoples believe wholeheartedly and unquestionably in the healing power of culture (Hartmann and Gone, 2012; Gone, 2013; Moghaddam et al., 2015). This is further evidenced by the fact that health interventions that include cultural components have been shown to be more effective and generate greater community approval from Indigenous populations (Lowe, 2006; Walls et al., 2006; Hartmann and Gone, 2012; Goodkind et al., 2015). Involvement in traditional and spiritual activities (Kading et al., 2015; Bear et al., 2018) and connection to community (Greenfield and Marks, 2010) have been associated with positive mental health. Indigenous language use has been associated with lower youth suicide (Hallett et al., 2007) and lower rates of diabetes (Oster et al., 2014), and connection to land and nature has been linked to individual and community healing and resilience (Ritchie et al., 2014; Goodkind et al., 2015; Schultz et al., 2016). Culture is so vital to Indigenous health that accepted models of health and health care for this population rely on a foundation of culture (Lowe and Struthers, 2001; Hill, 2006; Ullrich, 2019).

Indigenous communities hold within themselves reservoirs of cultural knowledge, teachings, and practices that have the capacity to protect and promote holistic health. The boxes provided by the CAIH GLH are one example—rooted in cultural strengths and scientific evidence—of an intervention designed and driven by community feedback to holistically address wellbeing in the time of COVID-19.

LIMITATIONS

Due to the need to distribute boxes quickly, there was no empirical evaluation of the impact of the holistic boxes on health outcomes. Developing a pre/post evaluation would have considerably delayed distribution of the boxes. Thus, the impact of the wellness boxes on COVID-19 related physical and psychosocial health outcomes cannot be fully known. Future similar interventions could investigate the empirical impact of similar, culturally and scientifically grounded care packages on physical and psychosocial health. There are numerous innovative and Indigenous approaches to evaluation including storytelling, sharing circles, photovoice, and open-ended interviews, which may afford appropriate venues through which to explore the impact of these forms of gifting on holistic health (Kovach, 2009; Bennet et al., 2019). Despite our lack of evaluation, anecdotal feedback suggests that the holistic boxes facilitated relational connections and a sense of belonging, each of which are critical components of wellbeing (Hill, 2006; Ullrich, 2019).

CONCLUSION

For centuries, the Indigenous populations of North America have experienced disproportionate impacts from infectious diseases (Indian Health Service, 2019; Hatcher et al., 2020). The emergence of the COVID-19 pandemic has layered new psychosocial and physical health risks on existing health

inequities in Indigenous communities (Indian Health Service, 2019; Canada Statistics, 2020). In seeking to provide COVID-19 relief in Indigenous communities, the voices of those most affected should be considered the central authority on their own needs and systems for frequent, bi-directional communication based on mutual respect and trust should be established in order to ensure responsive action and honor the knowledge and needs of community members.

COVID-19 has taken a toll not only on physical health, but also on mental, spiritual, emotional, and cultural health. A holistic response approach that strengthens existing sources of strength, resilience, and healing may be a useful addition to interventions striving to address physical and psychosocial wellbeing during COVID-19. In Indigenous communities, drawing on cultural strengths, knowledge, and teachings can be a powerful tool for protecting and promoting health (Lowe, 2006; Walls et al., 2006; Hartmann and Gone, 2012; Goodkind et al., 2015). The holistic wellness boxes prepared and distributed by our team are an example of such an intervention that, based both in scientific evidence and cultural knowledge and grounded in years of CBPR, provided a unique form of relief during the COVID-19 pandemic.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/**Supplementary Material**. Further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

KA and MW conceptualized of, and coordinated, the writing of this manuscript as well as elaborated major portions of all manuscript sections. NW, KS, SG, TM, and MG contributed expertise and elaborated sections of the introduction and discussion sections. ET, AL, ER, and AB-S all contributed to the creation of the holistic wellness boxes and assisted with citation preparation and proofreading for the current manuscript.

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SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fsoc.2021.612637/full#supplementary-material>.

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Primary Disease Prevention for Southwest American Indian Families During the COVID-19 Pandemic: Camp in a Box

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The goal of the American Indian Youth Wellness Camp in a Box was to engage, educate and empower families to improve their health and overall well-being during the COVID-19 pandemic. Camp in a Box was a 9-week program, inclusive of a 1-week intensive camp component followed by an 8-week booster component with content focused on nutrition, mental health and physical activity education. The Camp in a Box is a Tribal/Urban Indian-University partnership, and materials were developed to replace an existing weeklong residential camp and to comply with social distancing guidelines. Fourteen American Indian families from Tribal/Urban Indian communities in the southwestern United States participated (36 children aged 2–18 years; 32 adults). The intensive camp week included daily materials for families to complete together, Monday through Friday. Materials were provided for approximately 4 h of activities per day. The booster sessions began after camp week and included approximately 4 h of supplementary activities designed to be completed at any time most convenient for the family over the course of the week. Activities were designed to encourage interaction among family members with materials and supplies for parents and youth to participate. Self-reported outcomes suggested that families changed their eating habits to include more vegetables, less sweets and junk food. Parents reported an increase in family physical activity and that the activities brought the family closer together. Our Camp in a Box program was feasible and well-received until school began. During camp week, 100% of recruited families participated; at Booster Week 8, ten families (71%) remained enrolled and active. Camp in a Box is a feasible alternative to residential camps for promotion of health behaviors associated with metabolic disease prevention among American Indian families. In contrast to residential

camps for youth, Camp in a Box offers an opportunity to engage the entire family in health promotion activities.

Keywords: obesity, diabetes, health promotion, healthy lifestyle, youth, parenting

CONTRIBUTIONS TO THE FIELD

The COVID-19 pandemic has underscored American Indian health disparities and the importance of primary prevention of comorbid conditions, many of which stem from obesity. Obesity is highly prevalent among American Indian children and adolescents. Youth with obesity are at higher risk for type 2 diabetes, hypertension and dyslipidemia, non-alcoholic fatty liver disease, and breast or colorectal cancers. Obesity during childhood and adolescence is a strong predictor of adult obesity and there is a critical need to intervene. The American Indian Youth Wellness Camp in a Box was to engage, educate and empower families to improve their health and overall well-being during the COVID-19 pandemic. Self-reported outcomes suggested that families changed their eating habits to include more vegetables, less sweets and junk food. Parents reported an increase in family physical activity and that the activities brought the family closer together. Our Camp in a Box program was feasible and well-received. Camp in a Box is a feasible alternative to residential camps for promotion of health behaviors associated with metabolic disease prevention among American Indian families. “This program demonstrates self-sufficiency in American Indian families as they are able to learn, understand, and implement activities without direct supervision of program staff. This method is an approach that has potential to be replicated or modified with similar community-based programs and perhaps clinical approaches like a diabetes prevention program.”

INTRODUCTION

The COVID-19 pandemic has underscored American Indian health disparities and the importance of primary prevention of comorbid conditions (Hatcher et al., 2020), many of which stem from obesity. Obesity is highly prevalent among American Indian children and adolescents (Story et al., 1999; Caballero et al., 2003; Gachupin et al., 2017), who suffer disproportionately from poverty, lack of basic infrastructure, historical trauma and poor access to resources. Youth with obesity are at higher risk for type 2 diabetes (Pinhas-Hamiel and Zeitler, 1996), hypertension and dyslipidemia (Freedman et al., 1999), non-alcoholic fatty liver disease (Cruz et al., 2005), and breast or colorectal cancers (Calle and Kaaks, 2004). Obesity during childhood and adolescence is a strong predictor of adult obesity (Spruijt-Metz, 2011) and there is a critical need to intervene. The American Indian (AI) Youth Wellness Camp program was developed to address this critical need, based on the concept that the health of American Indian youth is broader than the absence of disease and includes psycho-emotional stress management (Minich and Bland, 2013).

We previously developed a summer camp focused on promoting health and supporting American Indian youth and their families regarding healthy lifestyle changes, with an emphasis on physical activity, healthy eating, and mental health (Gachupin and Joe, 2017). The established residential camp program introduced and reinforced key health education topics for American Indian youth and communities. For example, the nutrition classes cover topics such as: introduction to traditional foods, how to read food labels, components of Choose MyPlate, and 8-5-2-1-0 messaging (8 h of sleep, 5 fruits and vegetables, 2 h of screen time, 1 h of physical activity, and 0 sugared beverages), with a particular focus on sugar-sweetened beverages. The physical activity sessions include traditional games, Zumba, yoga, circuit training, archery, basketball, kick ball, dodgeball, and hiking. With the COVID-19 pandemic, it was not appropriate to conduct the residential camp in its typical format; however, given the continued importance to continue to address obesity prevention among American Indian youth and their families, the remote, socially-distanced Camp in a Box was developed. Camp in a Box was conducted with the aid of camp materials sent through the U.S. Postal Service to participating families' homes. We did not change the educational messaging component of our camp program, we changed the implementation approach to ensure engagement was conducted in a safe environment.

We utilized results from our previous work to inform our Camp in a Box focus and education messaging. For example, 2019 American Indian campers (aged 10–15 years) reported: 1) 15.2% sometimes do not have enough to eat; 2) 39.4% reported drinking more than one sugar sweetened beverage per day; 3) 42.5% reported eating deep fried foods such as French fries or potato chips more than once per day; 4) 81.8% reported being physically active for less than 60 min per day during the past 7 days; 5) 51.2% reported playing video or computer games on an average school day for three or more hours per day; 6) 45.5% reported watching TV for three or more hours on an average school day; and, 7) 35.5% reported being bullied on school property during the last 12 months (Gachupin et al., 2019a). Based on 24-h dietary recall data, American Indian youth diets were high in calories, fat, and sodium, and low in fiber, calcium, and potassium (Gachupin et al., 2019b). Very few youth met the recommendations set forth in the Dietary Guidelines for Americans 2015–2020 (U.S. Department of Health and Human Services and U.S. Department of Agriculture, 2015) for daily vegetable intake, and no participants met recommended limits on calories from solid fats and added sugars, which accounted for approximately 40% of total energy intake (primarily sugar sweetened beverages and snack foods).

Herein we describe how “camp” was continued and expanded to include families and adapted to function without face-to-face interaction with counselors. Our program did not charge camp

fees or registration, adhered to the Centers for Disease Control and Prevention (CDC), Tribal/Urban Indian, State and City COVID-19 pandemic guidelines, and was offered distanced, as Camp in a Box.

MATERIALS AND METHODS

Overview

The American Indian Youth Wellness Camp in a Box was a nine-week program made up of a one-week intensive camp with daily activities and eight weeks of booster materials and activities, all focused on healthy eating, mental health, physical activity education, and parenting support. The intensive camp week included daily materials and occurred Monday through Friday. Materials were provided for approximately 4 h of activities per day. The booster sessions began after camp week and included supplementary materials to continue healthy lifestyle education focused on nutrition, physical activity, mental health and parenting support. The booster activities could be completed at any time most convenient for the family over the course of the week and included materials for approximately 4 h of activity over the week. Activities were developed to encourage interaction among family members, for example, there were enough supplies provided within the box so that parents and youth had their own materials for participation. The instructions were written in large, user friendly font, easy to follow wording, and with descriptive images, so that steps were easy to follow. The materials for youth were written at the level of an adolescent reading and comprehension level (7th grade) and materials for parents were written at the level of a non-professional adult. Each set of instructions included a table of contents, step by step instructions, illustrated educational materials, and easy to follow work sheets targeted to the various topics covered in every session: nutrition, physical activity, mental health, and parenting support. To encourage family time, Camp in a Box included arts and crafts activities.

The Camp in a Box is a Tribal/Urban Indian-University partnership, and materials were developed to replace an existing weeklong residential camp and to comply with social distancing guidelines. The approach described within this article was developed in consultation with Tribal/Urban Indian partners. During camp planning meetings, the schedule of focus areas and topics to be covered for camp week and all eight booster sessions were developed. The Camp in a Box education content was largely adapted from the Centers for Disease Control and Prevention, and curricula used in other positive youth development camp programs (Gachupin and Joe, 2017; Gachupin et al., 2019c). Activities were designed to be interactive with attention to reading level and range of ages of family members. The program content operationalized Social Cognitive Theory (Bandura, 2004) and the Information Motivation Behavioral Model (Fisher and Fisher, 2002) to address behavior change through the provision of relevant health information and, resources to promote skills and self-efficacy and thus advancement in motivation toward healthier behaviors and did so at the individual and family levels.

As individual specific activities were finalized, the supplies and materials needed were ordered. Although most likely related to the pandemic, many supply items had order limits placed on them. We often had to go through multiple vendors to fill the order for an item and depending on the demand of items, had to wait several weeks for delivery. All items were shipped to a Native woman owned shipping, receiving and fulfillment business where a 200 ft² warehouse space was rented. Program materials for camp and booster activities were shipped in boxes on a weekly basis via the United States Postal Service to the participating families and Tribal/Urban Indian partners (see **Figure 1**). Activities were completed within private family residences on the families' schedule. The camp, booster sessions, and all related communications were conducted in English. Camp in a Box occurred between July–September 2020.

Camp Enrollment

Camp fliers were distributed to partnering Tribal/Urban Indian Health Department, Diabetes Program and Community Health or Wellness Program personnel who shared information with families within their respective Tribal/Urban Indian community or client lists. Interested American Indian families, who had at least one child between the ages of 10–15 years of age, were invited to participate. One parent from each interested family was asked to contact health program personnel to obtain registration materials which included the informed consent form, media release for photos, and the camp registration form. The registration form included demographic and household survey questions regarding family access to the internet, food security, and perceived stress. Program staff members verified consent and confirmed current and complete mailing address and cell phone number.

Families were enrolled in two waves, 11 families in Wave 1, and three families in Wave 2 (see **Figure 1**). The curricula and corresponding box materials were sent according to the family enrollment wave. Wave 2 began one week after Wave 1. A second wave was necessary due to additional families registering after the Wave 1 boxes had been mailed. Waves 1 and 2 were merged into a single group by booster session four (week five of Camp in a Box). This was achieved by consolidating two booster weeks into a single booster week for the Wave 2 participants, i.e., boxes containing instructions and supplies for both boosters were sent in the same week.

Camp Staff Members

Camp in a Box program staff members included a camp director, two coordinators, two undergraduate students, and seven field-based team members (92% American Indian). Staff members participated in training led by the camp director prior to the beginning of camp and ongoing training as the camp curriculum unfolded. The trainings included chronic disease among American Indians; camp curriculum development; community-based participatory research; privacy and confidentiality; data collection, management and quality assurance; how to establish and maintain rapport; cultural sensitivity; COVID-19 impacts on Tribal/urban Indian communities; Tribal/Urban Indian partnership building; and

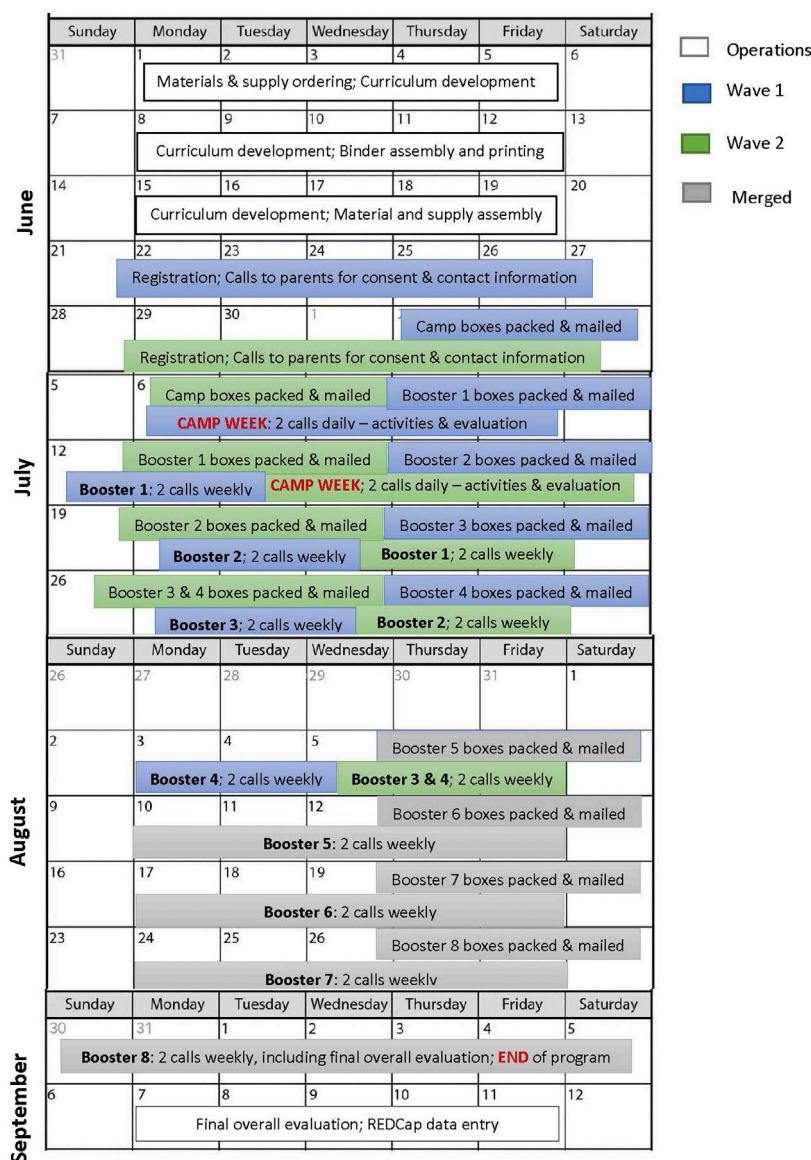


FIGURE 1 | Southwest American Indian camp in a box program overview.

university operational systems and policies. The coordinators and undergraduate students were responsible for designing camp activities, compiling camp education materials, obtaining consent, communicating with assigned families to confirm receipt of boxes and to complete oral evaluations. Evaluations were completed daily during the intensive camp week and once per week during the booster component. The coordinators and undergraduate students all worked remotely from their private residences for the entirety of Camp in a Box.

The field-based team members were responsible for reviewing camp and booster materials to prepare items and supplies needed for each box, which were personalized to families based on size of the family and sex and ages of the children. Camp in a Box items were mailed prior to the start of the camp day and booster week. The boxes included all the supplies needed for the various activities

and were clearly labeled for each activity. Each box also included a healthy snack for each member of the family and no less than 30 boxes were shipped on a weekly basis. Preparations included addressing and labeling and database list maintenance as several families moved during Camp in a Box. An essential component of the initial box materials was a binder with activity instructions and reference materials, including education materials, for each day of the week. Materials for the booster sessions were sent weekly and included new instructions and educational content to be added to the binder. The binder was prepped with colored card stock dividers for addition of materials for subsequent booster sessions. All final materials were printed, collated, 3-hole punched and sorted into respective binders and folders on a weekly basis over the entirety of camp. The number of pages per session ranged from 31–47 pages. All activity related supplies,

Nutrition <ul style="list-style-type: none"> • Be a good nutrition role model • Choose MyPlate • Energy In-Energy Out • Family meals • Food security • Go, Slow, Whoa foods • Grocery store map • Healthy food in the home • Healthy snacks • How to prepare, eat and enjoy vegetables • Menu preparation on a fixed budget • My Native Plate • Planting beans • Serving size vs. portion size • Understanding food labels 	Physical Activity <ul style="list-style-type: none"> • 60-second challenge • Bingo • Charades • Circuit training • Daily walk or run • Dance off • Family fitness • Football • Frisbee throw • Hopscotch • How to make sedentary time more active • Jump roping • Overcoming barriers to being active • Ping pong • Scavenger hunt • Simon says • Tag • Volleyball 	Mental Health <ul style="list-style-type: none"> • Breathing exercises • Creative expression • Family reflection • Imagery • Journal writing • Meditation • Mindful coloring pages • Mindful eating • Planting flowers • Positive thinking • Puzzle assembly • Reading • Setting and achieving goals • Support group
Parent Corner <ul style="list-style-type: none"> • Ways you can help your teen be physically active • Ways you can help your teen choose vegetables, legumes and whole grains • Ways you can help your teen manage bedtime and achieve good sleep • Ways you can help your teen manage their TV and screen time • Ways you can help your teen select and enjoy healthy drinks 	Personal Protection <ul style="list-style-type: none"> • Face masks • Family boxes • Hand washing • Home hygiene • Importance of drinking water • Importance of sleep • Personal hygiene • Play it safe in the sun • Social distancing 	Arts and Crafts <ul style="list-style-type: none"> • Birdhouse painting • Canvas painting • Chalk art • Checkers mate • Coloring book • Dream catcher • Painted desert • Rock and ornament painting • Sun bead bracelets • Scrapbooking • Scratch art • Tie dye beach towel

FIGURE 2 | Southwest American Indian camp in a box program content.

for example, arts and crafts, were combined in zip lock bags and clearly marked by activity so they were easy to locate for family members. A total of 470 Camp in a Box boxes were shipped or received from June–September 2020.

In addition, a non-Native medical student, under supervision of a board-certified child and adolescent psychiatrist trained in mind-body medicine, assisted with development of mental health education materials for Boosters 2 and 5–7. The material was adapted from The Center for Mind-Body Medicine's standardized curriculum (Gordon et al., 2020). The same psychiatrist led six, 90-min evening mind-body skills groups; techniques taught included meditation, guided imagery, and the use of expressive writing, movement and drawings. These groups have been shown to improve mental health in youth and adults (Gordon et al., 2008; Staples et al., 2011; Gordon et al., 2016; Jones et al., 2020).

Camp Curriculum (see Figure 2).

Nutrition

Nutrition education materials helped families to identify food groups using ChooseMyPlate (www.choosemyplate.gov) and My

Native Plate (Indian Health Service, 2020), and to determine the sodium, saturated fat and sugar content of their foods through label reading. Other nutrition activities helped families understand energy balance and energy density (e.g., portion size, nutrient density), and provided guidance on selection of healthy snacks and the importance of growing vegetables. Because the pandemic has affected food security, income, and regular access to food sources (many tribes faced travel restrictions), nutrition educational materials also focused on menu planning and food purchasing on a fixed budget. Families also received healthy snacks (i.e. dried fruit, popcorn, rice crisps) each day of camp week and every week during booster sessions.

Physical Activity

Physical activities included, for example, Frisbee throw games, circuit training, 60-s challenge, scavenger hunts, ping pong, charades, dance-off, hopscotch and a daily run or walk, either early or late in the day. Circuit training is comprised of individual exercise stations such as run in place, jumping jacks, lunges, frog

jumps, crunches, squats, push-ups and wall sits, and participants are instructed to complete each exercise for 30 s at high intensity, modeled after the Indian Health Service Physical Activity Kit (U.S. Department of Health and Human Services, Indian Health Service, 2021). The participant then rotates to the next station and completes that exercise for 30 s at high intensity. The entire circuit is repeated for three rotations and participants are instructed to go at their pace and to drink water. The 60-s challenge was requested by a parent and participants were challenged to track how much of a given exercise can be completed in 60-s. The exercises included push-ups, lunges, jumping jacks, squats, sit-ups, tricep dips and tuck jumps (abdominal exercises). The participants were provided with sheets for daily and weekly tracking.

The necessary equipment was provided (i.e., Frisbees, ping pong paddles/balls, jump ropes) and written materials included detailed instructions, images of movements, work sheets, tracking sheets and links for additional resources. The physical activity materials were designed to support families in achieving the recommended 60 min per day of physical activity (U.S. Department of Health and Human Services, 2018; <https://www.cdc.gov/physicalactivity/basics/index.htm>). Activities and related materials were also designed to promote activity as an individual or family, to be adapted by a range of age groups and to reduce the risk for activity-related injury. When possible, physical activity promotion materials included alternative intensities and versions of specified activities, to allow multiple options for families to try. For example, for tag, instructions for freeze tag, hide and go seek tag, sock tag, triangle tag, and blob tag were included.

Mental Health

The mental health education materials included teaching the family about creative expression by providing them with conversation prompts and guidance for family self-reflections. Prompts were general and designed to foster journaling and family discussion. Examples of questions included: *A genie gives you three wishes, what are they?; You were granted a superpower today, what is it?; and, What's a new trend you'd start tomorrow?* Additional mental health activities included breathing exercises, emotion expression, various forms of meditation, guided imagery, positive thinking, mindful eating, finding meaning and purpose, and reading. Some activities included the entire family, and some were specific for either just the youth (with parent guidance) or for the adults. The sessions covered self-expression through sharing in the group, as well as the use of drawings, music, movement, breathing techniques, guided imagery, body scan, and different forms of meditation. The mental health activities were created to be engaging and meaningful for American Indian youth and parents.

Parent Corner

Parenting education materials included strategies parents could use to help their children be successful in achieving health behavior goals of the program. Tips were based on food and physical activity parenting practices that promoted structure,

responsiveness and autonomy support (Vaughn et al., 2016; O'Connor et al., 2017a; Mâsse et al., 2017). This included parenting practices that focused on creating a healthy home environment in which the parents served as role models and encouraged their child using positive language and clear expectations. Additionally, parents were encouraged to use autonomy supportive parenting practices to engage with their child in brainstorming activities to try, helping with grocery shopping, and preparing healthy dishes for the family. Parenting contexts covered physical activity, nutrition, screen media use and sleep, and corresponded to the other camp material content delivered that week. Additional parent focused education materials included how to prepare meals on a budget, how to make family time, how to talk back to negative thoughts, making healthy food more available and accessible in the home with work sheets, tracking sheets and links offered as additional resources.

Personal Hygiene

The personal hygiene education materials included COVID-19 prevention information (<https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html>), such as the importance of handwashing, use of face masks, social distancing, and sheltering in place, and other healthy living information, including sun safety (for example, use of sun screen, wearing long sleeves, limiting time in direct sunlight), importance of sleep, and proper hydration. Over the course of the nine weeks, several “family boxes” were delivered to the family residence, which included supplies to help the family achieve personal hygiene behavioral goals including use of sun screen, insect repellent, shampoo, hand soap, body soap, materials to make face masks, sun beads to monitor direct sun exposure, foot powder, dish soap, gloves, hand sanitizer, paper towels and napkins. The family boxes were in addition to the Camp in a Box materials.

Arts and Crafts

Each box contained arts and crafts materials to promote creative time including rock painting, making dreamcatchers, scratch art, tie-dye of beach towels, canvas painting, birdhouse painting and creating checker boards using duct tape. Supplies were provided so that *all* family members could participate, and all came with instructions to store the supplies for use in subsequent arts and crafts activities.

Staff Follow-Up

Staff members were assigned individual households that were contacted once per day during camp week to review the daily activities and associated materials, and to ask the parent to evaluate the previous day's activities. Each week of the booster sessions, calls were made by the same staff member early in the week to confirm receipt of the box(es) and at the end of the week to evaluate booster activities. Evaluation questions were specific to given activities. For example: *Did you review the food label materials?; Did your children write in their journal?; Will your kids play ping pong again?; and, Did your children enjoy planting beans?* The staff members scheduled the best day and

TABLE 1 | Demographic characteristics, adult participants completing registration form ($n = 14$) variable.

	Frequency (n)	Percentage (%)
Sex		
Female	11	79
Male	3	21
Employment		
Full time work	11	79
Part time or temporary work	1	7
Unemployed (seeking work)	1	7
Unemployed (non seeking work)	1	7
Retired	0	0
Education		
Less than high school	1	7
High School/GED	4	29
More than high school	9	64
Health status		
Excellent	1	7
Very good	5	36
Good	4	28.5
Fair	4	28.5
Poor	0	0
Household benefits		
Food stamps	5	36
WIC	2	14
Unemployment	1	7
Social security	0	0
Veterans affairs	0	0
None	9	64
Health insurance		
Medicaid	7	50
Indian health service	4	29
Private insurance	2	14
Kidscare	1	7
Medicare	0	0
Uninsured	0	0

time to call during the booster week with the respective parents for booster evaluations. The evaluation questions, directed to the parents, asked during booster weeks were general, open-ended questions. For example, *What did you like best about the booster activities this week?*; *What did you like least about the booster activities this week?*; *What did your kids like best about the booster activities this week?*; *What did your kids like least about the booster activities this week?*; and, *Do you have any suggestions?*

Database and Institutional Review Board Approval

Staff members entered registration and evaluation responses in the REDCap electronic data management system at the University of Arizona, which provides secure storage and automated data export. Statistical analyses were performed using IBM SPSS Statistics, version 27.0 (Chicago, IL). The American Indian Youth Wellness Camp in a Box was approved by participating Tribal/Urban American Indian Organization, through their Tribal Leadership, Board of Directors and Tribal/Urban Indian Health Programs, and the university Institutional Review Board, 1911168177A001.

RESULTS

Demographics A total of 14 American Indian households (68 individuals; 100% American Indian) representing several different Tribal/Urban Indian entities in the southwestern United States participated. The households included 36 youth (aged 2–18 years; 62% female) and 32 adults including parents, grandparents, nieces, aunts, uncles, and cousins (aged 19–56 years; 79% female). The average number of children living in the house was 2.6 (range 1–6) and the average age of children living in the house was 11.7 years (range 2–18 years). Almost two-thirds (64%; $n = 9$) of families reported a family history of type 2 diabetes.

Fourteen adults completed the registration form to enroll their families in Camp in a Box. All parents completing the registration form were American Indian, a majority of whom were women (79%) (see **Table 1**). Most of our parents were employed and had more than a high school education. Over two-fifths (43%) of responding adults reported their health status to be either ‘excellent’ or ‘very good’. Over half of responding adults reported receiving public assistance. All responding adults reported having some sort of health insurance.

Household Information

Over a quarter (28%) of responding adults reported their family was unable to get either food, clothing or utilities at some point in time during the past 12 months (see **Table 2**). Half of the responding adults reported being worried that food would run out often or sometimes, before getting money to buy more, during the past 12 months. Almost all (93%) of the participating families use their cell phone when accessing the internet. More than one-third of parents stated that internet access was costly, needed help on how to use the internet, or had very limited internet access, data not shown.

Support, Stress and Anxiety

Although most Tribal/Urban Indian communities have strict social distancing rules and guidance, most responding adults reported being able to see or talk to people they care about and feel close to. Over three-quarters of responding adults reported feeling unable to control important things in their life, fairly or very often.

Beginning at Booster 4, weekly evening online mind-body skills groups were offered. The sessions ranged in attendance from 3 to 7 total participants, with at least one parent present at all sessions. A total of three different parents joined with one parent attending five sessions; two parents joined one session each.

Overall Camp in a Box Evaluation

Overall evaluations of this pandemic-compliant program were highly favorable (see **Tables 3 and 4**). Parents reported that Camp in a Box instructions were easy to follow, informative, and that supplies were adequate to ensure participation by all. Parents reported that the Camp in a Box items were useful, and the family spent more time together than usual as a result of participating in Camp in a Box. The eight-week booster sessions inclusive of two

TABLE 2 | Food security, internet access, and stress, adult respondents ($n = 14$).

Question	Frequency (n)	Percentage (%)
During the past 12 months family was unable to get		
Food	2	14
Clothing	1	7
Utilities	1	7
Other—Hygiene products	1	7
None	12	86
During the past 12 months, family worried that food would run out before getting money to buy more		
Often true	1	7
Sometimes true	6	43
Never true	7	50
Frequency see/talk to people you care about and feel close to		
Less than once a week	1	7
1 or 2 times per week	2	14
3 to 5 times a week	5	36
More than 5 times a week	6	43
Internet		
Home internet access	12	86
Use internet/Email	14	100
How do you access internet when you use it? (Choose all that apply)		
Cell phone	13	93
Tablet	7	50
Other—laptop 4; computer 3	7	50
How stressed are you?		
Not at all	2	14
A little bit	6	43
Somewhat	5	36
Quite a bit	1	7
Very much	0	0
Felt unable to control important things in your life		
Never	0	0
Almost never	0	0
Sometimes	3	21
Fairly often	6	43
Very often	5	36
Felt confident about ability to handle personal problems		
Never	3	21
Almost never	4	29
Sometimes	5	36
Fairly often	1	7
Very often	1	7
Felt difficulties were piled too high to overcome		
Never	1	7
Almost never	7	50
Sometimes	4	29
Fairly often	0	0
Very often	2	14

calls per week from program staff to confirm receipt of boxes, review curricula, and evaluate the program were acceptable in frequency and duration. Parents reported that children were active for at least 60 min per day and they would now incorporate many of the lessons (e.g., healthy eating, physical activity, relaxation, arts and crafts) more regularly into the family schedule. Twenty percent of respondents said they would incorporate *all* of camp lessons now. A couple of parents also indicated they would continue to use the binder as reference.

When asked what families liked best about camp, the overall program with the intensive camp week and booster sessions, 36.2% of responses related to the arts and crafts activities, including scrapbooking, scratch art, dreamcatcher, tie dye,

checkerboard, rock painting, chalk art, and sun beads. Almost 14% of families liked all components of Camp in a Box. Twelve percent of respondents liked the different physical activities, such as the 60 s challenge, jump roping, circuit training, the scavenger hunts, charades, Frisbee, ping pong and walking. Families enjoyed having the chance to spend time together to do Camp in a Box activities, the snacks, and having their children doing something positive. The nutrition information and the family box, which contained household items, were liked by the families.

When asked what families liked least about camp, the overall program with the intensive camp week and booster sessions, the most frequent response (28.1%) was that they did not like specific snacks, such as apple chips, banana chips, dried apricots, and

TABLE 3 | Camp in a box evaluation, questions following camp week.

Question	Frequency (n)	Percentage (%)
Were the instructions overall easy to follow?		
Yes	14	100.0
No	0	0.0
Were enough supplies provided for everyone to participate?		
Yes	14	100.0
No	0	0.0
Were your kids active for at least 60 min per day?		
Yes	14	100.0
No	0	0.0
Were the family box items provided useful?		
Yes	14	100.0
No	0	0.0
As a result of this week's activities, did the family spend more time together than usual?		
Yes	11	78.6
No	3	21.4
<i>Camp in a box evaluation, questions following booster component</i>		
Were the two calls a week okay?		
Yes	12	92.3
No	1	7.7
Were the education materials informative?		
Yes	13	100.0
No	0	0.0
Were the 8 weeks of booster sessions okay?		
Yes	11	84.6
No	2	15.4
Is there anything from these lessons that you will now incorporate?		
Yes	13	100.0
No	0	0.0
If yes, please specify		
Nutrition (eating healthier, improving food habits)	6	25.0
Physical activity (dancing, jump rope)	4	16.7
All of them	4	20.0
Mind body medicine (relaxing, breathing techniques, being positive)	3	12.5
Arts and crafts (as a family)	2	8.3
Refer back to binder information	2	8.3
Increased family time/Communication	2	4.2
What did families like best about camp in a box? (Summed from all weeks' responses; some named more than one thing in a given week)		
Arts and crafts (scrapbooking, scratch art, dream catcher, tie dye, checkboard, rock painting, chalk art, sunbeads)	55	36.2
All of it	21	13.8
Physical activity (60 s challenge, jump rope, circuit training, scavenger hunt, charades, frisbee, ping pong, walking)	19	12.5
Spending time with family	12	7.9
Snacks	11	7.2
Gave the kids something positive to do	7	4.6
Nutrition information (go slow whoa foods, vegetable bingo, planting beans)	7	4.6
Family box	6	3.9
Mind body medicine	5	3.3
Binder materials	2	1.3
Communication	2	1.3
Life lessons	2	1.3
Reading	2	1.3
Motivational messages	1	0.7
What did you families like least about camp in a box? (Summed from all weeks' responses; some named more than one thing in a given week)		
Snacks	9	28.1
Journal writing	4	12.5
Online schooling makes it hard to do activities	4	12.5
Tie dye clean up	3	9.4
Checkerboard (duct tape stickiness)	3	9.4
Goal setting	2	6.3
Dreamcatcher (was frustrating)	1	3.1
Frisbee retrieval	1	3.1
Getting up early	1	3.1
Juggling work with camp	1	3.1
Mind body medicine	1	3.1
Morning walks	1	3.1
Take into consideration age gaps	1	3.1

TABLE 4 | Camp in a box evaluation, questions following booster component.

Question	Frequency (n)	Percentage (%)
Were the two calls a week okay?		
Yes	12	92.3
No	1	7.7
Were the education materials informative?		
Yes	13	100.0
No	0	0.0
Were the 8 weeks of booster sessions okay?		
Yes	11	84.6
No	2	15.4
Is there anything from these lessons that you will now incorporate?		
Yes	13	100.0
No	0	0.0
If yes, please specify		
Nutrition (eating healthier, improving food habits)	6	25.0
Physical activity (dancing, jump rope)	4	16.7
All of them	4	20.0
Mind body medicine (relaxing, breathing techniques, being positive)	3	12.5
Arts and crafts (as a family)	2	8.3
Refer back to binder information	2	8.3
Increased family time/Communication	2	4.2
What did families like best about camp in a box? (Summed from all weeks' responses; some named more than one thing in a given week)		
Arts and crafts (scrapbooking, scratch art, dream catcher, tie dye, checkboard, rock painting, chalk art, sun beads)	55	36.2
All of it	21	13.8
Physical activity (60 s challenge, jump rope, circuit training, scavenger hunt, charades, frisbee, ping pong, walking)	19	12.5
Spending time with family	12	7.9
Snacks	11	7.2
Gave the kids something positive to do	7	4.6
Nutrition information (go slow whoa foods, vegetable bingo, planting beans)	7	4.6
Family box	6	3.9
Mind body medicine	5	3.3
Binder materials	2	1.3
Communication	2	1.3
Life lessons	2	1.3
Reading	2	1.3
Motivational messages	1	0.7
What did you families like least about camp in a box? (Summed from all weeks' responses; some named more than one thing in a given week)		
Snacks	9	28.1
Journal writing	4	12.5
Online schooling makes it hard to do activities	4	12.5
Tie dye clean up	3	9.4
Checkerboard (duct tape stickiness)	3	9.4
Goal setting	2	6.3
Dreamcatcher (was frustrating)	1	3.1
Frisbee retrieval	1	3.1
Getting up early	1	3.1
Juggling work with camp	1	3.1
Mind body medicine	1	3.1
Morning walks	1	3.1
Take into consideration age gaps	1	3.1

raisins. The popcorn received many positive comments and the beef jerky depended on variety, with different varieties liked better than others. Two parents liked the dry beef jerky so much that one asked for vendor information and another asked if it might be distributed again during Camp in a Box booster sessions. Additionally, twelve percent of respondents shared they did not like the journal writing activity and twelve percent responded it became hard to complete the booster activities once the school year started. Other respondents reported not enjoying the clean-up process following some of the camp and booster activities.

Family Participation in Camp in a Box

Our Camp in a Box program was feasible and well-received until school began. We had 100% participation for camp week (see Table 5). With all students attending school online, the booster sessions quickly became burdensome. Although families requested to continue receiving weekly booster boxes, some could not complete activities within the prescribed week and could not complete evaluations. At Booster 8, we had retained ten families (71%). All but one family (who was lost to follow-up) completed the final overall camp evaluation (93%).

TABLE 5 | Family participation in camp in a box.

Camp Component	Number of Families Participating	Percentage (%)
Camp week		
Monday	14	100
Tuesday	14	100
Wednesday	14	100
Thursday	14	100
Friday	14	100
Booster sessions		
Week 1	13	93
Week 2	14	100
Week 3	13	93
Week 4	12	86
Week 5	11	79
Week 6	11	79
Week 7	10	71
Week 8	10	71
Final overall evaluation		
Final survey	13	93

Evaluation Communications

Over the course of Camp in a Box, there were 175 documented communications with parents (see **Table 6**). The most frequent ways the staff members communicated with the designated parent was through cell phone calls (97.1%). Most of the calls were with the mother and it often took a single call to get in touch (38.3%; 1–14 calls). Preferred time was established with the initial call and the calls occurred most frequently after work for calls that lasted between 5 and 10 min (45.7%).

Parent Comments

Parent communications were valuable and provided timely feedback. Several communications were especially heartwarming and some reinforced that the purpose of Camp in a Box was achieved:

“I really enjoyed this camp. You guys have done an excellent job in providing educational value to us. I am very thankful for your camp because one of my kids was very closed off from the rest of us but because of this camp she broke out of her shell and demonstrated high levels of communication with us. Thank you, guys, again for this wonderful camp.”

“The activities really helped from the standpoint of bringing us closer together, it helped our communication outside of the camp.”

“Ideas from Booster 2 helped the entire family with meal planning.”

“We plan to do more meditation sessions and make it part of our weekly activities for the family. The kids are more aware of intensity of exercise now because of this booster.”

“We downloaded a weekly exercise journal from the CDC to keep track of exercises.”

“We liked the Rethink Your Drink activity because it’s a good reminder of what’s good/what’s not good and of all the sugar that can be in drinks.”

“We liked the Mindful Eating session. The kids usually don’t take their time with food and they eat really fast, so it was good to make them aware.”

“It was exciting to learn about dream catchers and where they came from.”

“My daughter was looking forward to the tie dye project. She looked ahead in the schedule and was excited for Booster 6 art project.”

“I like all the information that you guys provide and how you guys walk us through step by step for the activities.”

“My daughter likes everything. She gets excited when things come in the mail.”

Social Media Metrics

Postings were made each day during the work week over the duration of camp to Facebook, <https://www.facebook.com/AIWellness/>. The posts included images of families completing the different camp activities, motivational messages, and reinforcement of education materials. Examples included reminders to exercise, to eat healthy meals, and to be mindful of stressors. Facebook metrics were collected from July 1–July 31 and from August 1–31. Camp in a Box had 190 followers in July with 186 Likes and a reach of 3,294 views. In August, there were 195 followers with 191 Likes and a reach of 2,392 views. There were 159 Shares in July and 119 Shares in August. Followers were primarily female (78%) aged 35–44 years of age (24%).

TABLE 6 | General contact information for camp and booster evaluations (n = 175).

Variable	Frequency (n)	Percentage (%)
Communication type for evaluation		
Cell phone voice	170	97.1
Cell phone text	4	2.3
E-mail	1	0.6
Communicated with		
Mother	130	74.3
Niece	21	12.0
Father	13	7.4
Grandmother	11	6.3
Number of contact attempts (Avg = 2.6)		
1	67	38.3
2	42	24.0
3	28	16.0
4	17	9.7
5	5	2.9
6	7	4.0
7	2	1.1
8	5	2.9
10	1	0.6
14	1	0.6
Time of call		
Before 10:00am	12	6.9
10:00am - 12:00pm	20	11.4
12:01pm - 5:00pm	68	38.9
After 5:00pm	75	42.9
Duration of call		
Less than 5 min	76	43.4
5–10 min	80	45.7
More than 10 min	18	10.3
Couldn’t connect	1	0.6

DISCUSSION

The key findings of our study are that a health promotion program with enhanced parental involvement can be implemented with relatively high response and retention rates during a pandemic (90.4% over entirety of Camp in a Box including final overall evaluation); that a health promotion program can be implemented without reliance on the internet; and, that written materials and minimal, yet essential and effective, communications with parents were sufficient to convey health promotion related information and elicit self-reported behavior change. These findings are especially important because the behavioral risks for chronic disease are high among American Indian youth and their families. It is exactly during times of challenge, such as the COVID-19, that prevention efforts focused on youth and their families need to be prioritized. Furthermore, the pandemic has placed heavy emphasis on digital learning, telehealth, Zoom meetings and our program provided valuable and needed reprieve from technology. “This program demonstrates the resiliency in American Indian families’ ability to learn in a non-virtual or in-person capacity.”

Findings presented herein contribute to our understanding of how to design, deliver and assess a health-themed, positive youth development (Catalano et al., 2004), family-oriented summer camp for American Indian children and adolescents. The goal of the American Indian Youth Wellness Camp in a Box was to engage, educate and empower families to improve their health and overall well-being. During pre-camp planning meetings with Tribal/Urban Indian-University partners, once it became clear that an in-person camp was not feasible because of the COVID-19 pandemic, our Tribal/Urban Indian partners shared their concerns about offering the camp via internet due to the expense, lack of access and/or lack of coverage on or near Tribal/Urban Indian lands. These internet issues were also mentioned by Press et al. (2003) and Wood et al. (2003). Through ensuing discussions with colleagues within the university, the “boxed” approach was suggested in adherence with CDC, Tribal/Urban Indian, state and city pandemic guidelines and recommendations. The proposed approach was shared with the participating Tribal/Urban Indian entities and once they were assured online links would be recommended as resources only, the Camp in a Box curriculum was developed.

The COVID-19 pandemic limited Tribal/Urban Indian engagement. Several Tribal/Urban Indian entities that were interested in participating in camp activities were not able to due to other community priorities and restrictions related to infection rates, shelter-in-place rules, and need to focus public health personnel on contact tracing and follow-up. In one participating community, recruitment had just begun when all Tribal/Urban Indian health personnel were mobilized for contact tracing and could no longer assist with other “non-essential” projects or programs. The Tribal/Urban Indian challenges of balancing pandemic response and continuing program deliverables were the reason we recruited families in two separate waves.

The Camp in a Box curriculum was designed to focus on education and resources to address the risk for obesity and related metabolic diseases such as cancer, cardiovascular disease and diabetes, and to be receptive to family experiences due to the COVID-19 pandemic. As evaluations were reviewed, the comments and suggestions were added to the existing curriculum. For example, we received requests for complex coloring sheets, puzzles, grocery store map, flower seeds and more challenging physical activities. In response, we incorporated circuit training and timed vigorous activities, such as 60 s challenge, as part of Boosters 3 and 7, sent more detailed coloring sheets as part of Booster 7, and included flower seeds and puzzles as part of Booster 8. Our overall curricula remains work in progress and we plan to complete additional formative qualitative work, for example, to adapt parenting materials to better meet the needs of American Indian families.

The entire Camp in a Box was designed to be user-friendly and to work within family constraints associated with the pandemic. We purposely limited communications to one designated adult per family for continuity of interactions and to cause as little stress as possible on families and communities alike. Based on questions included at registration, half of the parents (50%) worried that food would run out before getting money to buy more and 36% reported they felt unable to control important things in their life. Family boxes were sent in direct response to reported family food insecurity and included food sources. The finding that 86% of the participating households had home internet access did allow us to offer a weekly online mental health support group. Although the parent engagement with the mental health component was limited, those who did attend felt the sessions were extremely valuable.

Several of our findings may seem counter intuitive, for example, parents reported that their families liked arts and crafts the best and yet this camp is focused on addressing obesity. Southwest American Indians are well-known for their artistic talents and arts and crafts hold high importance and value within American Indian culture. There are research findings that Indigenous people who made traditional arts and crafts within the last year had reduced behavioral risks (Ryan et al., 2016). Furthermore, concepts related to American Indian “wellness include the creative arts, including art therapy, which have been beneficial in attending to spiritual and cultural values” (Herring, 1997).

Another finding that is somewhat contradictory is that select healthy snacks were not liked by some of the children and parents. It could be that these foods were unfamiliar to the family and that the new tastes of these foods were less than favorable. We did not ask if any of the provided snacks were new to the family, but several families volunteered information that some of the food items were indeed new to them. Our choice of healthy snacks was based on overall calorie count, sugar and salt content and price. Because our delivery was by postal mail, we could not ship fresh fruits and vegetables which would have been the ideal snacks to provide.

Limitations

There are several limitations to mention. First, evaluations relied solely on parent self-report. Although we tried to accommodate parent availability, several parents felt bothered by our calls and requests to complete evaluations as demonstrated by quick, less thoughtful responses, and repeated rescheduling of calls. There were several instances where families fell behind on evaluations and had to be reminded which activities were being evaluated, so responses may have been influenced by accuracy of recall (Coughlin, 1990). Question content was developed to reflect the Camp in a Box objectives and to measure the impact of health promotion efforts on behavioral indicators such as knowledge, skills, motivation and self-efficacy. Although the research team did discuss the possibility of collecting minimal data, for example, weight, we did not pursue because we would not have been able to calibrate scales or verify information. We also did not want to introduce additional financial burden to families who may not have had weight scales.

Second, it is possible that Camp in a Box attracted families that were already more knowledgeable about or more invested in health practices than the average American Indian family of a similar demographic. It is not known how families who participated differed from those who did not participate. For the families that did participate, it worked well to have individual staff members assigned to work with given families for the duration of the program. The staff members were able to establish rapport to get to know the individual families and to understand and work with their unique situations and circumstances. To accommodate parent schedules, the staff members were extremely flexible and made calls in the evenings and sometimes on the weekends. To ensure our curriculum benefits all American Indian families, we have posted the curricula materials and activities on our website, <https://www.fcm.arizona.edu/outreach/american-indian-youth-wellness-initiative/wellness-resources>.

Third, a limitation of the intervention is its brevity. The United States Preventive Services Task Force guidelines for weight loss, behavior change, and cardiometabolic risk reduction in youth suggest high dose and long-term interventions (O'Connor et al., 2017b). Although Camp in a Box was nine weeks in duration, longer follow-up and more support and guidance to help participants sustain health behaviors would be ideal. Even with the nine-week intervention, the last few weeks were challenging for families. Our Camp in a Box program was feasible and well-received until school began. With students attending school online, the booster sessions quickly became burdensome for some families. It is unknown whether similar challenges would be encountered in a non-pandemic school year.

Exploring New Directions Under the Impact of COVID-19

Across the United States, Tribal/Urban Indian entities have been disproportionately impacted by COVID-19 (Hatcher et al., 2020). Amid this devastating pandemic, it becomes even more important to engage American Indian families in primary

prevention and health promotion initiatives to keep health disparities from increasing. The American Indian Youth Wellness Camp in a Box is an example of a program working to engage youth in healthy lifestyles, including mental health, and the inclusion of parents ensures a family-based approach and acknowledges Tribal/Urban Indian values. Parents can influence behaviors at home such as shopping for healthier foods and helping youth set limits on screen time. Evaluation results indicate that the program had a positive effect and increased participants' knowledge, skills and behaviors regarding nutrition, physical activity, and mental health.

It is important to note that planning, staying on track, and organization were essential to Camp in a Box. Most of our weekly materials were not ready until the day before boxes needed to be shipped and much of the copying and collating that needed to be completed were within hours of the boxing of items to be shipped. The camp director and one field-based member were subject to strict tribal lock-down mandates for the entirety of Camp in a Box and had to fulfill program deliverables on designated travel days (Tuesdays and Saturdays) and return home before curfew. We know that parents were similarly constrained and some of our telephone communications were scheduled around local tribal curfews and COVID testing days.

Our program has the potential to make an impact on lifestyle choices in at-risk American Indian youth and thereby reduce the prevalence of youth at risk for obesity and related disease conditions such as diabetes and cardiovascular disease. Although there are select health promotion and disease prevention camps among American Indian communities, few assess impact on health (Teufel-Shone et al., 2009). Our plans for next steps are to explore hybrid approaches that continue some of the Camp in a Box core elements, to begin our intervention earlier in the summer so that conflicts with school are minimized, to expand our booster sessions for longer than two months and to expand our involvement of parents, and to utilize feedback received from program participants in all future planning, implementation and evaluation endeavors. Through our social media posts, we received several requests from American Indian families for more information on the camp, so we know there is interest in the curriculum and materials.

Now is the time to invest in promoting American Indian family resilience and enhancing physical and mental health and well-being in their respective communities and we are committed to answer the challenge.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

ETHICS STATEMENT

The studies involving human participants were reviewed and approved by the University of Arizona Human Subjects

Protection Program and each participating Tribal/Urban Indian community. Informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

AUTHOR CONTRIBUTIONS

JB, PC, JR reviewed and approved Camp in a Box; FG designed the camp program and data bases, designed camp curricula, completed data analyses, wrote the initial draft manuscript, approved manuscript for publication; EC, CC, DH, TJ recruited families, edited and reviewed the manuscript, approved it for publication; CG, VR, KG, CG, KG, VG, BG contributed to camp material development and distribution, manuscript revision; ER secured funding and provided critical manuscript revisions; JS, RB, KT, TF contributed to camp material development and design, data collection, data analysis, manuscript revision; CT provided input on camp design, health behavior measures and curriculum and review of manuscript content; NR supervised the development of mental health materials, led the online mind-body skills groups, assisted with manuscript preparation; MH contributed to intellectual content for the intervention (parenting), interpretation of the data, critical revision of the manuscript; TO contributed to intellectual content for the intervention (parenting), interpretation of the data, critical

revision of the manuscript; DR contributed to design of data collection instruments, data interpretation, review of the manuscript; VG contributed to intellectual content for the intervention (physical activity); SS assisted with development of mental health materials; JRJ designed the overall camp program, reviewed the manuscript.

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Case Report: Indigenous Sovereignty in a Pandemic: Tribal Codes in the United States as Preparedness

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Indigenous Peoples globally and in the United States have combatted and continue to face disease, genocide, and erasure, often the systemic result of settler colonial policies that seek to eradicate Indigenous communities. Many Native nations in the United States have asserted their inherent sovereign authority to protect their citizens by passing tribal public health and emergency codes to support their public health infrastructures. While the current COVID-19 pandemic affects everyone, marginalized and Indigenous communities in the United States experience disproportionate burdens of COVID-19 morbidity and mortality as well as socioeconomic and environmental impacts. In this brief research report, we examine 41 publicly available tribal public health and emergency preparedness codes to gain a better understanding of the institutional public health capacity that exists during this time. Of the codes collected, only nine mention any data sharing provisions with local, state, and federal officials while 21 reference communicable diseases. The existence of these public health institutions is not directly tied to the outcomes in the current pandemic; however, it is plausible that having such codes in place makes responding to public health crises now and in the future less reactionary and more proactive in meeting community needs. These tribal institutions advance the public health outcomes that we all want to see in our communities.

Keywords: indigenous governance, COVID—19, public health, emergency preparedness, indigenous law and policy

INTRODUCTION

Combating disease, genocide, and erasure is not new to Indigenous communities in the United States and globally. Colonial efforts sought to eradicate Indigenous communities as a matter of government policy (Deloria, 1988; Coulthard, 2014; Dunbar-Ortiz, 2014). While the current pandemic affects everyone, minority and Indigenous communities in the United States experience its effects disproportionately (Hatcher et al., 2020; Hathaway, 2020; Power et al., 2020; Rodriguez-Lonebear et al., 2020). To combat these effects, Native nations have asserted their inherent sovereign authority to protect their citizens (Curley, 2020; Gunderson, 2020; Lakhani, 2020; Walker, 2020). Whether these assertions are made by declaring states of emergency, securing borders, or adopting public health codes, Native nations are demonstrating the importance of having public health and emergency preparedness infrastructures in place to effectively meet community needs during this global public health crisis.

While a few nations have drafted and adopted public health and emergency codes during the pandemic, some Native nations have been building or using existing infrastructure to address the

2019 novel coronavirus (COVID-19) crisis. For example, Lummi Nation implemented a rapid response using its existing Emergency Health Powers Code adopted in 2017. The Lummi Nation began preparing a COVID response in February 2020 when the vast spread of the virus appeared inevitable. Lummi elected leaders and health officials began gathering medical supplies including test kits and arranging for test processing (Mapes 2020). COVID-19 on the Navajo Nation has attracted national media and highlights nation-specific efforts to address the public health emergency, which included creating communication materials in Navajo and declaring a public health emergency order in mid-March that prohibited mass gatherings and advised citizens to stay at home (Nation, 2020). Six months later, Dr Anthony Fauci, director of the National Institute of Allergy and Infectious Diseases, has publicly stated that the Navajo efforts could serve as a response model (Armas, 2020). These stories and the many others demonstrate the importance of tribal public health systems during a national crisis to better position Native nations to assert their sovereignty in the best interests of their citizens and communities.

Tribal Public Health and Framework for Tribal Public Health Law

Scholars are pushing back on the deficit narrative that focuses on disparities, inequities, and disadvantages in tribal public health (Tingey et al., 2016; McKinley et al., 2019). Hoss (2019a) begins to shift this narrative by providing a framework for tribal public health law that includes four pillars: 1) Native nations are inherently sovereign; 2) federal Indian law impacts intergovernmental relationships among Native nations, states, and the federal government (and, as a result, public health); 3) Native nations exert authority through tribal law; and 4) interventions without tribal consent can further undermine public health and promote structural violence. We situate this brief research report in this framework to understand the public health institutional capacity that exists in Indian Country during this current pandemic. We add to this discussion the importance of incorporating Indigenous Data Sovereignty and the role of the CARE Principles for Indigenous Data Governance for outside researchers, governments, and organizations when Native nations are adopting public health and emergency preparedness policies (RDA International IDSov IG, 2019).

Indigenous Data Sovereignty express a nation's authority and jurisdiction over information derived from its territories, citizens, communities, and interests (Kukutai and Taylor, 2016; Snipp, 2016; Rainie et al., 2017). Indigenous data governance activates Indigenous data sovereignty by aligning the collection, application, use, and stewardship of Indigenous Peoples' data with their values, cultures, and interests (Walter et al., 2018; Carroll et al., 2019). The rapid response that occurs during times of emergencies such as the COVID-19 pandemic does not excuse outsiders from disregarding or neglecting to follow Indigenous data sovereignty practices. During this time, it is even more important to practice good data governance and build partnerships that honor tribal sovereignty. Such practices and partnerships fall within the

CARE Principles framework, which affirms Collective Benefit, Authority to control, Responsibility, and Ethics (RDA International IDSov IG, 2019). The UN Special Rapporteur on the rights of Indigenous Peoples, José Francisco Cali Tzay (2020), emphasizes engaging representative institutions during this time; however, this warning assumes infrastructure and capacity exists in most communities. As we begin to examine existing public health and emergency infrastructure, we see there are areas for Native nations to grow and develop to meet the demand (Groom et al., 2009).

Governance of tribal public health sits outside of federal and state authority; however, in no way does this recognition relieve the United States from its treaty obligations and trust responsibilities to Indigenous Peoples. In the 1980s, as control over health care services and facilities began to shift from the federal government to the tribes, the predominant focus on treatment began to change. The Indian Health Service (2015) (IHS), an agency within the Department of Health and Human Services responsible for providing federal health services to federally recognized tribes, began to invest in preventative care and environmental services (Sequist et al., 2011). This period saw a growing number of tribes governing health services according to their own needs and assuming a larger role in the delivery of health care to their own peoples. This trend was concurrent with increased attention to preventative programs as well as to behavioral and mental health issues (Rainie et al., 2015).

Since the Indian Self-Determination and Education Assistance Act of 1975 (ISDEAA, P.L. 93–638) and its amendments, the United States government has met its obligations to provide health care through direct services or the provision of funds for tribes or other American Indian organizations to provide services. The ISDEAA and amendments began a shift in tribal control of IHS health care funding and facilities (Rainie et al., 2015). A series of amendments to the ISDEAA—P.L. 100–472 in 1988, the Indian Health Care Amendments of 1992 (P.L. 102–573), and the Tribal Self-Governance Amendments of 2000 (P.L. 106–260)—enhanced tribal control through the creation of self-governance compacts for health care services that provide money through block grant-like mechanisms for Native nations to administer programs and design services to meet tribal priorities (Dixon, 2001; Rainie et al., 2015). In essence, the amendments gave tribes the right to decide how to use federal funds. IHS administers the contracting and compacting processes provided under the ISDEAA and Tribal Self-Governance Act. As of 2016, IHS had negotiated 90 self-governance compacts with federally recognized Tribes.¹ In 2017, through P.L. 93–638 Self-Determination contracts, Native nations and Alaska Native corporations administered 19 hospitals, 284 health centers, 79 health stations, and 163 Alaska village clinics.² This shift in federal policy has broadened public health and emergency

¹Tribal Self-Governance. Indian Health Services, https://www.ihs.gov/sites/newsroom/themes/responsive2017/display_objects/documents/factsheets/TribalSelfGovernance.pdf. Accessed September 25, 2020.

²Quick Look. Indian Health Services, <https://www.ihs.gov/newsroom/factsheets/quicklook/>. Accessed September 25, 2020.

opportunities for Native nations to proactively meet the health needs of their communities rather than constantly having to react to the emergency at hand.

The federal government acknowledges that the 574 federally recognized Native nations maintain sovereign authority to build and sustain public health systems that are part of the broader patchwork of public health authority across the United States (see 45 C.F.R. 164.501). While tribal control of health care services and facilities has increased, a need remains for investments in tribal public health infrastructure in order to monitor public health, address emerging needs, provide services, and create informed policies (Warne, 2005; Tribal Epidemiology Centers, 2013). In addition, Native nations see challenges to exercising that authority such as building public health infrastructure; establishing relationships, roles, and responsibilities with state, county, and local health departments; and data and information sharing (Richmond and Ross, 2009; Hernandez and Robinson, 2014). To do this, nations need access to resources. Oftentimes this means access to federal programs and services that are vastly underfunded. In the United States, health inequities between Indigenous and non-Indigenous mainstream populations have existed for decades (Rhoades et al., 1987; Brennenman et al., 2000; Johnson and Rhoades, 2000). As a result, we see variation in the effectiveness of tribal public health systems in Indigenous communities in the United States.

During a crisis, emergency infrastructure constitutes an important companion to public health systems. The direct relationship between Native nations and the United States Federal Emergency Management Agency (FEMA) is fairly new. The Robert T. Stafford Disaster Relief and Emergency Assistance Act (Stafford Act) of 1988 authorizes the United States' President to declare an emergency or major disaster in situations where the responses are beyond the capacity of a state or local government. Since the Sandy Recovery Improvement Act of 2013 (P.L. 113-2), "The Chief Executive [or Governor] of an affected Indian tribal government may submit a request for a declaration by the President that a major disaster exists consistent with the requirements." Prior to this law, tribal governments had to rely on state governors to request a presidential declaration on their behalf (Sunshine and Hoss, 2017). However, Native nations were not simply waiting on the United States to intervene when addressing emergency or disaster efforts in their communities. Native nations have passed emergency management plans as early as 1990 in the case of the Navajo Nation (2020). Since 2013, more than 40 Native nations have directly requested presidential declarations to address areas of COVID-related matters, severe storms and flooding, and other natural disasters.³ Sunshine and Hoss (2017) argue that Native nations might consider using emergency declarations as "critical" public health tools to access resources and loosen the bureaucratic red tape that often impedes a nation's ability to respond. By passing emergency tribal laws, Native nations assert another level of governing authority to respond to public health crises.

Native nations continue to address the neglect and failure of the federal government in living up to its treaty and trust responsibilities. In doing so, Native nations are developing sophisticated healthcare, public health, and emergency systems that are grounded in their own understanding of how to address community needs and in their own values and beliefs. Examining tribal public health and emergency codes provides a lens to examine Native nation innovation for self-determination and governance during a public health crisis.

Tribal Public Health Codes

More policy research is needed on tribal public health and emergency management. The enactment of tribal public health and emergency codes has occurred at a lower rate than the codification of other governmental authorities such as economic development and law and order. In 2014, the National Congress of American Indians (NCAI) found 520 public health-related codes that fell into 10 different categories: agriculture and food safety; alcohol, tobacco and other drugs; animal management and control; emergency planning and management; environmental health; health data; health services; health systems governance; infectious disease management; injury and violence prevention; public health infrastructure; and health and cultural resource protections. As NCAI notes, many public health provisions adopted by Native nations are often framed around public safety. Bryan et al. (2009) conducted a similar study finding 56 publicly available tribal codes that address public health. Similar to NCAI, the authors categorized the codes into broad themes: "environmental health and sanitation; public safety and injury prevention; protection from violence and abuse; substance abuse, mental illness, and tobacco; communicable disease control, surveillance, and research; and other." These studies begin to provide more evidence of the ways in which Native nations are actively asserting their sovereign rights around public health and emergency management in preparedness to meet these needs. Additionally, in the mainstream United States, the Centers for disease Control and Prevention's Tribal Emergency Preparedness Law (2017) provides an understanding of what is needed during emergencies such as incident command centers, points of contact, and health communication systems.

During the COVID-19 pandemic, many public virtual convenings have featured tribal leaders sharing their nation's response to this virus such as National Congress of American Indian's (NCAI) Tribal Governments in Action webinar series.⁴ Some of the tribal leaders and employees have mentioned that having a tribal law in place helped coordinate the nation's response efforts, which led us to survey the types of public health and emergency laws that exist and the areas in which Native nations are asserting their authority and preparing the resilience of their communities to combat the destruction

³Tribal Affairs. Federal Emergency Management Agency, <https://www.fema.gov/about/organization/tribes>. Accessed September 26, 2020.

⁴National Congress of American Indians. COVID-19 Resources for Indian Country. COVID-19 Forums and Webinars, <http://www.ncai.org/Covid-19/resources-for-indian-country/ncai-covid19-webinars> [Accessed September 29, 2020].

attending this disease.⁵ Given that public health and emergency preparedness are connected in a public health crisis, we argue that natural/climate, public health, and safety preparedness should all be linked in the institutions that nations are building rather than siloed.

METHODS

In this pilot study, during the months of May–September 2020 we collected and thematically coded 41 tribal public health and emergency preparedness codes from 37 federally recognized Native nations in the United States to gain a better understanding of the institutional public health and emergency capacity that exists during COVID-19. We searched and accessed any publicly available codes through the Tribal Law Gateway on the National Indian Law Library and the Tribal Court Clearinghouse databases. To make sure that we exhausted all databases, we conducted a google search using “tribal public health code” and “tribal emergency code” key terms. The code titles range from Communicable disease, Vaccination, and Quarantine Ordinance, Community Health, Emergency Management and Homeland Security to Environmental and Public Health Ordinance, Health and Safety, Health and Sanitation. Using an iterative process geared toward pandemic public health response and based off previous work by Hoss (2019b), CDC (2017), NCAI (2014), and Bryan et al. (2009), we identified twelve themes: environment, crimes against health, health communications, quarantine and isolation, incident command systems, point of contact for tribal public health issues, sovereignty/governance, culture, emergency, communicable diseases, self-governance compact, and data sharing. Some of the themes represent common trends that we observed after reviewing the codes such as crimes against health (separate from a nation’s criminal code), communicable diseases, and environment.

Using a dichotomous 0/1 coding, two researchers read each code and coded the eleven themes using 0 to represent not addressing the theme and 1 as affirming the theme. Any differences were resolved in conversation or by a third researcher’s input. To understand when most of the activity occurred, we documented the year when the last activity occurred, being either amendment or enactment. We understand that Native nations are not required to post their own nation’s law for public consumption and there may be many instances where some nations have enacted public health and emergency laws and chosen not to share them publicly. Therefore, those tribal public health and emergency codes that are not made publicly available by Native nations are not included in this dataset.

We used a narrow search and coding process. As a result, we did not include articles or chapters that were not specific to public

health and/or emergency preparedness. For instance, there are multiple health related mentions in tribal law and order codes, other criminal offenses codes, agriculture and food and safety, and sanitation concerns--as can be found in the NCAI (2014) data--that are not included in this dataset. Some outcomes of interest are the number of codes specific to Indigenous data sovereignty, culture, and geographic location of Native nations enacting codes. Our sole focus for this collection was to identify standalone tribal public health codes in an attempt to assess institutional capacity within Indian Country for public health disease surveillance, protection, and emergency preparedness, and less around criminalization within public health (Hoss, 2019b). We parsed the codes into two categories those enacted before 2020 and those enacted during the 2020 timeframe in which we conducted the search.

RESULTS

Out of the 41 codes collected, only seven (17%) Native nation codes are specific to emergency preparedness and management in all years; however, 17 (47.1%) codes (public health and emergency) have emergency provisions included (**Table 1**). More than half ($n = 23$, 56.1%) of the Native nations have pre-existing self-governance compacts, which suggests that as nations are acting on a nation-to-nation basis with the federal government, they are building institutions to support their sovereign efforts to address the welfare of their citizens. Of the codes enacted prior, from 1988 to 2019, more are likely to address environment ($n = 18$, 54.5%). Of the 8 (100%) codes enacted in 2020, all addressed communicable diseases and quarantine and isolation. More than half of the codes passed in 2020 included provisions for emergencies ($n = 5$, 62.5%), health communications ($n = 6$, 75%), and point of contact ($n = 6$, 75%). In addition, half of the nations that passed codes in 2020 have self-governance compacts ($n = 4$, 50%) with IHS. Of the nine codes that included data sharing provisions for all years, five of those codes were passed in 2020.

To understand outbreak response and public health capacity during times of pandemic and emergencies, we created a subset of analysis that examines the emergency provisions ($n = 17$, 41.5%) found in the dataset, eight (47.1%) included a response to outbreaks and five (29.4%) respiratory surveillance (**Table 2**). We see Native nations including specific public health capacity arrangements that complement emergency preparedness. For example, of the nine (22%) data sharing points found in the dataset, eight (47.1%) of those are included in codes that also address emergency preparedness. The same is true for health communications and point of contact provisions. Of the fifteen (36.6%) total health communications points found, ten (58.8%) accompany emergency provisions. For tribal public health point of contact, twelve (70.6%) of the nineteen (46.3%) are included in public health codes that also address emergencies.

From 2006 to 2013, there was a steady stream ($n = 17$, 41.4%) of code enactment or amendments (**Figure 1**). As expected, we see a peak in activity in 2020 ($n = 8$ out of 41, 19.5%) where the largest number of codes were either enacted or amended in a single year.

Most of the activity for code enactment or amendment has occurred in the West and Midwest census regions with Native

⁵Seven Directions. Gathering Grounds Community Meeting IV: A Look at Lummi Nation’s Response to COVID-19, <https://www.indigenousphi.org/covid-resources/a-look-at-lummi-nations-response-to-covid-19> [Accessed September 29, 2020].

TABLE 1 | Frequency of public health and emergency preparedness themes in tribal public health codes 1988-2020 (*N* = 41).

Frequency table Themes	1988-2019 (33)		2020 (8)		Total all years (41)	
	n	%	n	%	n	%
Communicable diseases	13	39.4%	8	100.0%	21	51.2%
Crimes against health	9	27.3%	1	12.5%	10	24.4%
Culture	4	12.1%	1	12.5%	5	12.2%
Data sharing	4	12.1%	5	62.5%	9	22.0%
Emergency preparedness	12	36.4%	5	62.5%	17	41.5%
Environment	18	54.5%	0	0.0%	18	43.9%
Health communications	9	27.3%	6	75.0%	15	36.6%
Incident command systems	2	6.1%	3	37.5%	5	12.2%
Point of contact for tribal public health issues	13	39.4%	6	75.0%	19	46.3%
Quarantine and isolation	7	21.2%	8	100.0%	15	36.6%
Self-governance compacts	19	57.6%	4	50.0%	23	56.1%
Sovereignty/Governance	12	36.4%	3	37.5%	15	36.6%

TABLE 2 | Frequency of emergency preparedness themes in tribal public health codes 1988-2020 (*N* = 17).**Subset of emergency preparedness (n = 17)**

Themes	n	%
Data sharing	8	47.1%
Health communications	10	58.8%
Outbreak response	8	47.1%
Point of contact for tribal public health issues	12	70.6%
Respiratory surveillance	5	29.4%

nations sharing geography with the state of Washington having the most activity (**Figure 2**). In the West, we see the greatest mix of types of enacted codes being both public health and emergency-specific.

In 2020, we see code enactment occurring in some of the harder hit states (Johns Hopkins University and Medicine, 2020) such as Arizona, California, Louisiana, and Washington (**Figure 2**).

Discussion: Lessons Learned From Tribal Codes

Surveying publicly available codes provides insight into ways Native nations might approach public policy. The examples below offer broad considerations--that are by no means are exhaustive--for Native nations interested in strengthening tribal public health and emergency management governance.

Separate Public Health and Emergency Management Codes

Of the 37 Native nations, four Native nations have enacted separate public health and emergency management codes. One nation passed a public health code and a separate communicable disease code while another passed a public health quarantine and isolation code. Seven Native nations opted to pass Health and Safety codes, which typically cover animal control, fireworks, public safety, and sanitation issues. To further back up the nation's public health code, the Pascua Yaqui Tribe (PYT) adopted a Public Health Emergency Preparedness Plan that includes information on its health care delivery system, legal

authorities, and contractual partners among other points. PYT explains in its plan that it is a living document that is subject to annual review and revisions.

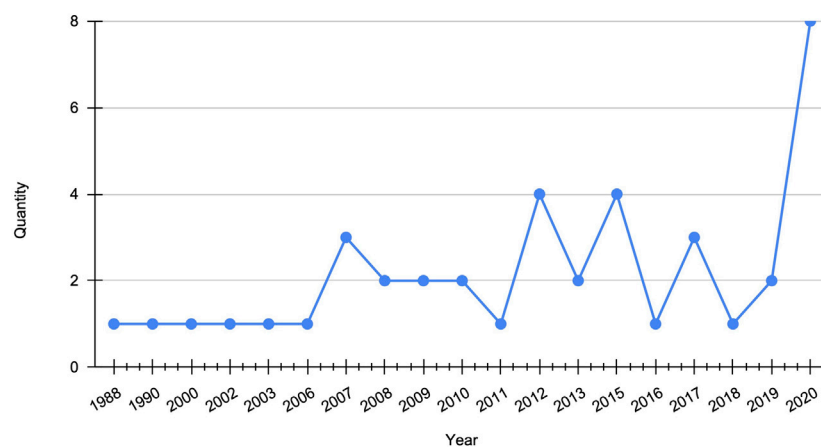
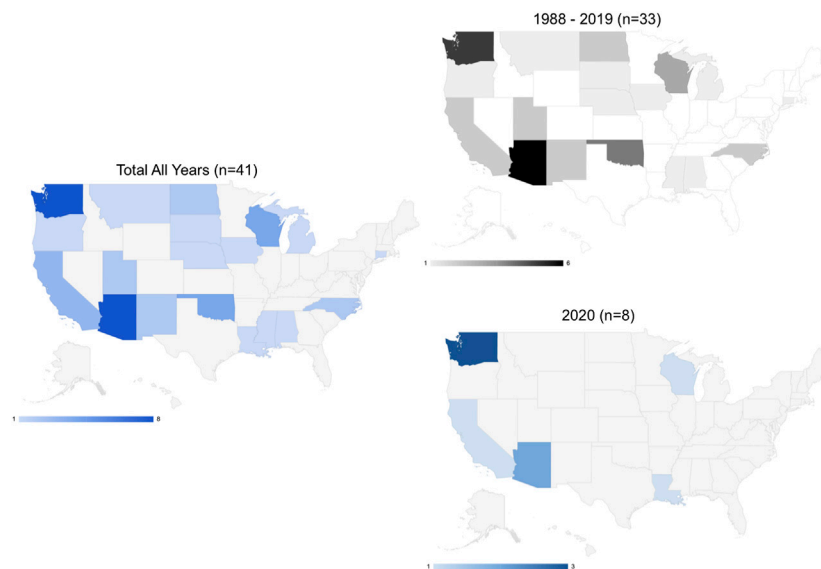
Communicable Diseases

Considering the current pandemic, we sought to identify how many of the 41 codes specifically addressed communicable diseases (**Table 1**); 51% (*n* = 21) of the codes mention communicable diseases. In 2007, in addition to its Public Health and Safety code, Stockbridge-Munsee adopted a Communicable disease, Vaccination, and Quarantine Ordinance that states the need "to prepare for possible bioterrorism issues and other communicable disease issues" and "if this area is left unaddressed, the political integrity, economic security, and the general health and welfare is threatened" (Stockbridge-Munsee Mohican Tribe). Jamestown S'Klallam Tribe's Public Health and Safety code states, "Tribal health care providers will assist local health officials in identifying exposed contacts of a communicable disease, when necessary, and assure appropriate testing, treatment, or chemoprophylaxis [sic] is carried out" (Jamestown S'Klallam Tribe, 2020). The Chitimacha Tribe of Louisiana includes a tracking section which states, "The Public Health Authority shall ascertain the existence of an illness or health condition that may be a potential cause of a public health emergency, investigate all such cases for sources of infection and to ensure that they are subject to proper control measures, and define the distribution of the illness or health condition" (Chitimacha Tribe of Louisiana, 2021). The Chitimacha code underscores what many public health officials have advocated for during the current pandemic. Not only is it important to report cases but it is important to track and trace to better contain a virus.

Public Health and Emergency Communications

In other areas of emergency, we see some nations including health communication systems and even fewer providing provisions for incident command systems. San Manuel Band of Mission Indians' Emergency Management Ordinance adopts the National Incident Management System using an incident command system to manage all emergencies within the nation's reservation. The ordinance states

Code enactment by year

**FIGURE 1 |** Tribal public health code enactment by year ($N = 41$).**FIGURE 2 |** Tribal public health codes by state ($N = 41$).

that once the Business Committee, the Chairperson, or its successor determines that a state of an emergency exists, they have the authority to declare an emergency (San Manuel Band of Mission Indians, 2020). Codifying how a nation organizes in times of emergencies allows the government to respond according to plan rather than react to meet the crisis at hand.

Sovereignty Authority and Culturally Appropriate Language

While the act of passing a tribally specific code is an assertion of tribal sovereignty, we were interested in seeing how many tribal codes explicitly mentioned the inherent sovereign authority of the

nation's government. Fifteen codes explicitly affirm a nation's authority. Other affirmations might be interpreted by the existence of self-governance compacts. Twenty-three (56.1%) of the Native nations included in this dataset have negotiated self-governance compacts with the federal government, which demonstrates a nation backing up its sovereign authority to negotiate a compact by passing its own rules and laws.

On the other hand, only five codes mention the distinct culture or belief system that guides the nation and serves as a foundation for sovereignty. The Confederated Tribes of the Umatilla Indian Reservation (CTUIR) includes a Tribal Health Philosophy in its Environmental Health and Safety Code. The section reads, "Spiritually, we do not separate ourselves from the surrounding

natural world. Therefore, the land, air, water and natural resources of the Umatilla Reservation must be maintained in a healthy and safe condition to sustain all forms of life using both traditional ways and modern technology. We recognize that the responsibility to intervene in human activities that create an unhealthy imbalance in nature is essential to protecting all natural resources” (Confederated Tribes of the Umatilla Indian Reservation, 2020). Here, CTUIR is articulating to its citizens and outsiders that the health decisions that are made align with its collective responsibility to the natural world.

Indigenous Data Sovereignty and Data Governance

In a time where access to health data is increasingly a challenge, we would expect to see more mentions of health data governance in the more recently passed public health and emergency codes. However, that is not the case. Of the 41 codes adopted, only nine (22%) include data sharing provisions. With respect to reporting authorities, the Yurok Tribe’s Public Health Ordinance states, “The Yurok Public Health Officer is authorized to report to a local health department, State Department of Public Health, and/or the Indian Health Service any information concerning a reportable disease or condition, an unusual cluster, or a suspicious event that they reasonably believe has the potential to be caused by or an indicator or bioterrorism” (Yurok Tribe’s Public Health Ordinance, 2020). Yurok public health officials have the authority to report public health concerns to outside governments; however, the code does not mention power to enter health data agreements. In March 2020, the National Indian Health Board (NIHB) surveyed the ability of tribal leaders, providers, and partners to adequately address the COVID-19 emergency. In addition to federal and state communication, and diagnostics testing, respondents listed one of the anticipated challenges as “planning for outbreak management” (National Indian Health Board, 2020). Indigenous Data Sovereignty affirms Native nations rights to outside and nation-specific data, and pandemic and pre-pandemic guidance asserts these nations’ need to access data in order to effectively plan for and manage potential outbreaks (Carroll et al., 2019; Rainie et al., 2017; Urban Indian Health Institute, 2020).

Preparedness During Times of Crisis

The code enactments and amendments from 2006 to 2013 coincide with the H1N1 pandemic that occurred in 2009 and ended in late 2010 (Figure 1). However, from 2006 to 2009 timeframe, the Sac and Fox Tribe of the Mississippi in Iowa (Health and Safety code passed in 2007) is the only nation in the dataset to have included provisions for disease outbreaks in its code, which are specific to notification procedures. Snoqualmie Tribe’s Emergency Management Department code defines its scope as “to mitigate, prepare for, respond to, and recover from injury and damage to persons or property resulting from emergencies or disasters, whether natural or man-made” (Tribe Snoqualmie, 2021). Whereas, as mentioned previously, Stockbridge-Munsee Tribal Law, 2007 Communicable disease, Vaccination, and Quarantine Ordinance states the need to prepare for bioterrorism. We can infer from the data that as Native nations are incorporating emergency provisions in their codes, tribal officials are making the effort to address the capacity in which these

emergencies might be met. Among the codes adopted or amended in 2020, we see Native nations creating institutions to sustain them during the pandemic particularly in two states where governors were arguably more resistant to act according to CDC recommendations (Figure 2).

CONCLUSION

Generally, we find that many of the codes use mainstream health and safety, and emergency language. In some instances, Native nations are adopting language from the state in which they share geography or explicitly adopting state law in these areas of law making. There is great opportunity for Native nations to position these codes to align with their own cultural values and understanding of how to address community challenges. Native nations are addressing governance challenges in other areas that can be transferred or applied in public health and emergency settings (Hiraldo et al., 2020).

Native nations are building culturally appropriate public health and emergency institutions to reinforce inherent sovereign rights and establish a standard of community public health. While the existence of institutions is not directly tied to the outcomes found during the current pandemic, it is possible to argue that having such codes in place make responding to public health and emergency crises now and in the future less reactionary and more proactive in meeting community needs. As the enactment of tribal public health codes evolves, Native nations are acting responsively to emerging needs. We view these institutions as advancing the public health outcomes that we all want to see in our communities.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

DH conceptualized the manuscript and drafted the manuscript, KJ curated data, investigated, and created data visualization, and as senior author SC contributed to the overall conceptualization, methodology, methods, and document editing.

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Development and Dissemination of a Strengths-Based Indigenous Children's Storybook: "Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19"

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The traditions, strengths, and resilience of communities have carried Indigenous peoples for generations. However, collective traumatic memories of past infectious diseases and the current impact of the coronavirus disease 2019 (COVID-19) pandemic in many Indigenous communities point to the need for Indigenous strengths-based public health resources. Further, recent data suggest that COVID-19 is escalating mental health and psychosocial health inequities for Indigenous communities. To align with the intergenerational strengths of Indigenous communities in the face of the pandemic, we developed a strengths- and culturally-based public health education and mental health coping resource for Indigenous children and families. Using a community-engaged process, the Johns Hopkins Center for American Indian Health collaborated with 14 Indigenous and allied child development, mental health, health communications experts and public health professionals, as well as a Native American youth artist. Indigenous collaborators and Indigenous Johns Hopkins project team members collectively represented 12 tribes, and reservation-based, off-reservation, and urban geographies. This group shared responsibility for culturally adapting the children's book "My Hero is You: How Kids Can Fight COVID-19!" developed by the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergency Settings and developing ancillary materials. Through an iterative process, we produced the storybook titled "Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19" with content and illustrations representing Indigenous values, experiences with COVID-19, and strengths to persevere. In addition, parent resource materials, children's activities, and corresponding coloring pages were created. The book has been disseminated online for free, and 42,364 printed copies were distributed to early childhood home visiting and tribal head start programs, Indian Health Service units, tribal health departments, intertribal, and urban Indigenous health organizations, Johns Hopkins Center for American Indian Health project sites in partnering communities,

schools, and libraries. The demand for and response to “Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19” demonstrates the desire for Indigenous storytelling and the elevation of cultural strengths to maintain physical, mental, emotional, and spiritual health during the COVID-19 pandemic.

Keywords: Indigenous, American Indian/Alaska Native, COVID-19, coronavirus, mental health, youth, childhood

INTRODUCTION

Indigenous (American Indian/Alaska Native/First Nations/Métis/Inuit)¹ peoples and nations are strong. Each tribe, village, and community carries knowledges, teachings, and practices passed down from their ancestors to current citizens that will continue to future generations. Though there are differences across tribes and communities, Indigenous knowledge “has sustained their communities and includes a deep belief in the connectedness of all creation across time and space, with relationships between past, present, and future entities. These relational connections correspond with responsibilities to place; all beings (self, family, people, clan, animals); the physical world (land, water, plants); ancestors (past and future); and the spirit world” (p. 4; Walters et al., 2020). In addition to providing meaning and a foundation for individual and community action, Indigenous knowledges and practices provide instructions for health and wellness (Walters et al., 2020). These intergenerational strengths have persisted against land theft, attempted genocide and ethnocide—including federal policies enforcing cultural oppression—and ongoing interpersonal and institutional racism.

Infectious diseases have been a threat to Indigenous populations since the arrival of Europeans. Historical records show that waves of diseases like smallpox, cholera, scarlet fever, influenza, and tuberculosis took more Indigenous lives than wars, enslavement, and starvation combined (Nabokov, 1999). Further, stories of intentional spread of diseases as a form of biological warfare against Indigenous peoples (e.g., smallpox blankets) are well-documented (Nabokov, 1999; Smith, 2013). Ancestral traumatic memories of these devastating events remain within Indigenous communities (Brave Heart and DeBruyn, 1998).

Today, a legacy of broken treaties and institutional injustices has led to persistent underfunding of federal programs that contribute to social and health inequities within many American Indian/Alaska Native communities (U.S. Commission on Civil Rights, 2018). For example, the Indian Health Service, the primary agency responsible for American Indian/Alaska Native healthcare in the U.S., was funded in Fiscal Year 2020 at \$6.4 billion (Indian Health Service, 2020a), ~\$41.6 billion dollars less than what is needed to adequately serve American Indians/Alaska Natives (National Tribal Health Budget Formulation Workgroup, 2020). The resulting social determinants that underlie health inequities among American Indian/Alaska Native communities, include, but are not limited

to, poverty, food and water insecurity, and inadequate access to hospitals, schools, housing, roads and public transit, internet, and cellular phone service (U.S. Commission on Civil Rights, 2018). These factors and existing inequities have increased coronavirus disease 2019 (COVID-19) risk transmission and its impact, resulting in American Indians/Alaska Natives experiencing COVID-19 incidence that is 3.5 times higher than the incidence among White individuals, and the highest COVID-19 hospitalization rates of all racial groups in the U.S. (Hatcher et al., 2020; Rodriguez-Lonebear et al., 2020; Centers for Disease Control and Prevention, n.d.). A study conducted in April 2020 examining associations between household and community characteristics and COVID-19 infection rates in 278 American Indian reservation communities in the U.S. found strong correlations between COVID-19 incidence and lack of indoor plumbing and non-English speaking households (Rodriguez-Lonebear et al., 2020). Further, overcrowded homes limit the ability to abide by physical distancing and quarantining COVID-19 guidelines, while inadequate access and infrastructure of internet and cellular phone service prevent access to telehealth and educational resources (U.S. Commission on Civil Rights—Written testimony of President Fawn Sharp, National Congress of American Indians, 2020). Together, these data demonstrate profound injustices that are exacerbating the COVID-19 pandemic for many American Indian/Alaska Native communities (Rodriguez-Lonebear et al., 2020; U.S. Commission on Civil Rights—Written testimony of President Fawn Sharp, National Congress of American Indians, 2020).

Moreover, the mental and spiritual health impacts of COVID-19 related losses are particularly profound given traditional values emphasizing the importance of family, community connectedness, and intergenerational learning (Cajete, 2000; Ullrich, 2019). These impacts may include loss of tribal Elders who are carriers of Indigenous knowledges and languages, the inability to engage in ceremonies and community gatherings, reliving memories of past traumas, and isolation from extended family (Indian Health Service, 2020b; National Indian Health Board, 2020; Urban Indian Health Board, 2020). A survey of 1,400 Indigenous peoples (First Nations/Métis/Inuit) in Canada ages 15 and older showed that 60% reported their mental health had worsened since physical distancing was implemented as a COVID-19 prevention strategy (Arriagada et al., 2020). In the same survey, nearly half of Indigenous women and approximately one-third of Indigenous men described most of their day as “quite a bit” to “extremely stressful” (Arriagada et al., 2020). Though we currently do not have equivalent data in the U.S., these data likely represent similar mental health impacts experienced by American Indians/Alaska Natives

¹We acknowledge all Indigenous peoples and nations are strong across the world. In this manuscript we focus on North American Indigenous populations, who were the target audience of the current storybook.

given that traditional lands cross country borders for some tribes, as well as similar experiences of collective trauma and contemporary health inequities in both countries (King et al., 2009). Helping Indigenous children and families cope with such hardship is critical to comprehensive COVID-19 response and recovery efforts.

Indigenous peoples and nations are demonstrating their commitment to protecting their communities during the COVID-19 pandemic. For example, tribal nations in the U.S. are showing “sovereignty in action” through mandated stay-at-home orders, in-person contact tracing and supportive isolation, and developing incident command systems – all exemplars that can be replicated at local, state, and national levels in non-Native communities to slow the COVID-19 spread (Native Governance Center, n.d.). To align with the strengths and collective action of Indigenous communities, the public health response must also include strengths-based approaches aligning with Indigenous knowledges and practices to provide practical, accessible, and culturally-driven resources for families and communities. This reinforces reshaping the COVID-19 narrative from one of fear, despair, and helplessness, to one of empowerment and hope that draws upon the inherent intergenerational values and strengths in Indigenous children, families, and communities to overcome this current challenge. Further, developing persuasive and inspirational messaging related to COVID-19 that reflects Indigenous values can form the basis of a social justice solution grounded in Indigenous health promotion and survivance (Vizenor, 2008).

The purpose of this paper is to describe the development and dissemination of “Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19” (OSWOSM), a storybook written for the Kindergarten to 5th grade age group and their families, to provide strengths- and culturally-based public health education and mental health coping resources in response to the COVID-19 pandemic. OSWOSM is an adaptation of “My Hero is You: How Kids Can Fight COVID-19!,” a book developed by the Inter-Agency Standing Committee Reference Group on Mental Health and Psychosocial Support in Emergency Settings (Kovach, 2010; Inter-Agency Standing Committee, 2020). The choice to adapt this book as a story told for and by Indigenous caregivers and their children is guided by recognition of the importance of Indigenous storytelling as a tradition that has supported the well-being and resilience of Indigenous communities since time immemorial (Kovach, 2010). While there are specific and important tribal and community differences in knowledges, values, and cultural teachings, we aimed to tap into the shared practice of storytelling with characters representing broad traditions and Indigenous geographies to reach and relate to as many Indigenous children and families as possible.

MATERIALS AND METHODS

Adaptation Process

The Johns Hopkins Center for American Indian Health (CAIH) formed a collaborative team of 14 child development, mental health, and health communications experts, public health professionals, and a Native American youth artist. The

collaborator workgroup represented 12 tribes, both on- and off-reservation, and urban Indigenous geographies, as well as non-Indigenous allies, whose purpose was to culturally adapt content and illustrations to represent Indigenous peoples, values, and communal experiences with COVID-19. Of note, the majority of the collaborator workgroup were parents and/or grandparents with children and grandchildren within the targeted age range of the storybook. This allowed collaborators to provide input based on both their professional expertise as well as their personal experiences about how children and families are impacted during the COVID-19 pandemic. In addition, some workgroup members read early drafts to their own children in the targeted age range of the book and the feedback from children was incorporated into subsequent drafts.

The workgroup met a total of three times virtually via video conference. The first meeting aimed to reach consensus for story themes, character development, and to discuss other major adaptations from the original “My Hero is You: How Kids Can Fight COVID-19!” book. After the initial meeting, one of the workgroup members (Crystal Kee, Diné; fourth author) developed a storyboard for OSWOSM. During the storyboard development, Kee also consulted with two knowledge keepers (including one Elder) from her tribe and integrated their input into the storyboard. This storyboard was presented to the full workgroup for feedback during the second video conference meeting. Following this meeting, the CAIH team integrated feedback from the workgroup as they drafted the first version of OSWOSM. Written feedback and direct edits to the book content were obtained via email from workgroup members. The Native American youth artist also presented sketches during the second and third video conference meetings to receive feedback from the workgroup about how the characters and scenes reflected content and themes. Final illustrations were presented via email to the workgroup for final feedback before being added with the content into OSWOSM.

In addition, the workgroup identified the importance of developing parent resources and children's activities to accompany the book. A subgroup with multi-disciplined Indigenous mental health and child development expertise volunteered to draft and revise the parent resources and the Native American youth artist developed illustrations. Each individual in the subgroup volunteered for a particular resource to draft content, emailed the draft to all other subgroup members for feedback, and the CAIH team provided final edits. Nine total resources were developed. The Native American youth artist developed six coloring pages from illustrations found throughout the OSWOSM storybook. Finally, the CAIH team used these coloring pages to develop six Indigenous language activity pages to encourage children and families to learn and practice speaking their tribal languages.

Dissemination of the Book

We used several dissemination strategies to encourage the broadest reach and impact of the book and ancillary materials across Indigenous communities. First, we created a webpage where the book and materials could be downloaded for free (<https://bit.ly/NativeStrongMedicine>). We developed a social

media campaign to promote the storybook and parent/child resources through the CAIH Facebook, Instagram, and Twitter accounts, as well as the CAIH newsletter, which currently has 6,781 subscribers. In addition, we shared the webpage and social media posts with eight national U.S.-based Indigenous advocacy and grassroots organizations to promote the book among additional online audiences.

To mitigate the lack of broadband access within some Indigenous communities (U.S. Commission on Civil Rights, 2018; National Congress of American Indians, n.d.), which may prohibit some communities from accessing the book and resources online, we also disseminated print books to Indigenous communities through several methods. First, we used CAIH's nationally recognized home-visiting program, Family Spirit®. Family Spirit is an evidence-based, culturally tailored home-visiting program that promotes optimal health and well-being for parents and their children (Barlow et al., 2006, 2013, 2015; Walkup et al., 2009). It combines the use of paraprofessionals from the community as home visitors and a culturally focused, strengths-based curriculum as a core strategy to support young families from pregnancy until their child's 3rd birthday. Parents gain knowledge and skills to promote healthy development and positive lifestyles for themselves and their children. Family Spirit has been scaled nationally to programs called "Family Spirit Affiliates" in over 130 tribal communities and 4 non-Native sites across 21 states. All Family Spirit Affiliates were contacted via email with a survey asking how many active families they serve. All sites that completed the survey were sent one book per family served to distribute.

Second, the CAIH has a long-standing memorandum of understanding with the Indian Health Service (IHS). We leveraged this existing partnership to disseminate the storybook to families through IHS service units. Third, CAIH distributed wellness boxes to individuals and families in several tribal partner communities (e.g., White Mountain Apache Tribe, Navajo Nation, and 11 Ojibwe Bands) where the CAIH has offices operated by local Indigenous employees. "Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19" was included in these wellness boxes for families with children in the target age range. Finally, we advertised that IHS or tribal/village health departments, community-based organizations that serve Indigenous families, and intertribal or urban Indigenous health programs could order bulk print copies for Indigenous families they serve. These orders were coordinated on a first come, first served basis through the CAIH website and direct emails with the storybook team.

Dissemination Evaluation

As part of our dissemination efforts, we piloted an evaluation strategy to understand the reach and impact of OSWOSM. This included indicators of reach by tracking the number of books printed, number of books sent to regional sites for distribution, number of families or individuals that received the books (tracked through REDCap (Harris et al., 2009), an electronic data capture tool hosted at Johns Hopkins University sent to those distributing the book), number of webpage visits, and the volume of social media impressions and engagements. We also attempted

to measure the social and emotional impact the book had on children through an anonymous caregiver survey using Qualtrics (Qualtrics, Provo, UT; Qualtrics, 2020) distributed through a QR code in the book and on the webpage. The survey questions were developed to measure overall satisfaction with the book, COVID-19 knowledge, and caregiver assessment of children's self-efficacy to implement protective behaviors and strategies against COVID-19.

RESULTS

Adaptation

The cultural adaptation process and finalizing book content and illustrations took 5 weeks. The rapid production time was intentional in order to address the COVID-19 crisis as quickly as possible with this resource. The final content of the book features youth twins, named Tara and Virgil, as narrators who live with their mother (a nurse), their father (a tribal leader), and their grandmother (**Figure 1**). During the adaptation process, the workgroup shared that some tribes have traditional stories about twins. Featuring fraternal twins was also done in an effort to allow a wide range of children to identify with the kids in the story. Finally, the Native American artist and workgroup collaborated during meetings to decide how each character is depicted. For example, the group felt that the twins should both feature long hair and not be clearly dressed in stereotypical gendered clothing. Further, the workgroup aimed to capture three important roles that community members are serving in to assist with the COVID-19 response: nurses, tribal leaders, and children's intergenerational caregivers (grandmother). The workgroup decided to portray the twins' mom as a nurse, a frontline COVID-19 worker, and their dad as a tribal leader, who might be guiding policies for community well-being during the pandemic. The twins' grandmother represents an important cultural keeper as an Elder who teaches the twins about traditions, such as learning the importance of earning eagle feathers through acts of service and demonstrating respect and responsibility.

Within the story, the twins have a dream in which they visit four friends in each of the four directions with their grandfather, who has passed on to the spirit world. Their grandfather takes the form of an eagle, an important cultural symbol (e.g., spiritual messenger) for many Indigenous peoples. The friends each share their unique family and community experiences with COVID-19. For example, one friend shares that someone in the household got COVID-19 and how his family kept themselves and others safe when this happened. This friend also shared that a relative built a handwashing station for the family, to depict Indigenous families who experience water insecurity and how communities are working on solutions to these issues during the pandemic. Other friends reinforce public health strategies, such as practicing physical distancing, wearing masks, washing their hands frequently, and using protective cultural practices and learning these traditions from relatives. The following excerpt from the book exemplifies how public health messaging is intertwined with the promotion of cultural values, such as respect for Elders and others, in a way that demonstrates



FIGURE 1 | Front cover of "Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19."

intergenerational transmission of Indigenous values, traditions, and honors future generations. Jason, the twins' friend from the Northern direction, says:

"We are being extra careful because of my baby sister. We protect her future by telling our friends to stay home and wash their hands as often as they can. This will help keep our Elders and other people safe. We need our community strong so she [the baby sister] can grow up learning our history, language and culture."

There are also mental health coping strategies integrated throughout the story. For example, the twins talk to their grandmother about feeling scared. Their grandmother comforts them and teaches them to close their eyes and visualize a safe place with their favorite people. In another part of the story, one of their friends who lives near water teaches them a breathing exercise by mimicking making ripples in water to breathe slowly when they feel scared. Recognizing the potential impact of physical distancing on social isolation and loneliness, the story also demonstrates how the twins talk by phone to family and friends and share that they can stay socially connected while adhering to physical distancing guidelines. These pieces of

the story are meant to act as important mental health tools to encourage children to talk about their emotions in a safe and comforting environment with others who validate their feelings, as well as learn effective coping and self-regulation strategies.

In addition to the book, nine total parent resource materials and children's activities were collaboratively developed including: (1) counting the ways that the book characters stayed socially connected while staying at home; (2) ideas for how children and families can stay socially connected to others; (3) a family tree activity to recognize and honor relatives; (4) the meaning of earning feathers; (5) ways for parents to feel strong and how to talk with children about their worries during the pandemic and what makes their children feel strong; (6) parent and child self- and co-regulation; (7) identifying and managing stress for parents; (8) tips for reading the book with varying age groups and how to personalize the story; and (9) a vocabulary page defining terms found throughout the book. Further, six coloring pages and six Indigenous language activity pages were developed to promote understanding of intergenerational family connections and traditional languages. These materials were developed based on current recommendations during the COVID-19 pandemic from organizations including Zero to

Three, American Academy of Pediatrics (AAP), the Centers for Disease Control and Prevention (CDC), Indian Health Service (IHS), and the Substance Abuse and Mental Health Services Administration (SAMHSA).

Dissemination Evaluation

Indicators of reach demonstrated widescale and diverse dissemination. Regarding print book distribution, 42,364 print books were distributed in all 12 IHS regions in the U.S. Books have reached 105 tribes across 27 states in the U.S., 12 First Nations communities in Canada, 56 intertribal and urban Indigenous health programs (U.S. and Canada), 42 IHS departments, 70 tribal health departments, 44 Family Spirit Affiliates (National Evidence Based Home Visiting Program), 20 Tribal Head Start Programs, 3 libraries, and 5 schools. In addition to this distribution, Indigenous communities, organizations, and health programs have been disseminating materials in their own creative ways. Several tribes, communities, and other organizations have featured “Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19” and accompanying resources on their websites, newspapers (print and online), and social media platforms (**Table 1**). For example, Yakama Nation News featured the book in their summer

newsletter along with a tribal language and coloring activity that was developed by CAIH to accompany the book (**Figure 2**) (Yakama Nation Tribal News, 2020), and featured a story about how the tribal program manager who ordered the books is distributing them within the community (Craig, 2020). The news story featured a photo of a child reading the book with a caption stating that the child shared what she learned about coronavirus with her grandma. Another example of unique ways tribes are interacting with the book is seen in the Pascua Yaqui Tribe Methamphetamine/Suicide Prevention Initiative program sharing a video of a tribal member reading OSWOSM on Facebook and YouTube (Pascua Yaqui Tribe, 2020). The 19-min video features photos from the book as the story is narrated. OSWOSM was also featured in The Navajo Times newspaper (Thacker, 2020) and the Department of Interior's monthly newsletter, *Journeys*, in their focus on Indigenous Cultures section (Department of the Interior, 2020). Finally, OSWOSM was featured by the World Health Organization in their online video about the global impact of “My Hero is You: How Kids Can Fight COVID-19!”

Results from the online dissemination strategy indicated 18,975 visits to the book's webpage and more than 119,256 impressions and engagements via social media. The most popular

TABLE 1 | Organizations and communities sharing OSWOSM and resources.

Organization name	Type of mention	URL
All in One Family (weekly Indigenous storytelling)	Video of book reading, shared link to resources	https://vimeo.com/421518840
California Indian Basket Weavers Association	Listed in resources	https://ciba.org/covid-19-resources/
Center for Native Youth	Shared CAIH Facebook post, listed in resources section	https://www.facebook.com/Center4Native/posts/our-smallest-warriors-our-strongest-medicine-overcoming-covid-19-this-indigenous-3124105330984997/ ; https://www.cnay.org/resource-hub/covid-19-resources/
Federal Emergency Management Agency	Shared resources on weekly blog	https://www.fema.gov/blog/communities-frontline-week-june-15
Laguna Division of Early Childhood	Listed in resources	http://lagunadec.ss3.sharpschool.com/for_students
National Native Child's Trauma Center	Listed in resources	https://www.nnctc.org/covid19-resources
Navajo Times	Interview with Dr. Victoria O'Keefe and Crystal Kee	https://navajotimes.com/edu/a-book-for-kids-story-focuses-on-smallest-warriors-to-teach-about-virus/
New York City School Library System	Listed in resources	https://nycdoe.libguides.com/COVID-19ebooks/free
North American Association for Environmental Education	Listed in resources	https://naaee.org/eeepro/groups/sustainable-cities-and-communities-k-12/discussions/responding-covid-19-through
Minnesota Autism Resources	Listed in resources	https://mn.gov/autism/covid-19-resources.jsp
Pascua Yaqui Methamphetamine and Suicide Prevention Initiative	YouTube video of book reading	https://www.youtube.com/watch?v=G27xR_pjm5k
Red Cliff Community Health Center	Listed in resources	http://redcliffhealth.org/what-we-do/behavioral-health/native-connections/
State of Michigan Home-Based Early Childhood Services	Listed in resources	https://www.michigan.gov/documents/mde/Home-based_early_childhood_services_-_Revised_-_07.15.2020_696522_7.pdf
U.S. Department of the Interior	Highlighted in their focus on Indigenous peoples during the 2019 coronavirus pandemic	https://www.doi.gov/sites/doi.gov/files/uploads/as-journeys-2020-06-final-508-compliant.pdf
Utah Paiutes	Description of book and links to webpage	https://www.utahpaiutes.org/coronavirus/our-smallest-warriors-our-strongest-medicine/
World Health Organization	YouTube video	https://www.youtube.com/watch?v=1QO66Kxsrk
Yəhaw Show	Book mentioned in interview with artist	https://yehawshow.com/blm-joelle-joyner

Our smallest warriors, our strongest medicine

Overcoming COVID-19!



How do you say these words in your language?

Elder: _____

Eagle: _____

Respect: _____

Protect: _____

Leader: _____

FIGURE 2 | Coloring and language resource developed by CAIH.

medium for accessing the book's webpage has been Facebook, which has had 91,286 reaches and 4,256 engagements. Other social media platforms included Instagram (668 likes) and Twitter (27,037 impressions). Finally, piloting of the survey measuring the impact of the book with children and families yielded 112 caregiver responses.

DISCUSSION

"Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19" was designed for Indigenous peoples across Turtle Island (North America) to portray a sense of communal efficacy, strength, and hope in the face of the COVID-19

pandemic. Our cultural adaptation process with a collaborative workgroup aimed to depict Indigenous characters and real community experiences with COVID-19 while providing public health safety messaging and mental health coping strategies. Further, this storybook is framed with an Indigenous strengths-based lens: (1) the format of this health promotion resource underscores an important Indigenous tradition, storytelling; and (2) the book content and additional resources/activities reflect Indigenous values, teachings, and practices that many families and communities may relate to and which have contributed to intergenerational strengths and wellness. Distribution strategies were derived to reach as many Indigenous families and communities as possible by making the book available free online and in print form for communities who lack broadband access. We continue to see and hear about Indigenous communities and organizations interacting with the book in creative ways and we have sold out of print books, indicating widespread reach and satisfaction.

This project and the resulting children's storybook have some limitations. First, it is challenging to develop Indigenous resources that apply to every tribe, band, village, or community in the U.S. and Canada. The workgroup was faced with the need to balance cultural specificity with concerns of transferability in the adaptation of the storyline. While the adapted storybook is general enough to apply to many Indigenous settings, the context may not be relevant for all readers. In addition, because of the wide geographic reach of the book and its availability online as a downloadable PDF file, it was difficult to implement a rigorous evaluation plan to analyze the book's impacts on mental health coping for children and caregivers. We did pilot an evaluation strategy with a low response rate. However, without a more defined sample and a desire to get the book to as many families as quickly as possible, we did not systematically analyze this data. Yet, this pilot strategy can help inform future iterations of the book and improve our evaluation of the book's impact on family and child functioning and well-being.

These limitations exist alongside numerous strengths. One of these strengths includes an ongoing high demand for print books from tribes, communities, and organizations across the U.S. and Canada, demonstrating that this Indigenous strengths-based resource is a useful tool during this pandemic. In addition, the book and ancillary materials were developed by a team of mostly Indigenous child development, mental health, health communications, public health professionals and scholars, Elders, and knowledge keepers. It is vital to have narratives that are developed and driven by Indigenous peoples to accurately and respectfully represent and portray community experiences (First Nations Development Institute and Echo Hawk Consulting, 2018).

Future directions of this project include distribution of additional print copies, recording videos of Elders and other community members reading the book to share online, and developing a sequel or potentially a series of books as the public health response to COVID-19 changes over time and across communities. A high priority for the potential series is to portray how K-12 schools (e.g., Bureau of Indian Education, tribally controlled, public, private) are conscientiously preparing

and implementing virtual or in-person instruction, public health messaging around safety in differing school or home-based schooling situations, and addressing the potential mental health and psychosocial stress of children, caregivers, and families in the educational context. Indigenous media is highlighting the importance of this topic, as parents and tribal leaders are grappling with schools' re-opening plans (Pember, 2020). In pursuing this topic, we plan to expand our collaboration group to bring in relevant expertise from Indigenous teachers, caregivers, school administrators, and tribal leaders. This future work may include more rigorous evaluation strategies to understand the impact these types of materials have with Indigenous children and families. In addition, future qualitative research may explore the impact OSWOSM has had on Indigenous children and families who have read the book and to better understand Indigenous strengths, knowledges, and practices promoting their well-being during the pandemic and beyond.

The strengths-based approach used in OSWOSM communicates that Indigenous peoples and communities have the historical resilience (House Committee on Appropriations—Written testimony of Abigail Echo-Hawk, 2020) and cultural knowledge to overcome the COVID-19 pandemic. The book emphasizes that children can help to prevent the spread of COVID-19 in their communities, a unique cultural approach to promoting public health messaging. This approach is not new to Indigenous communities, whose value systems revere children as “considered to be special, sacred gifts” and “carriers of the future” (p. 96; Cajete, 2000). Further, this storybook conveys important teachings about intergenerational, family, community, and environmental connectedness that can promote Indigenous children's wellness (Ullrich, 2019). In remembering and passing on these values and traditions alongside public health messaging in the form of storytelling, “Our Smallest Warriors, Our Strongest Medicine: Overcoming COVID-19” aligns with the cultural strengths of Indigenous communities and exemplifies on many levels shared traditional beliefs that children are “strong medicine.”

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

AUTHOR CONTRIBUTIONS

VO'K, TM, AI, CK, KM, AB, and EH drafted, reviewed, and approved this manuscript. In addition, a collaboration team (see Acknowledgments for list) reviewed and/or approved of this manuscript.

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Indigenous Peoples' Data During COVID-19: From External to Internal

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Global disease trackers quantifying the size, spread, and distribution of COVID-19 illustrate the power of data during the pandemic. Data are required for decision-making, planning, mitigation, surveillance, and monitoring the equity of responses. There are dual concerns about the availability and suppression of COVID-19 data; due to historic and ongoing racism and exclusion, publicly available data can be both beneficial and harmful. Systemic policies related to genocide and racism, and historic and ongoing marginalization, have led to limitations in quality, quantity, access, and use of Indigenous Peoples' COVID-19 data. Governments, non-profits, researchers, and other institutions must collaborate with Indigenous Peoples *on their own terms* to improve access to and use of data for effective public health responses to COVID-19.

Keywords: Indigenous Peoples, data sovereignty, data governance, data sharing, public health

INTRODUCTION

Governments have used real-time data and disease trackers quantifying the size, spread, and distribution of the novel coronavirus SARS-CoV-2 (COVID-19) that emerged in 2019 to inform and influence decision and policy making. Indigenous Peoples have been disproportionately affected by COVID-19, whether through infection, fatality, economic losses, or changes to social interactions. While Indigenous Peoples need timely, relevant, high-quality data to inform their own pandemic response, the collection and use of such data are not without risk (Carroll et al., 2020c; Curtice and Choo, 2020; del Pino and Camacho, 2020; Nagle, 2020; Paulin, 2020; RNZ, 2020; Tahir and Cancryn, 2020). In recent months, concerns have been raised around data harms, group privacy, consent, racist surveillance, algorithmic profiling, and more (Carroll et al., 2020c; Furlow, 2020a,b; Paulin, 2020; Timothy, 2020; United Nations, Department of Economic and Social Affairs, 2020; World Health Organization, 2020).

This paper explores the particular issues that COVID-19 has highlighted for Indigenous Peoples focusing on data for governance. Drawing on current global examples, we underscore the inclusion of Indigenous Peoples in COVID-19 activities as the basis of data-related policy recommendations to increase the use of timely, relevant data for decision-making while reducing risk and harms.

INDIGENOUS PEOPLES: DATA, SOVEREIGNTY, AND GOVERNANCE

Over 370 million Indigenous persons belong to more than 5,000 diverse cultures and inhabit over 90 countries worldwide (United Nations, 2009). However, this is a dated and gross underestimation, particularly for certain countries (e.g., low income) and regions; the most recent assessment from Asia alone estimates over 411 million Indigenous persons living in those countries (Asia Indigenous Peoples Pact, 2019). Indigenous Peoples as political collectives with inherent sovereignty share continuity with their pre-colonial societies (Martinez Cobo, 1982). Through their own social, political, and economic systems, Indigenous Peoples preserve, develop, and transmit their cultures, knowledge's, and relationships with their territories and resources to future generations (Martinez Cobo, 1982). In this paper we use Indigenous Peoples, nations, and communities together to denote the variety of ways in which Indigenous Peoples organize and refer to themselves. When referring to a specific Indigenous Peoples, we use the preferred terminology of those peoples (e.g., Pueblo of, First Nation, Māori).

Indigenous data are information or knowledge in any format that impact the lives of Indigenous Peoples collectively and individually, including data about lands and resources; information about individuals; and collective cultural and traditional knowledges (Maia Wingara, 2018; Te Mana Raraunga, 2018; Carroll et al., 2019, 2020a; Rainie et al., 2019). In the COVID-19 context, Indigenous data comprise information about COVID-19 testing (including community level measures such as municipal waste water), cases, hospitalizations, health service access, deaths, and comorbidities (Research Data Alliance COVID-19 Indigenous Data Working Group, 2020). Indigenous data also encompass related Indigenous Knowledges about COVID-19 and information on the socioeconomic and environmental correlates and impacts of COVID-19 (Research Data Alliance COVID-19 Indigenous Data Working Group, 2020). Data include information and metrics (i) for Indigenous Peoples as defined by geographic jurisdiction, (ii) for community members, and (iii) that include Indigenous nation-affiliation or Indigenous identifiers or affiliation (e.g., nation, tribe, ethnicity) within nation-state and local data systems. These are all data about Indigenous Peoples, lands, and resources, regardless of where individuals reside or where the data are held.

Epistemicide through settler colonial practices that have suppressed and co-opted Indigenous knowledge systems has created a state of data dependency (Carroll et al., 2019). Inconsistent, inaccurate, and irrelevant data; lack of Indigenous control and ownership of data; negative experiences with untrustworthy, exploitative research and policy practices; lack of investment in Indigenous Peoples' data infrastructures and capacity; and deficit focused data use and application mark and perpetuate data dependency (Kukutai and Taylor, 2016; Rodriguez-Lonebear, 2016; Walter, 2016; Rainie et al., 2017b). Within epidemiology specifically, these issues are also apparent for Indigenous Peoples in relation to data on Indigenous health and well-being (Anderson et al., 2016; Paradies, 2016; Prussing,

2019; Paine et al., 2021). As a result, many Indigenous nations rely on other governments, organizations, and institutions to provide both the data about their communities and the expertise to use and apply those data (Kukutai and Taylor, 2016; Rodriguez-Lonebear, 2016; Snipp, 2016; Carroll et al., 2019). Furthermore, outside data professionals often become the experts to which both Indigenous nations and other entities refer to for information and analysis using Indigenous Peoples' data (Smith, 2012; Walter and Andersen, 2013; Kukutai and Taylor, 2016). Indigenous Data Sovereignty serves to counter these actions and this narrative, recognizing and revitalizing Indigenous Knowledges to guide data practices.

Indigenous Data Sovereignty draws upon the United Nations Declaration on the Rights of Indigenous Peoples which reaffirms the rights of Indigenous Peoples to govern the collection, application, re/use, and stewardship of their data (United Nations, 2007, 2018, 2019; Davis, 2016; Kukutai and Taylor, 2016; Snipp, 2016; Rainie et al., 2017a). Substantial variations in nation states' recognition of sovereignty across the globe differentially affect (1) the existence, availability, and access to COVID-19 related data for Indigenous Peoples and (2) Indigenous Peoples' assertions of self-determination and data governance. In contrast to Indigenous Peoples in Aotearoa New Zealand, Australia, Canada, and the United States (US), in low- and middle-income countries Indigenous Peoples (1) have even less access to data and information, (2) represent a large proportion of Indigenous Peoples worldwide, and (3) suffer increased persecution during the pandemic crisis (del Pino and Camacho, 2020; United Nations, Department of Economic and Social Affairs, 2020; World Health Organization, 2020). Currently, the only COVID-19 data for developing countries is available through the United Nations Humanitarian Data Exchange¹. Unfortunately these data are reported at nation-state level due to sensitivities and are not disaggregated by race or ethnicity. Thus, the majority of the examples presented here address COVID-19 data situations in Aotearoa New Zealand, Australia, Canada, and the US. Yet similarities in COVID-19 data challenges for Indigenous Peoples exist internationally (del Pino and Camacho, 2020; United Nations, Department of Economic and Social Affairs, 2020; World Health Organization, 2020).

The CARE Principles for Indigenous Data Governance (Collective benefit, Authority to control, Responsibility, Ethics) are propelling international discussions around Indigenous Peoples' data during a global pandemic and beyond (Research Data Alliance International Indigenous Data Sovereignty Interest Group, 2019; Carroll et al., 2020a,b; Research Data Alliance COVID-19 Indigenous Data Working Group, 2020). Using the CARE Principles as a framework, the Research Data Alliance (RDA) COVID-19 Working Group set forth guidelines that underscore the need to engage Indigenous Peoples across COVID-19 data lifecycles and ecosystems (Research Data Alliance COVID-19 Indigenous Data Working Group, 2020). These guidelines demand investments in Indigenous community governance and control of data, while also making visible the information access and quality challenges that restrict the

¹<https://data.humdata.org>.

flow and use of COVID-19 data for public health response. Additionally, Indigenous Peoples' have rights to self-determine COVID-19 responses and to participate in broader decision-making (United Nations, Department of Economic and Social Affairs, 2020; World Health Organization, 2020).

DATA FOR GOVERNANCE

Governments, institutions, corporations, health care systems, and individuals require relevant and timely data for decision-making with respect to COVID-19 and future pandemic planning, mitigation, and surveillance. Indigenous Peoples and nations need these data for governing, determining policy, and evaluating program performance (Rodriguez-Lonebear, 2016; Smith, 2016; Snipp, 2016; Rainie et al., 2017b). These data also provide a lens to assess the impact of COVID-19 emergency response efforts at the national, regional, and local levels. Systemic policies related to genocide and racism, historic and ongoing marginalization, have led to lack of timely, accessible and representative COVID-19 data for Indigenous Peoples (Rodriguez-Lonebear, 2016; Walter, 2018; Carroll et al., 2019). There is a long history of lack of epidemiologic and other data for Indigenous Peoples (Anderson et al., 2006, 2016; Gracey and King, 2009; King et al., 2009; Axelsson et al., 2016; Paradies, 2016; Agyepong et al., 2017). To complicate the lack of data, existing laws and relationships are often ignored; for instance in the US, Indigenous nations are public health authorities with the same rights and responsibilities as state and local governments, yet many state governments refuse to share COVID-19 data with them (Tahir and Cancryn, 2020).

Many Indigenous Peoples across the globe lack access to data disaggregated by Indigenous affiliation or identification (e.g., nation, tribe, ethnicity). In the US, disaggregated data were not available for COVID-19 infection rates for Indigenous Peoples at the start of the pandemic (Nagle, 2020). This same scenario still exists in some US states and across the globe (Curtice and Choo, 2020; Hatcher et al., 2020; United Nations, Department of Economic and Social Affairs, 2020; World Health Organization, 2020). Misclassification or lack of classification on death certificates also leads to unavailable or underreported COVID-19 mortality data (Carroll et al., 2020c; Peeler, 2020). As a result, Indigenous Peoples lack the data to track the size, spread, and distribution of cases and fatalities for Indigenous nations and populations (both within and outside of Indigenous communities) for prevention, surveillance, mitigation, and evaluation purposes.

However, in the absence of Indigenous Peoples' participation in decision-making and access to data held by others during the COVID-19 pandemic, risks of data weaponization, stigmatization, and racialization rise (Carroll et al., 2020c). In the US, a COVID-19 hospital policy racially profiled pregnant Native American women using zip code level COVID-19 data made public by the State of New Mexico on an online dashboard (Furlow, 2020a). In the state where the hospital is located, COVID-19 case data are made public on an online dashboard by the state government. COVID-19 case data on tribal lands

are included on this dashboard without tribal permission. A federal investigation found that the hospital singled out Native American patients with reservation zip codes by requiring them to undergo COVID-19 testing even though they did not necessarily have a higher risk for exposure to the virus to stop the spread of the disease (Furlow, 2020b). The hospital also failed to provide explicit options for either refusing or requesting the testing. Furthermore, some of the affected mothers and newborn babies were separated during an important period of postpartum bonding while awaiting test results. For Native Americans, the hospital's discriminatory and unethical policy is even more problematic because it is reminiscent of US Federal Indian Policy that allowed for children to be removed from their homes and separated from their families and communities during the boarding school era.

In Australia, recommendations regarding protecting "vulnerable people" from COVID-19 included that "People aged 70 and over should stay at home and self-isolate for their own protection to the maximum extent practicable," and that "These arrangements should also apply to those with chronic illness over 60 and Indigenous persons over the age of 50" (Rev, 2020). While this advice appears precautionary, it is insulting for Indigenous Peoples and there is no information available to indicate how the advice was formed or what data were used to inform the advice. As a result, the advice for Indigenous people was later amended to those who are 50 years *with a chronic health condition(s)* to reflect a more generic and correct broader statement for those with chronic health conditions (Australian Government Department of Health, 2020). Indigenous Peoples require access to accurate data to understand the extent of risk and evaluate policy statements about risks.

In many places we have seen the continued underfunding of Indigenous public health during the pandemic, which further limits the access and use of data for the distribution of resources and investments in infrastructure and immediate needs. Additionally, even when funds are provided, often they come with strings such as excess regulation and micro-management and/or fear from Indigenous Peoples to assert their own governance systems and Indigenous knowledge's to curb the spread of SARS-CoV-2 (Carroll et al., 2020b). When the COVID-19 pandemic hit, an \$82 billion emergency response package was announced by the Canadian federal government for the country (Harris, 2020). Within that, two separate funds totaling \$305 million were announced by the federal government to address the specific and immediate pandemic needs of First Nations, Inuit, and Métis peoples (Government of Canada, 2020). This amount is less than proportionate to investments in the general Canadian population (Yellowhead Institute, 2020). This lack of sufficient resource allocation limits Indigenous efforts to track and mitigate the spread of the virus. Improved funding could lead to better community data infrastructure, greater capacity development, and ultimately decrease the potential for negative outcomes relating to COVID-19.

The COVID-19 pandemic has been used to apply further restrictions to already marginalized groups. In Myanmar there has been a mobile internet shutdown in some areas, movement restrictions implemented, and a blocking of aid that have a

significant potential to cause a major COVID-19 outbreak in camps (Human Rights Watch, 2020). The continued invisibility of Indigenous Peoples in COVID-19 data effectively erases their existence, paving the path for continued harms. Ameliorating these challenges requires actions to support Indigenous Peoples' access to and use of data.

ACTIONABLE RECOMMENDATIONS

This section outlines tangible data-related policy recommendations for governments, non-profits, researchers, and other institutions that emerge from the del Pino and Camacho (2020), Research Data Alliance COVID-19 Indigenous Data Working Group (2020), United Nations, Department of Economic and Social Affairs (2020), World Health Organization (2020), scholars (Anderson et al., 2006, 2016; Gracey and King, 2009; King et al., 2009; Axelsson et al., 2016; Paradies, 2016; Agyepong et al., 2017), and Indigenous Peoples and allies worldwide.

Invest in Indigenous Community-Controlled Data Infrastructures and Technology to Support Community Capacity, Response, and Resilience

Data collection in, and repatriation to, Indigenous communities is required to ensure communities and nations can make decisions affecting them. Data creation, storage, and use by Indigenous Peoples necessitates investments in community-controlled data infrastructure and technology. In Australia, there are early indications of establishing regional data infrastructure so Indigenous nations can use data for development (National Agreement on Closing the Gap, 2020). One policy proposal to assist in the current COVID-19 environment for Indigenous communities to respond to COVID-19 is to invest in technological solutions such as a syndromic surveillance system for Indigenous community-controlled/based data systems where there are options to do so, and appropriate Indigenous data governance can be applied. Syndromic surveillance is where automated generation of statistical alerts through monitoring of disease indicators can occur in real time or near real-time to detect potential outbreaks of disease earlier than would otherwise be possible with traditional public health methods (Henning, 2004).

Even in low resource, rural environments options exist to support community-data infrastructure. In Brazil, the Coordination of the Indigenous Organizations of the Brazilian Amazon and the Amazon Environmental Research Institute collaborated on a mobile application (app); the "COVID-19 Indigenous Alert" app assists Indigenous communities in monitoring the spread of the pandemic on their lands and informing mitigation efforts (IAPM, 2020). The Kuikuro Indigenous Association of Upper Xingu in Brazil further customized their response by enhancing already existing data infrastructure, collaboration, and governance activities for territories and sacred sites to serve as a COVID-19 monitoring

and tracing app (Contreras, 2020; Dias, 2020). Nested within other mitigation techniques, the app has proven useful in controlling outbreaks.

Involve Indigenous Peoples' Leaders, Activists, and Scholars in the Mainstream Science/Data/Policy Nexus Decision-Making Processes

Essential to good governance is good decision making. For populations where decisions need to be made, involving people and communities from those populations in decision making is core to governance (Cornell and Kalt, 2000; Jorgensen, 2007). During the pandemic, Australia implemented a policy to involve Aboriginal and Torres Strait Islander community organizations and experts in a Taskforce for planning and decision making (Australian Government, 2020). The Taskforce is co-chaired by the peak national group representing Aboriginal Community Controlled Health Organizations and the Australian Government Department of Health. The group convened in March 2020 to create a COVID-19 national management plan made up of several activities including establishment of community controlled respiratory clinics; point of care testing; development of online training COVID-19 infection control training; advice on community preparedness and communications.

In Aotearoa New Zealand, Māori rights to self-determination and inclusion in nation-state governance, which includes data governance, is grounded in the nation's founding constitutional document the 1840 Te Tiriti of Waitangi (Treaty of Waitangi) (Ruru, 2016). The last decade has seen growing pressure on public sector institutions to embed and implement policies and practices that give effect to Te Tiriti, particularly in the health sector (Waitangi Tribunal, 2019). Early on in the pandemic, Māori openly challenged the government's failure to meaningfully include them in pandemic response decision-making (Kukutai et al., 2020). Tribal and community leaders, some of whom set up their own community-controlled checkpoints, questioned the government's exclusive authority to make decisions in the best interests of Māori. The national Māori pandemic group, Te Ropu Whakakaupapa Urutā, called for a "by Maori, for Maori, about Maori" response strategy (Te Ropu Whakakaupapa Urutā, 2020). Key to the strategy is the critical need for reliable, routinely-available and ethnicity disaggregated data and real-time monitoring to inform Māori sovereign decisions.

Institute Data Access and Sharing Protocols Between Indigenous Peoples and Other Governments and Data Holders

In Canada, the First Nations Information Governance Centre's Principles of OCAP® (Ownership, Control, Access, and Possession) have contributed to the development of research policy and practice for the governance of First Nations' information (First Nations Information Governance Centre, 2020). For instance, the Government of Canada's Tri-Council Policy statement that guides ethical research includes

specification in Chapter 9 for Research Involving the First Nations, Inuit and Métis Peoples' in Canada (Canadian Institutes of Health Research et al., 2018). Chapter 9 acknowledges and respects the diversity of Indigenous people's lives and experiences throughout the research process (Canadian Institutes of Health Research et al., 2018). Within these frameworks, the administrative health data holders, known as Institute for Clinical Evaluative Sciences (ICES), and the Chiefs of Ontario (COO), the coordinating body for the 133 recognized First Nations communities in the province of Ontario, entered into a Data Governance Agreement. This agreement honors the First Nations' Principles of OCAP® and enables ICES, as the provincial data custodian, to carry out health-related analyses at the request of COO and the First Nations communities that COO supports and advocates on behalf of Pyper et al. (2018). During COVID-19, the existing Agreement allowed First Nations' communities and leadership to access timely and reliable information to respond quickly. Challenges persist, as funding and support limitations restrict improvements in First Nations' data availability, infrastructure and capacity (Trevethan, 2019).

Tribes in the US have had varied success in accessing their COVID-19 data held by the federal and state governments (Carroll et al., 2020c; Nagle, 2020; Tahir and Cancryn, 2020). Some states have denied tribal sovereign rights to control sharing of their COVID-19 data (Carroll et al., 2020c). In recognition of Indigenous Data Sovereignty, the State of Arizona withheld tribal zip code data until tribal data sharing permissions were obtained to publicly release tribal data. Data sharing involves both the release of tribal information as well as the sharing of tribal information that other governments hold, such as COVID-19 related data, with tribes. A number of states and the federal government have denied tribal rights to access data for decision-making (Tahir and Cancryn, 2020). There is a recognized need for other governments and organizations to establish data sharing agreements and mechanisms with Indigenous Peoples (Research Data Alliance COVID-19 Indigenous Data Working Group, 2020; United Nations, Department of Economic and Social Affairs, 2020; Urban Indian Health Institute, 2020; World Health Organization, 2020). Indigenous nations' own codes and policies can be instituted to bolster this response, such as data sharing requirements and relationships as part of tribal public health codes in the US (Hiraldo et al., 2021).

Require Collection (and Validation) of Indigenous Identifiers or Affiliation (e.g., Nation, Tribe, Ethnicity)

Decision making relies on accurate reliable information. Data used for Indigenous nation and community decision making relies on collection of Indigenous nation affiliation and/or other markers or proxies for Indigenous affiliation, such as ethnic identifiers. We strongly urge reconsidering the use of race as a proxy for Indigenous affiliation or identification. Racialized data for Indigenous Peoples often assumes homogeneity of an Indigenous community which may lead to damaging and essentialized genetic conclusions and adopts settler-colonial tools

of race-making and Indigenous erasure (Russel, 2005; Tallbear, 2013; Ratteree and Hill, 2017; Rodriguez-Lonebear, 2020). Indigenous affiliation and other identifiers more appropriately represent the rights of Indigenous Peoples to define who belongs to their communities.

During the time of COVID-19, the need for disaggregated data on Indigenous Peoples at various geographic levels is needed. Without this, COVID-19 cases and death rates are obscured due to their small population sizes relative to the majority population. As a result, it is difficult to identify emerging hotspots for infections and the need for taking preventative actions.

The United Nations, Department of Economic and Social Affairs (2020), World Health Organization (2020), and the Pan American Health Organization (del Pino and Camacho, 2020) call for the inclusion of identifiers or affiliation for Indigenous Peoples and individuals in COVID-19 data (direct and indirect) and the need to make those data available to decision-makers and Indigenous Peoples. In the US, there has been a call for the availability of data disaggregated by Indigenous nations and tribal affiliation themselves, with the caveat that this must be done within the context of Indigenous governance of those data, including data sharing agreements (Urban Indian Health Institute, 2020).

Increasing the Number of Indigenous Epidemiologists to Improve Information for Effective Public Health Response

Realizing Indigenous Peoples capability in responding to health emergencies requires increasing the number of Indigenous epidemiologists practicing in Indigenous communities and at other institutions. Dedicated training and education pathways for Indigenous people are needed to bolster public health expertise and to decolonize public health practice. This is in recognition that epidemiology and public health practice has a long history of harm under the guise of protecting public health (Parsons, 2008; Prussing, 2019; Cormack and Paine, 2020). It also aims to negate the influx of outsiders who are required to be brought up to speed or think that generic cultural awareness makes for safe practice (Kurtz et al., 2018).

An Australian program could serve as a model, the field-based epidemiology training with Aboriginal and/or Torres Strait Islander people based on the Centres for Disease Control Field Epidemiology Training Program results in 50% of trainees going on to PhDs and working in public health, environmental health and academia (Guthrie et al., 2011).

CONCLUSION

Indigenous Peoples suffer inequitable direct and indirect effects of the COVID-19 pandemic. A number of Indigenous Peoples, international organizations, journalists, and scholars have shed light on COVID-19 challenges and successes for Indigenous Peoples. Many have provided recommendations for the advancement of Indigenous rights and interests during the pandemic. However, with respect to data, few have gone beyond calling for disaggregated Indigenous COVID-19 related

data. Since data are critical for decision-making for pandemic planning, mitigation, and response, and Indigenous Peoples' participation in data stewardship can increase the benefits of data use and decrease the harms, the involvement of Indigenous Peoples' with COVID-19 data is of paramount importance. The recommendations outlined here serve to increase Indigenous Peoples governance of and access to data across data lifecycles and data ecosystems for an enhanced response to the COVID-19 pandemic. Implementation of these recommendation can lead to better pandemic responses and planning for future events for Indigenous Peoples worldwide. In a global context where diseases know no boundaries, improvements in response in Indigenous communities protects everyone by closing all lingering reservoirs and refugia for the virus to propagate, mutate, or re-initiate after a seeming cessation of cases. Addressing the effects of COVID-19 on Indigenous Peoples necessitates enhancing Indigenous nations and communities' data infrastructures and access.

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AUTHOR CONTRIBUTIONS

SC conceptualized, drafted, edited, and coordinated the manuscript. RA, PC, DC, TK, RL, MS, and RR contributed to the overall conceptualization, writing, and editing. All authors contributed to the article and approved the submitted version.

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Concrete Lessons: Policies and Practices Affecting the Impact of COVID-19 for Urban Indigenous Communities in the United States and Canada

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Throughout the Americas, most Indigenous people move through urban areas and make their homes in cities. Yet, the specific issues and concerns facing Indigenous people in cities, and the positive protective factors their vibrant urban communities generate are often overlooked and poorly understood. This has been particularly so under COVID-19 pandemic conditions. In the spring of 2020, the United Nations High Commissioner Special Rapporteur on the Rights of Indigenous Peoples called for information on the impacts of COVID-19 for Indigenous peoples. We took that opportunity to provide a response focused on urban Indigenous communities in the United States and Canada. Here, we expand on that response and Indigenous and human rights lens to review policies and practices impacting the experience of COVID-19 for urban Indigenous communities. Our analysis integrates a discussion of historical and ongoing settler colonialism, and the strengths of Indigenous community-building, as these shape the urban Indigenous experience with COVID-19. Mindful of the United Nations Declaration on the Rights of Indigenous Peoples, we highlight the perspectives of Indigenous organizations which are the lifeline of urban Indigenous communities, focusing on challenges that miscounting poses to data collection and information sharing, and the exacerbation of intersectional discrimination and human rights infringements specific to the urban context. We include Indigenous critiques of the implications of structural oppressions exposed by COVID-19, and the resulting recommendations which have emerged from Indigenous urban adaptations to lockdown isolation, the provision of safety, and delivery of services grounded in Indigenous initiatives and traditional practices.

Keywords: COVID-19, urban indigenous, human rights, indigenous rights, Canada, United States

INTRODUCTION

The deadly Coronavirus 2019 (COVID-19) pandemic laid bare gaps in national and local public health care policies, including missing data, that neglect specific issues and concerns facing Indigenous peoples in cities in both the United States (US) and Canada. Moreover, the positive protective factors generated in vibrant urban Indigenous communities are very often overlooked and

poorly understood. As we show, the urban Indigenous experience with COVID-19 is shaped by historical and ongoing settler colonial actions which violate Indigenous human rights and are sustained through intersectional forms of systemic oppression and discrimination which exacerbate mistrust. We highlight Indigenous organizations, which are the lifeline of urban Indigenous communities, as they face challenges posed by key agencies that ignore or miscount their service populations, and the lessons provided as they adapted to lockdown isolation, the provision of safety, and delivery of services.

The rights of Indigenous peoples, as defined within the International Covenant on Economic, Social and Cultural Rights and the United Nations Declaration on the Rights of Indigenous Peoples, are inalienable and should not be diminished or extinguished when Indigenous peoples move to and through urban space (Belanger, 2011). Previously, we answered a special call from the United Nations Human Rights High Commission Special Rapporteur on the rights of Indigenous peoples, Francisco Calí Tzay, for his report to the United Nations 75th General Assembly (RISIU, 2020; UN General Assembly, 2020; UNHROHC, 2020). Ours was part of the response of the hemispheric-wide *Red de Investigaciones Sobre Indígenas Urbanos* (hereafter RISIU; Research Network on Urban Indigenous Peoples). The network includes several dozen academics, Indigenous and social movement leaders, and representatives of national organizations. The RISIU assembled information on the impacts of COVID-19 for urban Indigenous communities in nineteen countries of the Americas and was one of over 150 submissions received. In his UN report, the Special Rapporteur confirmed that Indigenous peoples were “the most harshly affected” by COVID-19 even though they only represent 6% of the world population because, Indigenous societies, already facing numerous existential threats, face higher risks of dying of the disease, of experiencing discrimination and a disproportionate impact as a result of confinement measures, and of being left without support to defend their peoples from intensifying rights violations even as the pandemic rages ... COVID-19 has created an unprecedented wave of fear, sadness and hardship around the globe, yet indigenous peoples feel particularly forgotten and left behind (UN General Assembly, 2020: 5).

This invisibility is compounded by dispossession, displacement, assimilation, and cultural oppression for Indigenous peoples in urban areas in the United States and Canada. In both countries, settler colonial cities were formed historically on ancestral Indigenous peoples’ homeland, especially lands that afforded access to trade routes and other abundance. Other colonial policies and practices further compelled Indigenous peoples’ movements between rural and urban areas, but also the survivance with which Indigenous peoples have created contemporary urban communities (Howard and Lobo, 2013; Howard, 2019).

Special Rapporteur Calí Tzay asked for reports on COVID-19 related experiences of Indigenous peoples in the specific areas of access to health care, information, culturally appropriate services, justice, education, shelter, and sustenance. He also wanted to hear about Indigenous leadership in the implementation of national

pandemic response, and the role of Indigenous healing models and traditional systems. We have taken up these areas of inquiry through the lens of Indigenous and human rights and a grounded methodology, referencing Indigenous community-based scholarship and comparative content analysis. The choice of documents and sources examined for our analysis in our original research was guided directly by the Special Rapporteur’s specific questions and included Indigenous and non-Indigenous COVID-19 information websites and policy statements issued by governments and organizations, media reports, review of Indigenous organization social media, webinars, and personal communications. Across these sources, we scanned for urban Indigenous content and the use of human and Indigenous rights discourse. In extensively expanding that work into the current article, we added to our analysis other written responses submitted to the Special Rapporteur’s call, which were selected for content from and about the United States and/or Canada with direct reference to urban Indigenous topics. In total eighty-four sources were examined in addition to the secondary literature cited.

UNITED STATES AND CANADIAN URBAN INDIGENOUS COMMUNITIES IN HEMISPHERIC CONTEXT

Indigenous peoples are interconnected through local, regional, and national experiences of the hemispheric dynamics of colonization and settler colonialism. Previous experiences of pandemics sickened and killed a large portion of Indigenous populations throughout the Americas since the arrival and colonization by Europeans. Today, movement and migrations over seasonal, short, and often extensive distances continue to be essential to Indigenous life throughout the hemisphere (Lobo, 2009). Despite continuing stereotypes that Indigenous peoples reside overwhelmingly in rural areas, since the early 19th century, they have moved from rural to urban areas within and across nation-state borders throughout the hemisphere, diversifying the Indigenous population that make up many cities.

The urban environment has not provided safe haven from COVID-19 for Indigenous peoples, and the impact has been devastating. In both the United States and Canada about three-quarters of all Indigenous people reside in urban areas (Rotondi et al., 2017; Congress of Aboriginal Peoples, 2019; Villarreal et al., 2020). As researchers who have focused much of our work on urban Indigenous topics for many years, we have observed and personally experienced the multiple effects, including impacts of and responses to COVID-19 for urban Indigenous peoples in the United States and Canada, while remaining cognizant of the hemispheric-wide domain within which the pandemic continues to unfold. There are varying degrees of health disparities experienced by Indigenous communities world-wide. However, as the World Health Organization’s (WHO) Commission on the Social Determinants of Health notes, the unhealthy life conditions endemic in many Indigenous communities is attributable to several chronic distal determinants, and “The inequity [in daily living conditions] is systematic, produced by

social norms, policies, and practices that tolerate or actually promote unfair distribution of and access to power, wealth and other necessary social resources.” Colonization is one of the common underlying causes of persistent health disparities for Indigenous peoples (World Health Organization, 2008: 2).

This international guidance situates understanding of the impacts of COVID-19 for Indigenous peoples by highlighting specific reference to “the enjoyment of the highest attainable standard of physical and mental health without discrimination ... the right of indigenous peoples to be actively involved in developing, determining, and administering health programmes through their own institutions ... and to their traditional medicines and health practices” (UN General Assembly, 2020: 5). In taking up this framework, Special Rapporteur Francisco Calí Tzay introduced the central role of “development-related activities,” which include urbanization, in the displacement of Indigenous peoples across and away from traditional territories, and in the denial of their sources of nutrition and “symbiotic relationships with their lands, [which] has deleterious effect on their health” (UN General Assembly, 2020: 6). Moreover, the Special Rapporteur acknowledges that Indigenous “collective memory is marked by pandemics” and underscores the interconnection of systemic racism and inequities in health status, access to health care, and socioenvironmental factors that diminish immune response and expose Indigenous peoples more starkly to COVID-19 (UN General Assembly, 2020: 8; see also; Paradies, 2006a; Paradies, 2006b).

As the Special Rapporteur confirms, these are significant factors that exacerbate the way data is not collected and disaggregated in meaningful ways so that Indigenous peoples “continue to be invisible in the consciousness of majority populations and are likely to be left behind in prevention and care programmes and in the provision of other socioeconomic support” (UN General Assembly, 2020: 11). As Calí Tzay also states, “where communities distrust the Government or wish to assert exclusive ownership of such information [and where] indigenous communities have collected data themselves, [these] were not reflected or only partially reflected in national periodic COVID reports” (UN General Assembly, 2020: 11–12). This finding was noted as particularly problematic in urban areas where infection and mortality are not tied to Indigenous identification and therefore not only lead to invisibility in public records, but also expose “the lack of culturally specific approaches to health care in cities” (UN General Assembly, 2020: 12).

Overall, the Special Rapporteur’s reference to Indigenous peoples in cities is not expansive; however, his report asserts that poverty, overcrowded housing, and “deep racism and structural discrimination further hinders access to basic health and social services and protective equipment” in urban areas where one might assume these would be more available than in remote, rural regions (UN General Assembly, 2020: 10). Of particular concern are the escalation of violence against women and children in relation to lockdown policies, and other deleterious effects of restrictions on the freedom of movement of Indigenous peoples, with noted attention to those living in urban areas, and the increase of existing crises in mental health and substance misuse (UN General Assembly, 2020: 8,17). The Special Rapporteur found that COVID-19 relief

in the form of economic, health, and protective supports has been painfully protracted and insufficient given the predictability that Indigenous peoples would be disproportionately affected. While this probe found that in some cases funding was set aside for Indigenous peoples, it was routed in ways that compounded the exclusion of urban Indigenous communities (UN General Assembly, 2020: 14).

Moreover, responses largely excluded Indigenous peoples from leadership and coordination, and especially “failed to adequately take into account their specific needs across their various lifestyles or whether they live in ... urban settings ... [or] take the risk of contracting COVID-19 by traveling to cities on public transport to collect financial assistance to which they were entitled” (UN General Assembly, 2020: 14). The report emphasizes the particular economic hardships faced by Indigenous peoples in urban areas who rely heavily on informal and precarious employment conditions, have been disproportionately turned out of housing, are finding it difficult to access basic sustenance, and are subject to an intensification of stigmatization (UN General Assembly, 2020: 19). These conditions are additionally harmful in a context where the importance of kin and community-based supports, traditional extended family co-residence, and communal food sharing and the practice of spiritual ceremonies are often disrespected, while especially needed at this time of crisis (UN General Assembly, 2020: 8).

UNITED STATES SETTLER COLONIAL POLICIES LAID BARE IN THE IMPACT OF COVID-19

In the United States, the known impact of COVID-19 on Indigenous populations overall is lacking although they are listed among the high-risk groups. The Kaiser Family Foundation estimates that American Indian/Alaska Native and Native Hawaiian/Pacific Islanders are at risk for contracting COVID-19 at a rate of 34% and 23% respectively, compared with 21% for Whites, 27% for Blacks, and 12% for Hispanics, between the ages of 18–64 (Artiga and Orgera, 2020: 3). Although the numbers lack completeness, disproportionate mortality rates are shocking in some areas such as New Mexico where Indigenous people account for 44% of COVID-19 deaths even though they constitute 11% of the state’s population, and Indigenous communities in Arizona have seen nearly 22% of COVID-19 deaths in that state where they make up 2% of the population. (National Congress of American Indians, 2020a: 2).

The poor health status of many Indigenous people is influenced by poverty, limited or lack of access to quality health care and the prevalence of chronic health problems or disabilities (Roubideaux and Dixon, 2001). In a nation with highly developed modern health care delivery systems, Indigenous peoples often face numerous barriers to disease prevention and quality health care, including lack of health insurance, structural racism, mistrust, and other factors such as access to technology. The convenience of working remotely is not possible for many Indigenous peoples employed in the service industry and/or other labor occupations (U.S. Census, 2010). They comprise a high percentage of front-line workers whose

employment poses unprotected exposure to COVID-19. In some areas of the country, these workers commute daily between rural and urban communities to work, to shop, to attend school or attend recreational activities; and in doing so, they are at risk for developing or transmitting the virus. For example, when the first case of COVID-19 was confirmed in the Navajo Nation, it was traced to an earlier evangelical church gathering that included reservation and off-reservation attendees (Lee, 2020).

While Indigenous people make up only about 1.7% of the United States population, some estimate that as many as 80% live in urban or off-reservation communities (Villarroel et al., 2020). For some younger generation, urban life has and continues to be their only living experiences. Despite their places of residence, tribal members who have federal recognition have certain rights that are retained and secured through treaties with the United States. The migration to cities for many Indigenous families has occurred over time. For example, some individuals or couples were relocated to the city from reservations under a federal relocation program in the 1950s and 60s (American Indian Policy Review Commission, 1976). The relocation program recruited young adults with promises of employment or job-training opportunities in selected cities. However, these promises were not realized, and instead, resulted in Indigenous people living in segregated neighborhoods, being assigned to poor or substandard vocational training that resulted in joblessness, poverty, and sometimes poor health (Lobo and Peters, 2001). Other Indigenous people elected to live in cities after military service or as graduates of forced off-reservation boarding school experiences (Howard and Lobo, 2013).

Seeking a place of acceptance in an unfamiliar urban environment, organizations in some cities established a safe gathering place such as the Oakland Intertribal Friendship House in California, or the Chicago American Indian Center in Chicago, IL (Online Archives of California, American Indian Community History, 2021). These organizations focused on creating protected places within the often threatening and racist urban environment; places to gather, form friendships, create social alliances, eat together, locate and share information and resources including health care, food and housing, economic opportunities, education, and to practice cultural life. These resources became powerful forces in creating and sustaining Indigenous urban communities and advocating for the assertion of Indigenous rights for Indigenous peoples living in cities. Local groups formed, like for example, the Chicago American Indian Community Coalition, and national coalitions grew such as the National Urban Indian Family Coalition that includes twenty-four cities and forty-five urban Indigenous organizations (National Urban Indian Family Coalition, 2020: 8; Online Archives of California, American Indian Community History, 2021).

The Historical and Disease Context for COVID-19

Mistrust reflects the devastating history left by cycles of epidemics that followed European contact. Lacking immunity and weapons

for protection, survivors faced dispossession of their ancestral homeland and most were forced into resettlement onto small plots of land (federal reservations), with little or no resources for sustainability. Warfare and epidemics are remembered as instruments of genocide that hastened the depopulation of the Americas as well as the decimation of many Indigenous groups. This includes threats of biological warfare. For instance, a proposal by an officer during the conflict over American land between England and France to distribute smallpox contaminated blankets to tribal warriors remains widely remembered among Indigenous people today (Jones, 2004: 94–95). Mistrust has also been steadily reinforced by policies of land dispossession and forced removal that ignited and expanded the erosion of ancestral Indigenous cultural history and strength (Lindquist and Zanger, 1993). The removal of Indigenous peoples to the most unproductive land and where they remained contained became ideal breeding ground for more epidemics, poverty, malnutrition, and ill health.

Tribes negotiated treaties with the federal government to secure Indigenous rights, as well as various forms of payment, including health care for ceding land. Treaty terms have rarely been honored by the government. In fact, history has often reflected lack of good faith, leadership and guidance in the way federal authorities have failed in their treaty responsibilities. Initially, the United States established a small Indian agency within the War Department, a federal agency responsible for warfare and containment, not health care. When the United States Department of Interior was established in 1849, the health care responsibility for Indigenous peoples was transferred to this new agency, but with no additional resources. Annual federal appropriations to support the programs in the Indian Affairs office in the Department of Interior were not only inadequate, but each dollar was earmarked for specific items, many of which were never purchased (Joe, 2003).

Over time, the health conditions of Indigenous peoples continued to decline while no substantial resources were implemented (Meriam, 1928; U.S. Commission on Civil Rights, 1966; American Indian Policy Review, 1977). Instead, the government in the 1950s once again moved the health responsibility for Indigenous peoples from the Department of Interior to the United States Public Health Service (PHS). Although there have been some improvements, a series of civil rights reports, some commissioned by the government, have repeatedly confirmed that the poor health conditions of Indigenous peoples had not greatly improved due to the lack of funding and meaningful policies or legislations (U.S. Commission of Civil Rights, 2003; U.S. Commission of Civil Rights, 2018). In 2017, Indian Health Service (IHS) expenditures per patient was reported to be \$2,834 compared to \$9,990 per person in federal health care spending nationwide (U.S. Commission of Civil Rights, 2018: 66). In addition, the funding allocated for urban Indian health programs is estimated to be only 22% of projected need (U.S. Commission of Civil Rights, 2018: 74). The urban health programs' share of IHS funding has not reflected the demographic shift from rural to urban communities (Artiga and Arguello, 2013).

Urban or rural, Indigenous populations in United States are haunted by multiple health disparities (Joe, 2015). The leading causes of death for Indigenous people include heart disease, malignant neoplasm, unintentional injuries, and diabetes (Indian Health Service, 2019). Until the mid-1950s, infectious diseases such as *tuberculosis*, glaucoma, and meningitis were the leading causes of death and hospitalization. Although these have declined, non-communicable diseases with an array of complications such as high rates of chronic liver disease and chronic lower respiratory diseases have escalated (Indian Health Service, 2019). Some infectious diseases are still prevalent as well as new ones including antibiotic resistant *tuberculosis*, HIV/AIDS, invasive pneumococcal infections, and diarrheal infections (Butler et al., 2001; Holman et al., 2011; Cheek et al., 2014).

Accessing Health Care

The rights of access to health care for Indigenous populations living on federal tribal reservations is determined by an array of local, state, or federal eligibility criteria, some imposed to limit as much as possible the exercise of these rights. For example, to be eligible to receive health care provided by the IHS, an individual needs to be enrolled in a federally recognized tribe (National Congress of American Indians, 2019: 11). Not all tribes have federal recognition; some have only state recognition and are not eligible for health care provided by IHS (James et al., 2009). Medicare and Medicaid provide other primary health care coverage for both reservation and urban-based Indigenous populations. IHS has its own longstanding medical data system in place and draws on this database to mark progress and document unmet health care needs for reservation-based populations only. A similar comprehensive system does not exist for Indigenous populations in urban communities.

This gap in services has led to the development of urban Indigenous health care organizations. Many followed the pattern of free store front clinics in the 1960s, which operated part-time and depended on donations and volunteer providers. The first clinics were established in San Francisco, CA, Seattle, WA, Minneapolis, MN, and Oklahoma City, OK. The services provided at these sites were either free or offered on a sliding scale. Because IHS could only provide health care to reservation-based tribal members, no federal assistance was available to these urban clinics until Title V of the Indian Health Care Improvement Act (P.L. 94-437) was passed by Congress in 1976. Even so, the Act authorized approximately 1% of IHS funding for urban clinics, which has not increased to meet the health care needs of the 80% of Indigenous peoples living in cities. The annual congressional appropriation for IHS has been and continues to be discretionary and is not an entitlement as it is for other federal programs such as Medicare. Inadequate funding prevented most storefront clinics from providing a full range of medical care until the scope of work for some clinics was expanded in 1988 with an amendment to the Indian Health Care Amendment (P.L. 100-713). The passage of the 1988 Anti-Drug Abuse Act also gave urban health programs the ability to deliver alcoholism and substance-misuse treatment and prevention programs (Namis, 2019).

Response to COVID-19

The first reported cases of COVID-19 in the United States were in Seattle, where the local Indigenous urban health programs serve about 6,000 patients annually (Ortiz, 2020). Following on the health rights history and context just described, these programs were not equipped nor had the resources to assist their patient population as the pandemic hit, a pattern repeated across North America (Crevier, 2020). Lack of funds and medical equipment disrupted or ceased some essential services provided by urban Indigenous health programs. The chaotic situation everywhere meant few supplies or equipment were available to small, non-profit clinics or health programs. In one case, an Indigenous clinic in Seattle requested medical supplies in March 2020, only to get a box of body bags the following month. The shipment was said to be unintentional, but when it arrived, the clinic's Chief Medical Officer said: "My team turned ghost white, we asked for tests and they sent us a box of body bags" (Ortiz, 2020).

The virus-related closing of other key urban resources was devastating for urban families, especially those who depended on them for many services. On average, the forty-five urban Indian organizations that are members of the National Council of Urban Indian Health serve approximately 77,000 patients annually. Reimbursement funds for their services are received from state and local governments, but the forced closure of these services threatened their survival (National Council of Urban Indian Health, 2020). For example, one program in St. Paul, MN, reported that their emergency shelter was losing \$14,000 a month due to stay-at-home and physical distancing requirements (National Urban Indian Family Coalition, 2020: 6). As the volume of patient load plummeted, the reduced services meant many of the health programs could not apply for third party insurance payments, a resource for over half of the budgets for many programs (National Council of Urban Indian Health, 2020). Kerry Hawk Lessard, Executive Director of Native American LifeLines, serving Baltimore, MD and Boston, MA, reported that because the program does not deliver direct medical services it could not offer COVID-19 testing. However, the program staff did not abandon their responsibilities, and called all their 770 patients to "ensure they know about COVID-19 risk, symptoms, and prevention and to understand the rates of positive cases and mortality. . . ." (Hlavinka, 2020a).

As the pandemic wore on with social distancing, quarantines, and the temporary closing of many urban Indigenous organizations, use of the internet to reach community members and for inter-agency communication expanded significantly. Essential information regarding resources, events, personal announcements and so forth that has been a rich part of in-person urban Indigenous organization experience increasingly took place through social media and online presence. For example, in Phoenix, AZ, the Indigenous health organization newsletter *Native Health News* had 57 internet pages in its September edition, and included extensive COVID-19 health tips and information regarding regional health and medical resources, tele-counseling, schedules for home food delivery, safe children's activities and programs (Native Health Phoenix, 2020).

Urban Indigenous communities were devastated by the sudden closing of their health and social service organizations. The Tucson Indian Center, in Tucson, AZ, locked its doors and posted emergency phone numbers, while shifting to serving clients remotely. Community events or celebrations were canceled but staff quickly reorganized to deliver food, medicine, and other necessities to those most in need. A major national Indigenous newspaper, *Indian Country Today*, started listing many important events or Indigenous enterprises that had been closed, canceled, or postponed, including special sacred ceremonial activities. By early June, some organizations were carefully beginning to return to limited activities, but the closing and cancellations impacted basic rights to practice cultural activities, spiritual well-being, and economic sustainability for urban Indigenous communities (Shah et al., 2020).

In Chicago, where the Indigenous population is approximately 27,000, researcher Larkin-Gilmore commented on how blame for COVID-19 is placed on “native bodies [as] somewhat more susceptible to COVID-19 when really the reasons for that is far more complicated and based in . . . structural and political disparities” firmly rooted in racism (quoted in Spoto, 2020). Moreover, because Illinois counts Indigenous people as “others,” the true picture of COVID-19 mortality and morbidity is lost in the data. The director of the urban clinic in Chicago reports that between the end of April and June 2020, 23% of the clinic’s Indigenous patients tested positive for the virus, a rate that is 7.5% higher than for other Chicago residents. Data obtained through the Freedom of Information Act, for a period between March and April 2020, showed a 15% coronavirus mortality rate for Indigenous people compared to 5% for the general population of Chicago (Spoto, 2020). These examples illustrate how deeply rooted erasure of basic human and Indigenous rights fatally manifest on Indigenous bodies in urban areas.

Indigenous Population Statistics, Health and Data Issues

Once registered in the mainstream health care delivery system, Indigenous patients’ ethnicity is often misclassified. It is not uncommon for a death certificate, or other racial or ethnic classification data entered on health records, to identify an Indigenous person as “white or unknown” (Centers for Disease Control, 1993; Haozous et al., 2014). The increase in multi-racial admixture for Indigenous peoples, especially those living in urban areas, adds to the complexity of racial/ethnic identity. Misclassification treats Indigenous people as an “invisible population” (Lobo, 2002; Liebler, 2018), and reflects persistent population debates where even the pre-contact population of Indigenous peoples and the extent of depopulations associated with epidemics and warfare continue to be questioned, although careful scholarship has estimated genocidal impacts on Indigenous demographics (Dobyns, 1983; Thornton, 2000; Jones, 2004).

Several local and national policies have mandated health surveillance systems with specific requirements on data collection, reporting, and data sharing. Included are required

reporting of deaths, births, hospitalization, and other reportable data used to track and evaluate changes in the health status of the population. While data reported by surveillance systems are reliable and useful, these can also pose problems when some important health data is not available (Jim et al., 2014). With COVID-19, the NCAI reported 42,085 Indigenous people diagnosed between March 23 and September 1, 2020, relying on IHS data (National Congress of American Indians, 2020b). The NCAI also indicates that the highest COVID-19 incidence rates among the Indigenous populations were in the Navajo Nation and two urban communities—Phoenix, and Oklahoma City. While this and other IHS data are important, data for Indigenous people living off-reservation or in urban communities are not routinely included. The establishment of 12 IHS-funded regional Epidemiology Centers is slowly changing and improving Indigenous health data, with one center focused on urban Indigenous health programs. In 2000, the Seattle Indian Health Board, home of the Urban Indian Health Institute (UIHI) was funded to establish this center, and it serves or collaborates with 62 urban-based programs nationwide. The Center’s goal is “to decolonize data for indigenous people, by indigenous people.” Although all the Epidemiology Centers have been granted official Public Health Authority by CDC, during the pandemic most national and state agencies refused to share or provide COVID-19 data with these centers; the typical reason for refusing was: “data is nonpublic” (Tahir and Cancryn, 2020).

For several decades, the problem of racial misclassification of Indigenous people, especially in cities, has hidden the health problems confronting Indigenous populations. Several states label American Indians as “other” including Texas, Florida, Michigan, New York, and California. Thus, for cities with large Indigenous communities like New York, NY, and Los Angeles, CA, also heavily impacted by COVID-19, there is no explicit data breakdown about Indigenous populations (Nagle, 2020). This leads to misinformation and diminishes understanding of the extent and significance of the impacts of COVID-19 for Indigenous peoples in urban areas. The missing data is a critical concern for Indigenous agencies working to address health disparities. This problem is not ignored by data keepers. For one, the CDC’s Morbidity and Mortality Weekly Report (MMWR) found COVID-19 cases for United States’ Indigenous population was 3.5 times higher than for non-Hispanic whites (Hatcher et al., 2020). The report was based on data obtained from only 23 states that routinely record race and ethnicity. This excessive absence of data represents an important gap in public health data and additional resources to support case investigation and reporting infrastructure in Indigenous communities are needed (Hlavinka, 2020b).

Even with these data problems, the United States Centers for Medicare and Medicaid Services (CMMS) reported in July 2020, that Indigenous people had the second highest rate of hospitalization for COVID-19 among racial/ethnic groups after Black Americans. One CDC report found that from among 340,059 confirmed COVID-19 cases, the rate of infection was 3.5 times higher for Indigenous people than it was for the population identified as white. This report also indicated infections were more common among younger Indigenous

people, with a median age of 40, compared to 51 years for whites (Smith-Schoenwald, 2020). Indigenous patients may also require complicated treatment for COVID-19 due to high comorbidity rates. Hospitalization for COVID-19 care is extremely expensive. The CMMS paid \$2.8 billion in Medicare fee-for-service claims for patients hospitalized with COVID-19 at that reporting time, with the average payout at \$25,255 per beneficiary (Centers for Medicare and Medicaid Services, 2020).

One Indigenous physician providing care at a Navajo Nation hospital notes that the pandemic further exposed all the deficiencies and inadequacies that were accepted as ‘normal’ pre-COVID-19 such as poor access to water, electricity and transportation (Krist, 2020). Many of the historical, structural, and contemporary inequities of settler colonial society are manifest in the inadequacies of the health care delivery systems serving Indigenous peoples in the United States. Yet, even as COVID-19 makes more starkly visible the reach of these inequities into the growing social, cultural, and economic divide of suffering experienced by Indigenous peoples, urban Indigenous peoples remain stubbornly invisible.

PANDEMIC COLONIALISM IN CANADA

This “normalization” of the structural oppression and invisibility of urban Indigenous peoples just described for the United States is mirrored in Canada even if the events that trace the patterns of settler colonialism and articulation of Indigenous rights are slightly different. Sixty-five to eighty percent of the two million Indigenous people in Canada live in urban and “off-reserve” communities (Rotondi et al., 2017; Congress of Aboriginal Peoples, 2019). Information on COVID-19 for Indigenous people living in these areas is not gathered effectively by the Canadian state. This is complicated by the overall problem that “no agency or organization in Canada [is] reliably recording and releasing COVID-19 data indicating whether or not a person is Indigenous” (Skye, 2020). Indigenous Services Canada (ISC) officially collects data for First Nations communities that explicitly excludes urban communities and individuals living off-reserve and in the territories. ISC relies on each “provincial chief public health officers work with ISC’s regional medical officers and nurses to provide medical support as needed when a positive case is reported” (Indigenous Services Canada, 2020). The Public Health Agency of Canada (PHAC) reports daily on COVID-19 rates for the country but includes disaggregated data on age and sex only, referring visitors to links to provincial and territorial agencies for more details. (Public Health Agency of Canada, 2021). These, in turn, vary in their reporting on Indigenous peoples’ health status, and generally do not publish data for Indigenous cases.

ISC may track Indigenous individuals diagnosed with COVID-19 who are members of First Nations and registered with the Inuit Health Board living in urban areas, but these are not distinguished as such. ISC has admitted that data collection needs to be improved on COVID-19 and is investing in alternative approaches. However, the ISC plan focuses on the idea that it is the remoteness and isolation of Indigenous peoples

in Canada that is the barrier to accurate data collection, with little attention to urban populations in these efforts, even as urban Indigenous representative organizations are ready and available to engage (National Association of Friendship Centers, 2020). While Canada claims it is acting on COVID-19 through engagement with Indigenous leadership, respect for treaty rights, and ending enduring inequities grounded in structurally racist policies, funding in practice is focused on immediate pandemic relief and mitigating risk (UN General Assembly, 2020: 12; Government of Canada, 2020). The state thus exercises pandemic colonialism, sustaining settler colonial status quo through a method of pairing intervention on proximal aspects of the pandemic with talk about structural oppression and Indigenous rights.

State relationships to Indigenous peoples are meant to be guided by the historically and constitutionally grounded fiduciary duties of the federal government to recognize and support Indigenous peoples’ self-government. However, this duty is diluted by the extent to which federal responsibility has devolved over decades to provincial, territorial, and local entities which handle health care monitoring and delivery. This has entrenched settler colonial erasure of Indigenous peoples’ health status. The census and other data collection mechanisms have been criticized for a long time with regards to inaccurate counting of urban Indigenous peoples (Howard and Lobo, 2013; Rotondi et al., 2017). It is a systemic problem that extends from faulty data collection even for Indigenous peoples who are counted, highlighted by the COVID-19 crisis (Dunne, 2020a; Dunne, 2020b). For example, the Aboriginal Peoples’ Survey (APS), conducted every five years focuses on education, employment, health, language, income, housing and mobility, but does not reach urban communities sufficiently, not counting people experiencing homelessness or living in non-permanent or collective dwellings. Statistics Canada promises that its alternative crowd-sourcing survey collection series includes information that will provide better understanding of these “hard-to-reach” populations, and how COVID-19 is experienced by urban Indigenous communities. To date these data remain insufficient or are hard to extrapolate. The scattered and insufficient ways data is collected about Indigenous peoples by the state is correlated to funding that does not meet the needs of urban Indigenous communities and constitutes a form of discrimination deeply ingrained in differential rights of acknowledgment as detailed below.

Disseminating Information to Urban Indigenous Communities in Canada

The PHAC funds the National Collaborating Center for Indigenous Health that provides a clearing house of COVID-19 resources ranging from general guidelines to podcasts, webinars, and fact sheets aimed at Indigenous individuals and communities though none are specifically urban. ISC did create preventative public service announcements about COVID-19 for radio available in 20 Indigenous languages. Each province’s health authority maintains websites with information specific for Indigenous peoples with content from general guidance on

avoiding disease spread to detailed Indigenous-engaged advice specific to Indigenous concerns, some in Indigenous languages. While we did not examine the impact of providing COVID-19 information in Indigenous languages, the value and significance of doing so is reported from a global standpoint at the website of the UN International Year of Indigenous Languages (IYIL n. d.) and merits further study.

Urban Indigenous communities are not differentiated at the government websites examined, however, some of the advice such as from Indigenous physicians on ceremonies, for countering stigma, and keeping Elders safe, would be useful in urban contexts if Indigenous peoples can find them. Some of the Indigenous provincial and territorial-level health authority counterparts include attention to urban Indigenous communities. For example, the First Nations Health and Social Secretariat of Manitoba maintains a COVID-19 Pandemic Response Coordination Team and provides detailed reporting on cases including for the province's major city of Winnipeg which has the largest urban Indigenous population in Canada. The Métis Nation of Canada (MNC) is a "distinct Indigenous people and nation recognized in the Constitution Act 1982," with many constituents in urban areas. The MNC issues daily COVID-19 messages and provides an extensive clearinghouse of information at its website. However, these may not be accessed by other Indigenous peoples.

Urban Indigenous Input on National Response and Programs that Affect Them

At the end of May 2020, the federal government pledged 90 million dollars to support off-reserve Indigenous organizations, increased from 15 million announced in March. The National Association of Friendship Centers (NAFC), which represents over 100 centers serving urban Indigenous people across Canada, spoke out about how urban Indigenous people were being left behind by the Canadian federal government's response to COVID-19, and that the funding promised did not cover all the needs across Canada. Even with the increased funding, the amount designated for urban and off-reserve communities is less than 10% of the overall amount of COVID-19 support allotted for Indigenous peoples. The NAFC emphasized how this highlighted the Canadian government's lack of acknowledgment of urban Indigenous peoples, and its disregard for their constitutionally and internationally protected rights (Canada's National Observer, 2020).

The NAFC also submitted a response to the UNHRHC Special Rapporteur, which noted that while the NAFC "continually provided context from the urban perspective and realities" the impact is variable and there remains a "large gap in urban Indigenous voices and perspectives being heard" (National Association of Friendship Centers, 2020). The NAFC submission goes on to emphasize the danger posed to accessing potentially life-saving services caused by the entrenched "jurisdictional wrangling," noted above. This frustrating business-as-usual approach by the state to the relationship with urban Indigenous leadership means that securing funds for urban Indigenous communities is not only

delayed, it is "not based on need or population" (National Association of Friendship Centers, 2020: 3). The fact that federally recognized Indigenous governments receive funding directly based on population, whereas urban Indigenous representative organizations have to competitively apply for grants lays bare the discriminatory nature of the state's policies and practices toward Indigenous peoples in urban areas. The NAFC called this "flawed and disrespectful" and underscores how the Canadian false dichotomy that distinguishes rural and urban Indigenous populations hurts Indigenous peoples in totality. The United Nations may agree, writing in a 2010 report about how this distinction globally serves the assimilationist interests of nation-state building (United Nations, 2010). It may be further argued that this approach violates the international conventions mentioned above, and to which Canada is a signatory, including the United Nations Declaration on the Rights of Indigenous Peoples, officially adopted by Canada in 2016.

The Congress of Aboriginal Peoples (CAP) which represents "the interests of Métis, non-status Indians . . . and all off-reserve status and non-status Indians" filed a legal action "over inadequate and discriminatory funding during COVID-19" in mid-May 2020 (Congress of Aboriginal Peoples, 2020). The court application framed the problem in terms of discrimination and violation of Indigenous rights enshrined in the Canadian Charter of Rights and Freedoms, and in Supreme Court precedent. In a press release, CAP wrote that "despite the federal government's laudable goals, the funding allocations have been discriminatory and at the expense of the doubly disadvantaged Indigenous populations served by CAP." The release further remarked on the Canadian government's disregard of CAP efforts to be heard and specified the urgency with which support is needed for health care including mental health, but also to address housing, education, food insecurity, and the special needs of Elders (Congress of Aboriginal Peoples, 2020).

In addition to these urban-specific organizations, the Assembly of First Nations, (2020), a national advocacy organization for First Nations' citizens, included urban Indigenous people in one of its several COVID-19 podcasts. However, as the national representative organization for reserve-based communities, the AFN has not generally used its power to tackle the rural-urban divide centrally taken up by the NAFC and CAP. Overall, the federal government funds acknowledge two major issues in Indigenous communities that have been exacerbated by COVID-19: the need for long-term income-support and to build and support shelters for women fleeing escalated domestic violence. This followed on news that Indigenous women's shelters closed, including one in Montreal, after "multiple attempts to get local health and social services personnel to come test residents, and a frustrating ordeal getting assistance" (Rowe, 2020). Extraordinarily, however, the NAFC reports that all of the shelter funding announced excludes urban Indigenous communities, despite the fact that "Indigenous women and their children face violence and need shelter in off-reserve contexts, and irrespective of whether they are First Nations, Métis, or Inuit" (National Association of Friendship Centers, 2020: 7).

Pandemic Exacerbation of Intersectional Discrimination and Human Rights Infringements

The above matters of discrimination that remain pervasive in Canadian policy and practice based on the on-reserve/off reserve distinction also ignores a deeper intersectional analysis that takes into account the multiple social identities that shape Indigeneity and the mutually reinforcing inequities that co-constitute numerous systems of oppression. Indigenous peoples' engagement with urban places and urbanization processes do not stand separate from socio-economic structures, gender and age diversity, and disability status, among other intersections. This exacerbates the impacts of COVID-19 if no relief is aimed at the particular systemic barriers faced by youth, Elders, and disabled, or for "Two-Spirit and LGBTQ + individuals, who are at higher risk for infection due to rates of poverty, social isolation, and systemic discrimination within the health care system. . . . Including an intersectional lens to distinctions will better position the Government of Canada to provide urban indigenous community members with the supports they need throughout and beyond this pandemic" (National Association of Friendship Centers, 2020: 5).

The PHAC identifies a series of "significant economic, social and health challenges that could play a role in how COVID-19 affects the lives of Indigenous people" including in urban settings. These are high levels of chronic disease, inadequate housing, multi-generational cohabitation, as well as isolation from, and discrimination in, health care facilities. The federal government also commissioned a brief study that correlates socio-economic data collected in the 2016 federal census and 2017 APS to known potential risks and challenges of COVID-19. This study emphasizes that high rates of poverty, food insecurity, and the inability to cover an unexpected expense make Indigenous people, especially women and children in urban areas very vulnerable to immediate and long-term impacts of COVID-19, including slowing the spread of disease, stunting access to education, and increasing the risk of homelessness (Arriagada et al., 2020). In its submission to the UNHRHC Special Rapporteur, the Government of Canada confirmed these particular differential impacts for what they called "intersectional and unique sub-populations" (Government of Canada, 2020: 8). The report shares plans to initiate "Indigenous-led engagement related to a continuum of supportive care services . . . to further inform the comprehensive community-based approaches that support the most vulnerable Indigenous people," however, it generally steers clear of any detailed discussion of urban Indigenous community concerns, focusing on the direct effects of isolation and shutdowns of services and businesses (Government of Canada, 2020: 8).

Meanwhile, it appears that some provinces to whom the federal government devolves responsibilities for many of these issues, identify more directly the structural contexts for COVID-19's differential impacts on Indigenous peoples. As part of a global analysis of social determinants and COVID-19, Public Health Ontario acknowledges that Indigenous "communities face

health inequities associated with complex influences of colonization, residential schools and continued experiences of systemic racism" and references other research on these issues that includes urban sources (Reading and Wein, 2009; Beckett et al., 2018). While this provincial recognition is significant it may validate federal renegeing on its Indigenous treaty-based responsibilities and translate into inappropriate or insufficient support.

The Native Women's Association of Canada (NWAC) also submitted a response to the UNHRHC Special Rapporteur, which provides results of its survey (n = 750), "The Impacts of COVID-19 on Indigenous Women and Gender-Diverse People in Canada." The submission centers on NWAC's ongoing work to hold the Canadian government accountable to its national action plan to attend to the "Calls for Justice" issued in findings of the National Inquiry on Missing and Murdered Indigenous Women (National Inquiry into Missing and Murdered Indigenous Women and Girls, 2019; Native Women's Association of Canada, 2020a). The survey illuminates the glaring correlation between state responsibility for the ever-expanding violation of Indigenous people's "absolute right to physical and mental integrity," and a clear upsurge in domestic violence in conjunction with the conditions of COVID-19. The survey concludes, "actions from government at all levels are needed to address the issue of systemic violence against Indigenous women and gender-diverse people." Again, in its submission to the UNHRHC, the Government of Canada appears more focused on a proximal understanding of violence particular to the temporary context of the pandemic. Referencing its "engagement strategy" and national action plan, it states that the "challenges of family violence and mental health during isolation, or the needs of LGBTQ and Two-Spirit individuals or those with disabilities requires particular attention during the pandemic" (Government of Canada, 2020: 8).

As a national advocacy organization and clearinghouse of information, the NWAC provides an extensive list of resources in the context of messages from the association's president and in-house Elder who acknowledge the particular struggles of women and Two-Spirit people, including in urban areas. They state, "disease outbreaks affect women and men differently, and women and gender-diverse people are far worse off, especially when it comes to treatment and care." (Native Women's Association of Canada, 2020b). They also draw attention to the way women's roles as caretakers of people and in relationship with water, which has been in a contamination crisis also largely ignored by the federal government, complicates their positions in relation to the pandemic (see Human Rights Watch, 2020; Thompson et al., 2020).

The National Aboriginal Council of Midwives (National Aboriginal Council of Midwives, 2020) has developed considerable information on how COVID-19 not only compromises pregnancy and birth, but also the care midwives provide "beyond the clinic" including for Elders and others who are immune-compromized, "living in overcrowded homes, struggling with mental illness, substance use and trauma." Their work has increased awareness "of the inequitable burden

of COVID-19 on marginalized populations” including amplification of “already inequitable access to safe sexual and reproductive care . . . [and] how racism contributes to ill health and lack of access to healthcare” (Toronto Foundation, 2020). Discrimination and racism against Indigenous peoples in urban areas has been already widely reported and exposed in health care (Allan and Smylie, 2015; Brian Sinclair Working Group, 2017). The alarm has been raised by Indigenous leaders about how fears and lack of trust present barriers to Indigenous people using mainstream health care services, which can translate into waiting with COVID-19 symptoms, avoiding testing and potentially vaccination. It is more urgent than ever that Indigenous organizations are supported in administering testing and health care services themselves, as well as being fully engaged in critical care settings and vaccination delivery (Waakebusiness-Bryce Institute for Indigenous Health, 2020a; Waakebusiness-Bryce Institute for Indigenous Health, 2020b).

Urban Indigenous Initiatives and Traditional Practices

To best understand the impacts of COVID-19 for Indigenous peoples in urban areas, look to the initiatives of Indigenous social movement organizations which have worked since the mid-20th century to deliver culturally appropriate services to this sector of the population and which form the basis of vibrant, self-determined urban Indigenous communities. (Howard and Proulx, 2011; Howard and Lobo, 2013). There are many concerns clustered at the top of the lists of urban Indigenous community organizations about COVID-19: homelessness or instable housing, crowded housing, opioid use, food insecurity, mental health issues, trauma, the inability to access cultural, Indigenous-led services, and higher rates of chronic disease associated with COVID-19, severe complications and death.

Urban Indigenous organizations have repeatedly noted that they faced difficulties finding help when the outbreak started, and devised plans to care for the community on their own (Waakebusiness-Bryce Institute for Indigenous Health, 2020a; Waakebusiness-Bryce Institute for Indigenous Health, 2020b). While this translated into insufficient and late-coming funding noted above, the crisis has illustrated how vital it is for Indigenous people to lead, and for those controlling non-Indigenous resources to support Indigenous community leadership. For example, NACM emphasizes the long-standing colonial inequitable system in which midwives operate, their crucial role as advocates for reproductive justice and as carriers of deep ancestral knowledge, key to mediating spiritual and mental well-being amid the pandemic. In the urban context, Seventh Generation Midwives in Toronto illustrate how important these dimensions of their work are in their adaptations to the pandemic, emphasizing their approach to “care through the lens of social justice . . .” Also in Ontario, the Alliance for Healthier Communities includes ten Indigenous community-led primary health care organizations that “provide a combination of traditional healing, primary care, cultural programs, health promotion programs, community development initiatives, and social support services.” One of

these, Anishnawbe Health Toronto, started a “Mobile Healing” RV to provide COVID-19 testing as well as its other services including primary care.

Na-Me-Res, a shelter for Indigenous men in Toronto, is one of over 40 Indigenous organizations in that city. The shelter already had a pandemic plan in place when two cases of COVID-19 occurred in late March. They implemented action even before the WHO declared the pandemic. Na-Me-Res shared this plan within the network of shelters throughout the province and coordinated with other Indigenous organizations in the city through long-standing relationships of cooperation. However, Na-Me-Res also reported that useful help was not forthcoming from mainstream public health agencies which advised isolation, impossible to implement in the 71-bed shelter. The management team quickly organized to act without outside help and successfully remained free from further COVID-19 infection. “We are basically alone in this,” executive director, Steve Teekens noted in May 2020. He also found assurance in the strengths exhibited by the initial community-based response, “We have been through many pandemics in our history here on Turtle Island and I believe we will get through this one too” (Waakebusiness-Bryce Institute for Indigenous Health, 2020b).

Organizations specifically serving Indigenous LGBTQ people also offer considerable insights into effective holistic prevention and care that builds on historic experience with HIV, and anti-stigma/anti-discrimination activism. For example, the organization, 2-Spirited People of the first Nations, located in Toronto, first posted community-specific information to Facebook on March 9 and continued to safely carry out their food help and harm reduction programs after their offices closed. They and many other urban Indigenous community organizations rapidly adapted programming to social media and YouTube to include new online integrated emotional, mental, spiritual, and physical health services, and links to supports such as the *Two Spirit Journal’s* (2020) series, “In Our Own Voices: Two-Spirit People Responding to Covid-19.”

Indigenous health research organizations are responding to the immediate need for information as well as considering long-term impacts and strategies emergent from the COVID-19 crisis. The Waakebusiness-Bryce Institute for Indigenous Health and Well Living House use Facebook Live, and a YouTube channel to post basic information, as well as to feature speakers from the frontlines of Indigenous organizations to convey their needs and long-range perspectives. Highly important in-person cultural services and programming were canceled and postponed, but many urban Indigenous organizations adapted quickly, extending cultural services through telehealth technologies, and tools like Facebook Live and Zoom. Online prayer services, drum socials, craft classes, and other forms of engagement keep cultural contact going to curb the negative impacts of social distancing. Staff at the Native Women’s Resource Center (NWRC) in Toronto shifted to the phone and online quickly to ensure that the women and children they serve did not experience a discontinuation in the sense of community they usually enjoy within the walls of the center. This included access to healers, spiritual, and cultural service providers through online group and individual appointments. NWRC also

considers care for staff wellness, taking actions like supplying medicines and teas to use as they work from their homes. Weekly ceremonies such as sacred fires have continued in the city with creative suggestions like lighting a candle at home at the same time as these fires are started to maintain that connection (Waakebiness-Bryce Institute for Indigenous Health, 2020b). Even as these efforts may not reach the most vulnerable for whom the precarity of isolation, insecure housing, and exacerbated mental health and well-being, prevent access, they highlight the importance of Indigenous leadership and culture in COVID-19 short and long-term response.

CONCLUSIONS AND ACTIONABLE RECOMMENDATIONS

This research originated with a briefing paper submitted in response to the interest of the United Nations Human Rights High Commission Special Rapporteur on the rights of Indigenous peoples, Francisco Calí Tzay, to understand the impacts of COVID-19 in Indigenous communities. Our expansion on that document here exposes the extensive shortcomings associated with existing policies and practices which have accelerated COVID-19 morbidity and mortality for urban-based Indigenous people in the United States and Canada. We have situated these shortcomings the contexts of historical and ongoing settler colonialism, intersectional discrimination and human rights infringements, and the strengths of Indigenous urban community-building. We have underscored the longstanding lack of national uniform policies, rooted in the violation of Indigenous peoples' shared, historical nation-to-nation treaty-based and constitutionally protected rights and relationships as these extend to urban areas. The pandemic reveals how the United States and Canada, both settler-colonial nation-states, have each shirked responsibilities enshrined in these relationships, infringing on specific Indigenous rights, and more broadly defined basic human rights. These responsibilities extend not only to addressing biomedically defined health needs but, to overall community well-being through concrete actions against racist and misogynistic structures that perpetuate intersectional discrimination and human rights infringements. These include structures that sustain and escalate racial and gender-based violence, cultural disenfranchisement, and the dispossession of Indigenous peoples from the life-giving nourishment of their relationships to their lands. These basic nation-state responsibilities cannot be applied or neglected based on a distinction between the rural or urban location of Indigenous peoples.

The UNHRHC Special Rapporteur reminds states of this obligation under the authority of the international covenants to which they are signatories, when including among its seventeen recommendations, that states provide timely support and funding for prevention and broad care services identified by urban Indigenous communities and carried out through self-determined initiatives. Urban Indigenous leadership in both the United States and Canada have clearly stated the means through which to make this central recommendation actionable. Our

research brings to light specific actionable recommendations in three key areas of public health, funding, and culture.

First, public health policy makers need to engage with urban Indigenous leaders to take decolonizing steps that include applying understanding of the specific ways multiple and complex historical legacies intersect and impact urban Indigenous peoples' health and access to health care. These include consequences for data collection problems, mistrust, the perpetuation of racist ideologies of blame, and misrecognition of the nature of the barriers faced by urban Indigenous populations. Systemic violence against Indigenous women and gender-diverse people in urban areas has been woefully neglected.

- Urban Indigenous organizations must be supported in administering public health services themselves, be more fully engaged in critical care settings and in their networks of cooperation and knowledge sharing.
- Public health messaging should recognize the diversity of Indigenous peoples in urban areas, as well as the intersectionality of race, gender, and other structures of oppression, and ensure that the appropriate community authorities are supported in their approaches to reaching their constituents.
- Shelters are urgently needed for those fleeing domestic violence escalated by the pandemic.
- Health data collection policy is required that meets the needs identified by these communities themselves, and the resources to address these needs.

Lack of policy in both countries dismisses and undercounts the COVID-19 human consequences for Indigenous peoples, especially those residing in urban communities. Comprehensive data will be key in understanding how COVID-19 is affecting Indigenous people, directing resources to meet their needs, and measuring response outcomes and relief efforts. Without meaningful data, government response is often delayed or not given. Long-standing organizations like the NAFC in Canada and the Urban Indian Health Institute in the United States are critical to improving health data because they belong to the coalitions of urban-based agencies that serve Indigenous peoples.

Second, while it has been stated countless ways by many parties, federal assistance for the delivery of health care, including mental health, for and by urban Indigenous peoples needs to be substantially increased to match the needs of populations in urban areas and in coordination with urgently required improvements in housing, education, food security, and Elder care.

- There needs to be a concerted effort to develop with urban Indigenous leadership long-term economic security planning.
- Urban Indigenous organizations need more resources and clear-cut federal policies to support the services they provide.
- The competition-based approach to funding that pits urban against rural/reservation communities and among themselves needs to end.

- The pandemic highlighted the need for increased affordable access to basic personal computer equipment and the internet, often assumed to be a problem only for remote rural communities.
- Mediation of the vulnerabilities of Indigenous children to long-term impacts of COVID-19 needs to be attended to under the supported leadership of urban Indigenous communities, including family and kinship disruption, stunting access to education, and increased risks of homelessness.

Finally, safeguards to protect basic rights to practice cultural activities and access spiritual well-being need to be considered as important to overall health maintenance as sustenance and shelter. Women's roles as caretakers, and notably the positionality of midwives, provide insights into intimate forms of both suffering and coping, and the culture-based pathways to community health.

- Urban Indigenous community leadership need to be supported in their emphasis on delivering cultural and spiritual services.
- In addition to mediating against the discontinuity of cultural services, attention to social and health care service provider wellness should be integrated into future pandemic planning.

Urban Indigenous program staff adapted quickly to needs of their communities and their innovative approach and assistance are accepted and appreciated. Indigenous urban community

resiliency is rooted in the spirit of relationships, a form of strong intertribal kinship that makes every patient or client a kin or family member. Familiar agencies and other resources are successful because the cadres of these Indigenous first responders are trusted and committed. They are quick to change their role in some instances by delivering food and medicine, or by setting up alternative ways to find help. Where they cannot deliver medical care, they inform their constituents about keeping safe, where to go for testing, assist with contact tracing, and should continue leadership in vaccination roll-out. Knowing that viral transmission depends on human behavior embedded in structural inequities and social relations is as important as understanding virology, when preventing or slowing epidemics (Editorial, BJSP, 2020). To prepare a community to respond successfully to a life-threatening situation requires the messengers to be familiar, trusted, reliable, and a source of cultural safety.

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SL conceived of and presented the idea to JJ and HH-B to draft a contribution focused on urban Indigenous communities in the United States and Canada for the Red de Investigaciones Sobre Indígenas Urbanos. SL also wrote parts of the background and content on the United States. JJ proposed the article idea and wrote most of the United States content, as well as parts of the introduction, background, and discussion. HH-B initiated and organized the submission and authored the abstract, parts of the introduction, background, discussion and the Canadian content.

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Perceptions and Experiences of Frontline Urban Indian Organization Healthcare Workers With Infection Prevention and Control During the COVID-19 Pandemic

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Coronavirus disease 2019 (COVID-19) has created significant challenges for outpatient healthcare providers and patients across the United States (U.S.). Forty-one Urban Indian Organizations (UIOs), who provide a wide spectrum of health services for American Indian and Alaska Native (AI/AN) populations and other underinsured and uninsured populations in urban areas across the country, are no exception. The National Council of Urban Indian Health (NCUIH), in collaboration with the U.S. Centers for Disease Control and Prevention (CDC), set out to understand the needs, challenges, and opportunities for improvement in infection prevention and control (IPC) training and systems from the perspective of UIO frontline healthcare workers. As part of the CDC's *Project Firstline*, NCUIH was chosen as a partner in a national collaborative. The first task was to conduct listening sessions with frontline UIO staff to learn more about IPC practices in the context of the COVID-19 pandemic. Thirty staff from 16 UIOs, representing full ambulatory, limited ambulatory, outreach and referral, and outpatient and residential treatment programs participated in virtual video focus groups in July of 2020. Thematic and content analysis protocols guided data analysis and coding. Analysis of findings generated four major themes: staff adaptation in the context of resilience; responsibility and duty to protect patients, families, and coworkers; mental and emotional issues for UIO staff; and IPC challenges in the context of COVID-19. Participants' challenges ranged from lack of access to personal protective equipment (PPE) to the absence of standardized training. Significant disparities in social determinants of health experienced by Native American and non-Native populations served by UIOs create additional challenges to the delivery of and access to care during the pandemic. The diverse array of tribal cultural values and contexts of the people and communities served by UIOs reportedly serve as both facilitators and barriers to care, awareness, and uptake of infectious disease public health practices.

Keywords: public health, mental health, epidemic, COVID-19, healthcare worker, urban Indian health organization, American Indian and Alaska Native, minority health

INTRODUCTION

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes Coronavirus Disease 2019 (COVID-19), has created significant challenges for outpatient health care providers and patients across the United States (U.S.) (Corallo and Tolbert, 2020; Provenzano et al., 2020; Slavitt, 2020). Healthcare providers have had to quickly shift clinical practice and systems of care in response to the pandemic. Urban Indian Organizations (UIOs) are no exception. UIOs provide a broad array of health and public health services for American Indian and Alaska Native (AI/AN) populations and other underserved and uninsured populations in 42 major urban areas across the U.S. (National Council of Urban Indian Health, 2020).

There is scarce research about the risk, severity, outcomes, or protective factors for COVID-19 inclusive of Native American populations in the U.S. However, sporadic, slowly emerging data indicate that COVID-19 disproportionately impacts Native people and other people of color (Arrazola et al., 2020; Dorn et al., 2020; Hatcher et al., 2020; Laurencin and McClinton, 2020; Tai et al., 2020; Kakol et al., 2021). A U.S. Centers for Disease Control and Prevention (CDC) study found COVID-19 case rates for American Indian and Alaska Native people were 3.5 times higher than that of non-Hispanic white persons (Hatcher et al., 2020). A more recent study found the overall age-adjusted mortality rate for American Indian and Alaska Native people was 1.8 times higher than that of white persons; moreover, American Indian and Alaska Natives aged 30–39 were 11.6 times more likely to die than their white counterparts (Arrazola et al., 2020). Kakol et al. (2021) and Tai et al. (2020) argue that because of pre-existing health disparities linked to social determinants of health, Native peoples and other people of color are at a higher risk for COVID-19 infection. Underlying conditions such as diabetes and heart disease create persistent gaps in health status and increase the risk of complications from COVID-19 (Kakol et al., 2021). Further, long-standing historical, structural, and social injustices continue to perpetuate these inequities in social determinants of health (Rodriguez-Lonebear et al., 2020; Tai et al., 2020). Due to limited resources, including a lack of personal protective equipment (PPE), hospital beds, and chronic funding shortfalls, the Indian Health Service's (IHS's) capacity to serve the rapidly increasing number of cases of COVID-19 in tribal communities is limited (Dorn et al., 2020). Lack of treatment options and the inability to mitigate community transmission affect mortality rates across the country for Native peoples (Dorn et al., 2020; Kakol et al., 2021).

Urban Indian Health Care

According to the U.S. Census Bureau (2010), approximately 70% of American Indian and Alaska Native people live in urban areas (2010), with 25% living in areas served by UIOs (Indian Health Service, 2018). U.S. legislative and executive branches have long recognized that the federal government's treaty responsibility to provide for the health of American Indian and Alaska Native people is not restricted to the borders of reservations. The Federal Trust Responsibility instead includes the provision of healthcare wherever they reside (National Council of Urban Indian Health, 2020). The Indian Health Care Improvement Act of 1976 (1976)

(IHCIA) defines urban centers as “any community which has a sufficient urban Indian population with unmet health needs to warrant assistance under subchapter IV, as determined by the Secretary.” As independent non-profit health facilities, each UIO defines its service population, which can include both American Indian and Alaska Native and non-Native patients (National Council of Urban Indian Health, 2020). Over half of UIOs are Federally Qualified Health Centers (FQHCs), 11 of whom receive funding from the Health Resources and Services Administration, four also receive Healthcare for the Homeless program funds (National Council of Urban Indian Health, 2020). In 2018, UIOs reported serving 179,196 clients, of which 72,243 were American Indian or Alaska Native, according to IHS data (National Council of Urban Indian Health, 2020).

The IHS has been the primary source of funding for American Indian and Alaska Native healthcare as part of the Indian Health Service/Tribal Health Programs/Urban Indian Organization or I/T/U system of care (Indian Health Service, 2020). UIOs are principally funded by a single line-item in the IHS budget that constitutes <1% of the total IHS budget with a directive to serve members of all 574 federally recognized tribes and urban Indians (Indian Country COVID-19 Response Update, 2020). As a result of decades of chronic underfunding, UIOs are left to rely on a patchwork of third-party reimbursement options and grants to maintain operational and financial viability (National Council of Urban Indian Health, 2020).

The COVID-19 pandemic has exacerbated existing operational issues for some UIOs and created new problems for others (Indian Country COVID-19 Response Update, 2020). According to a survey conducted in September of 2020, 60% of UIOs reported a reduction in operating hours due to COVID-19. Forty percent of respondents are unable to provide testing, and an additional 20% of UIOs are unable to meet testing demand citing inadequate PPE or testing supplies, staffing issues, the rising cost of supplies, limited local or state support, or other challenges. No single UIO respondent felt they had the resources to conduct contact tracing, and none felt there were sufficient public health community resources to conduct contact tracing as needed for their patients. Nearly seventy percent of UIO respondents indicated their facilities lacked adequate space for triage or isolation. Every UIO respondent indicated a need for health information technology staff to facilitate telehealth service demand. Many UIOs requested funding and support for a wide range of telehealth service issues and equipment, including funding to assist low-income patients who lack the technology or the capacity to access telehealth services for virtual appointments. More than half of UIO respondents indicated they would be unable to maintain operations for more than 30 days if any lapse in federal funding were to occur, such as happened during the 2018–2019 federal government shutdown, which resulted in three UIOs permanently closing (Indian Country COVID-19 Response Update, 2020).

U.S. Indigenous Population Terminology

In the U.S., American Indian and Alaska Native “...race is a political status that confers access to health care services under treaty obligations of the U.S. government” for federally

recognized tribal members (Hatcher et al., 2020, p. 1168). In response to this political designation by the U.S. government, American Indian and Alaska Native (AI/AN) terminology has been largely adopted in the research literature. More recently, the term Native American has been used with increasing frequency, and the terms AI/AN and Native American are often used interchangeably (Connolly et al., 2019). The National Congress of American Indians (National Congress of American Indians, 2020) defines Native Americans as inclusive of all Native people from the U.S. and its territories, including Alaska Natives, as well as Native people from Canada, Mexico, Central and South America who are residents of the U.S. Listening session participants most often used the terms “Indian” or “Native” in their discussions or references to their patients or community members. (There is no UIO in the state of Alaska.) In recognition of the title for this special collection, in accordance with the large body of literature surrounding Indigeneity and Indigenous research methodologies, and reflecting the words of UIO participants, the terms Native or Native American will be used throughout the remainder of the publication. References to data, published works, or citations that specifically refer to political or federal designations or references to these populations in some explicit or directed manner, e.g., AI/AN, Alaska Native, American Indian, or by designated tribal affiliation(s), will maintain the original designation when deemed essential.

Infection Prevention and Control, Healthcare Workers Serving Native Peoples, and COVID-19

A literature review on infection prevention and control (IPC), healthcare workers, Native Americans, and the COVID-19 pandemic identified little U.S.-based research. There is a larger body of available research on IPC and healthcare workers from outside of the U.S. However, the potential relevance to UIOs and Native populations and Native-serving healthcare providers is limited. Therefore, to frame the present article in terms of utility and relevance to the current project and UIO audience, the existing literature review focuses primarily on U.S.-based research or recent systematic reviews or meta-analyses.

In September of 2020, there was minimal research or other published works available in medical or allied healthcare journals focused on U.S. healthcare workers in I/T/U settings during the pandemic. Four identified non-research articles offered “perspectives” from the field, “notes,” or insights into current practices (Close and Stone, 2020; Egan and Bonar, 2020; Kovich, 2020; Rosenthal et al., 2020). Three of these articles described healthcare workers’ experiences serving Navajo Nation patients and communities (Egan and Bonar, 2020; Kovich, 2020; Rosenthal et al., 2020), and one described a rural IHS Arizona hospital (Close and Stone, 2020). Three articles described work in hospital-based settings (Egan and Bonar, 2020; Kovich, 2020), including a critical access hospital’s expanded public health role that included contact tracing as a means for mitigating the spread of infection in crowded home environments, identifying early cases, and preventing hospital admissions (Close and Stone, 2020). Rosenthal et al. (2020) discussed the critical and evolving role of community health representatives

(CHRs) in the Navajo Nation’s response to the pandemic. Navajo CHRs have been responsible for an ever-expanding scope of practice, including contact tracing, monitoring curfews, delivering food boxes, and have increasingly gained community trust. Informal themes identified across two or more articles included:

- Adaptation of staff roles
- Adaptation of how or where services are provided, e.g., testing in patient homes, primary care in parking lots, telehealth services
- Importance of and transition to community-based and home-based care and services
- Long hours and high level of intensity of the work for staff
- High prevalence of multi-generational households and high occupancy households, which are high-risk environments for virus transmission
- Importance of partnerships and collaborations
- Need to organize and provide basic supplies for community members, including food and water
- Multiple provider types as options for contact tracing
- Healthcare workers as heroes

No IPC-related research inclusive of healthcare workers in I/T/U settings was identified in peer-reviewed journals when the present article was submitted. Houghton et al. (2020) conducted a rapid review at the start of the COVID-19 pandemic of barriers and facilitators to IPC practices among healthcare workers (not specific to I/T/U settings) during outbreaks. The review categorized findings from qualitative and mixed-methods research. They identified three main categories: (1) organizational factors, including safety climate and communication; (2) environmental factors, including facility concerns and availability and use of PPE; and (3) individual factors, including knowledge, attitudes, and beliefs. The authors outline continually changing guidelines, IPC workload increases, fatigue, a lack of training standardization, and lack of resources, including PPE, as barriers for healthcare workers to perform optimally (Houghton et al., 2020).

There are significant gaps in the research literature about the impact of COVID-19 on Native-serving healthcare providers, whom the authors conjecture face some of the most significant challenges given the populations served and systems in which they operate. Furthermore, there are implications for the unique cultural and historical aspects of Native populations regarding disease responsiveness (Santosham et al., 2007). The latter has implications for healthcare workers that are as yet unexplored in the context of COVID-19. For decades, studies of infectious disease epidemiology, prevention, and treatment among Native populations have provided insight into interventions and care that have reduced global morbidity and mortality (Santosham et al., 2007). The UIO listening sessions’ original aim was to gather information to inform the training needs and preferences of UIO healthcare staff. However, the systematic qualitative exploration and analysis of overall IPC perceptions and experiences amid the COVID-19 pandemic in this unique segment of the healthcare workforce that serves a population consistently under-represented in the research literature is the first of its kind. This paper provides a rare glimpse into issues

for the UIO workforce, and the findings may lead to greater understanding and serve as a foundation for future research.

METHODS AND MATERIALS

Aims

NCUIH is the only national non-profit organization devoted to supporting and developing quality, accessible, and culturally competent health and public health services for American Indians and Alaska Natives living in urban areas. NCUIH represents the 41 Title V UIOs funded by and under contract with the IHS. The CDC provided funding to NCUIH via a cooperative agreement to participate in *Project Firstline*, a national training collaborative for healthcare infection prevention and control training. *Project Firstline* aims to provide foundational and practical knowledge directly to more than 6 million frontline healthcare personnel and targeted components of the public health workforce to protect the nation from infectious disease threats, such as COVID-19.

Two of the first partner activities undertaken included a national healthcare worker survey and listening sessions facilitated by national collaborative partners. The national survey, developed and hosted by the CDC, was distributed electronically by NCUIH and other national partners. Survey questions solicited feedback on training preferences, including possible delivery mediums, topics, formats, and timing. Survey data was only reported to partners in aggregate form and was not made available for separate analysis. Results of the survey are not the focus of this paper. Locations and other identifiers have been omitted from quotes taken from survey responses.

Listening sessions with frontline healthcare personnel and other relevant stakeholders were convened individually by NCUIH and other external partners at the CDC's request. The primary objectives of NCUIH's listening sessions were to understand the needs, challenges, and opportunities for improvement in IPC training and systems from the perspective of UIO frontline healthcare workers in the context of the COVID-19 pandemic.

Design

Project Firstline listening sessions were not intended as research. At NCUIH's discretion, qualitative research methodologies that included Thematic Analysis protocols (Braun and Clarke, 2006) guided the process, along with other qualitative methods that were implemented to ensure analytic rigor, reliability, and validity of the findings (Morse, 2015; Hennink et al., 2019).

Setting and Participant Recruitment

IHS funds four types of UIO programs: full ambulatory, limited ambulatory, outreach and referral, and mental and substance abuse treatment centers (outpatient and residential). At the time of this publication, 22 full ambulatory programs provide direct medical care for 40 or more hours(h) per week. Six limited ambulatory UIO programs provide direct medical care for <40-h per week. Ambulatory programs offer diverse services and medical care, including nutrition, oral health, behavioral health, substance abuse, elder services, and more. Five outreach

and referral programs do not provide direct medical services but instead provide referrals to specialists and offer community programs, wellness, and prevention services. Eight programs offer a spectrum of services focused on residential or outpatient behavioral health services, including substance abuse. Staffing levels, patient encounters, service delivery models, and program expectations differ between UIO programs (National Council of Urban Indian Health, 2020).

UIO staff were recruited for the virtual listening sessions primarily through convenience and snowball sampling, with later purposive sampling to ensure participation from each of the four UIO program types (full ambulatory, limited ambulatory, outreach and referral, and treatment centers). Emails were sent to the NCUIH UIO e-news list over several weeks (~1,918 recipients; 4 emails). Also, targeted emails were sent to specific UIO Chief Executive Officers to request a recommendation for a staff member to participate in upcoming sessions in order to increase representation for certain UIO program types. Incentives for participation in the information gathering process, which included taking a modified CDC pre-session survey, participation in the two-hour listening session, and providing feedback on a summary of findings (member checking), were offered (\$150 gift card).

Data Collection Procedures

Five 2-h virtual video listening sessions (focus groups) were convened over two-weeks in July of 2020. Three sessions were scheduled for a maximum of up to 10 participants. Additional sessions were added to accommodate alternate days of the week for clinical providers (by request), schedule new participants from previously un-represented UIO program types, reschedule sessions for participants who missed original sessions, and triangulate initial themes identified in earlier sessions. Half of the NCUIH *Project Firstline* staff were tribally enrolled, including the primary facilitator and moderator. Listening session questions were derived from a CDC-developed semi-structured interview guide (see Supplementary Materials) adapted to allow for more culturally relevant and UIO specific discussion with participants. The interview guide was modified before and between sessions to facilitate conversational flow, incorporate new prompts focused on emerging issues, and ensure feedback was obtained on all critical areas. Online polling software was incorporated throughout the sessions to ease participant comfort in providing feedback in a group setting and facilitating sharing for limited audio or video capacity. An online survey distributed after each session solicited recommendations for process improvements and provided an opportunity for additional comments. Staff reviewed survey results immediately and incorporated relevant suggestions in future sessions. Video sessions were recorded, an edited transcription and set of notes were created, and then online recordings were deleted.

Analysis

Multiple strategies were incorporated to enhance rigor in the analysis process (Morse, 2015). Data collection and analysis occurred concurrently. After each session, a peer (team) debrief was convened, and a list was generated that consisted of

significant, new, or emerging themes. During subsequent peer debriefs, staff reflected on persistent themes as well as identified new or emerging themes. Persistent and potential themes identified during early peer debriefs were cross-checked or clarified during future listening sessions with participants to triangulate themes from earlier sessions (Morse, 2015). Braun and Clarke (2006) argue that saturation, a commonly used term in qualitative research to imply analytic rigor vis a vie information redundancy, is not a thematic analysis tenant. However, it was apparent that saturation was achieved on several significant themes identified via peer debriefs, confirmed via triangulation with subsequent listening session participants, or that arose naturally in the course of the discussions before coding commenced (Hennink et al., 2019). Dedoose Version 8.0.35 software (Los Angeles, CA: Socio Cultural Research Consultants, LLC) was used to organize listening session data (edited transcripts and notes), which was then analyzed and coded to indicate further areas of inquiry with feedback on parent and child codes by two reviewers (N.C. and J.C.) from the NCUIH *Project Firstline* team. One reviewer (J.C.) coded certain aspects of data for content analysis (aimed at categorizing responses), and a second reviewer (N.C.) coded primarily for themes. Two reviewers confirmed codes and subsequent themes during multiple encounters until consensus was achieved to ensure credibility and accuracy. Finally, after coding was complete, member checking (Morse, 2015) was conducted to solicit feedback on themes and subthemes via email and through a scheduled follow-up teleconference session.

Ethical Review

The project was reviewed by the CDC's Human Subjects Advisor and determined to be non-research as defined in 45 CFR 46.102(l); thus, Institutional Review Board review or exemption approval was not required.

RESULTS

Thirty staff from 16 UIOs and one urban behavioral health office program participated, representing full ambulatory (eleven participants), limited ambulatory (four participants), outreach and referral (eight participants), and outpatient and residential treatment (one participant) programs. Six participants did not identify a program type. A variety of roles and professions were represented among participants (Table 1). Participants also represented a wide range of geographic regions and urban areas.

Questions in the original interview guide covered four main topic areas. Interview guide topics were (1) Perceptions of IPC (2) Experience with IPC during COVID-19 (3) Training sources and delivery, and (4) Other supports.

Content Analysis

Multiple questions in the interview guide elicited close-ended or categorical responses. Content analysis of these questions included developing an initial set of code categories by reviewers, followed by assignment, and then comparing code frequencies for respondents across all five listening sessions. The following (Table 2) summarizes content analysis for key questions, with

TABLE 1 | Professional role of listening session participants.

Professional Role	Number of Participants
Registered Nurse / Licensed Vocational Nurse	8
Office Staff / Billing	5
Nurse Practitioner	3
Medical or Nursing Assistant	3
Public Health Professional	3
Behavioral Health / Social Work	3
Clinic Administrator	2
Physician	1
Community Health Worker	1
Dental Assistant	1

the most frequently identified codes listed in rank order and bold items representing codes selected with the greatest relative frequency within any one category. An asterisk (*) denotes if a concept or code was mentioned in all five listening sessions.

Thematic Analysis

Over the five listening sessions, analysis across all participant responses generated four themes. The themes included staff adaptation in the context of resilience; responsibility and duty to protect patients, families, and coworkers; mental and emotional issues for UIO staff; and challenges in the context of COVID-19, which included six subthemes (Table 3). Session facilitators also pointedly explored the unique cultural aspects of working for UIOs. The following listening session participant excerpts included verbatim transcriptions (direct quotes in italics) and staff notes (summary of the discussion not in italics).

Adaptation

Adaptation was a central recurring theme and appeared in multiple contexts. Most common was the need to adapt to new policies and procedures.

"...we had standard protocols for the way we handle infection prevention and control, but definitely had to revamp everything and make sure they were up to standards and change how we were going to do things moving forward."
Listening session 2 participant

Adaptation of roles and responsibilities was a second common, occurring subtheme under adaptation. In concert with staff having either new positions or roles in their facility, e.g., front desk workers or back of house staff conducting temperature checks ("all hands on deck").

Everyone's role had changed due to COVID-19... As a psychiatric social worker, her role, aside from providing mental health services, now involves psychoeducation related to safety, infection prevention, and general physical health monitoring.
- Listening session 5 participant

Before COVID-19, she did not have a role in IPC. Since the pandemic, she is now responsible for monitoring the temperature of her patients, asking them to use PPE as well as using PPE herself during all her face-to-face sessions. She predominately provides telehealth services, whereas before, “that was not a thing” at her facility.

- Listening session 5 participant

Significant adaptation to facility layout and workflow was common across all operating organizations. Most facilities are continuing to adapt their environment and physical space to be responsive to new policies such as social distancing or

conditions like weather (e.g., triaging patients in tents in >100°F outdoor temperatures).

[omitted] indicated that they were having challenges with that on multiple levels. . . . Recently his facility had a quarantine and isolation assessment team from [omitted] assess their ventilation system, which identified that their current circulation would need to be upgraded. They do not have a dedicated room to minimize exposure and will need to put a trailer outside. They are finding roadblocks with space issues. “We are willing to do the training and get certified and put together the layered approach to following up, but at the same time, we are finding roadblocks with space issues.” They moved to telehealth and had staff work from home and had to accommodate that. “We are resilient” “We are trying to negotiate the space challenge.”

- Listening session 2 participant

TABLE 2 | Most frequently identified codes listed in rank order and bold items representing codes selected with the greatest relative frequency within any one category.

What is your motivation to engage in infection prevention and control practices?

Protection of patients*

Protection of family

Protection of coworkers

Protection of self*

What are the most critical needs during COVID-19?

Space

Transportation

Cleaning, environmental maintenance

Staffing

Training and education

What is the single most important topic that you think should be addressed in training?

Mental health (staff)

Staffing

Patient resources for positive test results*

Proper use of PPE (ongoing)

Basics

Cleaning and environment

Who are your trusted sources of information?

CDC*

Department of Health*

Staff within UIO*

Other clinics and healthcare providers

An asterisk (*) denotes a term or code that was identified in all five listening sessions.

TABLE 3 | Listening session themes and COVID-19 challenges.

Majors themes	Subthemes of COVID-19 challenges
Adaptation	Personal Protective Equipment
Responsibility	Information Dissemination
Staff Mental Health	Space and Service Changes
Challenges in the Context of COVID-19	Staffing Issues
	Lack of Standardized Training
	Client Social Determinants of Health

Nearly all facilities have instituted new workflow processes, new meetings, or more training on various subjects, and there was a reference to the increasingly blurred lines between home and work interactions. The rise in telehealth visits as an option for continuing patient encounters was generally praised, though they present implications for both patients and providers.

Participants indicated in virtually all sessions that these necessary adaptations presented multiple opportunities for improvement. The speed with which changes are implemented (e.g., too fast, too slow), the number of implemented changes occurring at one time, and the need for basic training on new policies or procedures were suggestions participants believe leadership should consider for enhancing future process changes.

Notably, participants often framed the *need* to adapt in the context of the concept of resilience. Resiliency for several participants seemed to take on the meaning of having the capacity to adapt and excel quickly, coupled with the ability to frame or re-frame their situation positively, particularly in challenging or demanding conditions. Many participants feel there is an overemphasis on negative framing in Native healthcare contexts and that their adaptations during the pandemic should be viewed through a lens of positive action. Discussions of resilience and positive re-framing frequently coincided with discussions of the use and maintenance of cultural practices, specifically in Traditional or Native healing contexts and the use of healers for their staff within their organizations.

Responsibility

The second most frequent theme was **responsibility**, often discussed in concert with the concept of adaptation. Participants felt that they had a responsibility to their patients (first), families, and coworkers to be knowledgeable and implement safe practices. One participant said,

“It’s necessary for all staff to be trained and to be aware of IPC. We are responsible for keeping our patients and our community members safe.”

- Listening session 5 participant

"My motivating factor is to prevent the spread of infection. At [omitted], each person is responsible for taking our own temperatures, using hand sanitizer, and wearing masks. Our staff is staggered 50:50 where some staff are on site for two days and then alternate on Fridays while keeping 6 feet distance."

- Listening session 4 participant

Nearly all participants voiced that everyone has a responsibility or a duty to have at least some broad understanding of IPC. One participant mentioned that they had a sense of ethical duty to care for others' well-being and that engaging in proper IPC was an extension of their ethical duty.

Participants frequently mentioned duty and responsibility related to their motivation to continue training and seek out updates on continually changing protocols and guidelines. Some participants saw a desire for standardized IPC training and standardized information on policies, procedures, or protocols as a means to help increase confidence in their work.

"However, there are moments when a little bit of fear creeps in and adds to the motivation. Fear of infection and seeing the numbers spiking is a reminder that this is not over yet."

- Listening session 5 participant

Staff Mental Health

Participants discussed an increase in observed and potential **mental health concerns for staff** throughout their facilities, as well as for themselves. This was the third central theme identified across sessions. Fear, fatigue, stress, stigma, and other psychological and mental health issues presented as sometimes subtle and other times not so subtle ever-increasing challenges for participants in the listening sessions. Fear of the potential for family members becoming sick, fear of becoming sick themselves, and worry about at-risk community members were mentioned repeatedly.

"I don't deal with the frontline. They do the COVID testing... I'll look outside the window. Seeing the fear and the body language..."

- Listening session 2 participant

Several participants mentioned specific negative emotionally-laden scenarios that motivated them to take IPC precautions and maintain community safety. Staff fear of infection mingled at times with their frustration with patients' or community members' lack of compliance with policies (e.g., mask-wearing). Participants suggested this lack of compliance may result from overt disregard for policies, lack of knowledge, or misinformation. Staff frustration also resulted from a lack of consistent messaging from agencies providing COVID-19 guidelines or continuously changing external guidelines, which lead to ongoing changes in internal policies and procedures. Several participants pointedly identified "mental health" as the most crucial topic to address in IPC training.

The Thursday 'check-ins' were more of a check-in on everyone mentally and how they were doing and how this would affect their family... "They were very emotional, broke down, they didn't know how to respond, they didn't know it was okay to come to the circle, to a safe space and say I need help."

- Listening session 2 participant

The culmination of by-then several months of rapidly changing policies, procedures, and working under emotionally demanding conditions appeared to be taking their toll on UIO staff.

IPC training was vital to ensuring that staff was informed and supported on an ongoing basis. For [omitted], they use staff meetings, both functional and discussion on stand-ups. Initially, the staff was somewhat hesitant but readily engaged. As the COVID pandemic continued, the staff seemed less open and receptive due to fatigue, secondary trauma, peripheral care required for community and family, and the resurgence in their area. They are trying to do self-care, but this has transitioned into "fatigue," affecting the donning and doffing practices in the clinic.

- Listening session 5 participant

Some UIOs have also identified an increased demand for substance use and counseling services or other mental or behavioral health needs of their patients, with rising acuity levels, which has translated into increased stress and staff workload.

Challenges

Barriers and challenges to infection prevention and control during COVID-19 were specific questions. In addition to analyzing question-specific responses, reviewers examined and coded responses across listening session questions for text excerpts that could be characterized and coded as challenges.

Personal protective equipment (PPE) was the most frequently cited challenge and came up multiple times in every listening session. Lack of or limited access to PPE and supplies, concerns about the lack of training about safely putting on (donning) and taking off (doffing) PPE, and staff resistance to wearing masks in the clinic were primary concerns. Though select participants offered examples of clinics that felt they had adequate PPE supplies at the time, several noted they were operating at a very limited capacity. Other examples of promising or successful practices were described. One UIO identified safety teams used to monitor staff for proper donning and doffing procedures, and another described mock drills implemented to prepare staff for procedural changes.

An additional challenge was **information communication and dissemination**. This topic also came up multiple times in every listening session in multiple contexts. For example, the capacity to stay on top of and evaluate multiple external sources' guidance was an ongoing issue.

[omitted] felt that local, state, and federal guidelines also acted as a barrier to implementing IPC. "There is conflicting information. For example, the governor may state that masks should be worn, and then there are other guidance that do not mandate this."

- Listening session 4 participant

Communication issues also occurred within UIO organizations.

"Things were changing every day, and sometimes we were out of the loop and doing it wrong. Sometimes new things were implemented, and we were not informed. Sometimes people were just doing things on their own."

- Listening session 2 participant

These communications and information dissemination challenges also extended out from the UIO. Though UIO staff consistently identified themselves as a trusted source of information in their community in their capacity to educate and reach community members.

In [their] local area, there were 90 different tribes, and it was hard to get everyone on the same page. Their challenge is to get information out, not only healthcare-related but also about available tribal provided services.

- Listening session 2 participant

"People are reading a lot of stuff. A lot of it on social media. A lot of it is not true. Providing IPC training for our community from the facility would be great training for our Native community."

- Listening session 2 participant

Space and facility services came up multiple times in every listening session. Most UIOs were still not operating at their pre-COVID-19 capacity as of July 2020. Participants noted that the shift to telehealth for many facilities had been a challenge. One participant shared that their dental services had shut down completely, while two others noted that they had to discontinue all patient transportation services. The need to enhance social distancing and reduce patient-to-patient and patient-to-staff contacts has resulted in substantial patient flow and management modifications.

They staggered their visits as a safety measure and even provided curbside pick-up of drugs for their pharmacy. They also provide drive-through COVID-19 testing under a tent.

- Listening session 4 participant

There were many instances in which participants voiced concerns over the physical conditions and small space at their facilities. One UIO had separated symptomatic and non-symptomatic individuals, but due to a lack of available space, had set up a tent outside.

The heat index in [omitted] the day prior was 110 degrees. This is affecting outdoor testing and triage. The facility has obtained tents with air conditioning to help with outdoor screening/testing for COVID-19 patients. Wearing PPE in the heat is a safety issue.

- Listening session 1 participant

Social distancing requirements and facility capacity issues have contributed to limitations in the number of medical staff allowed on-site at any one time in some facilities. **Staffing issues** also came up multiple times in every listening session.

"We are kind of a small facility, so we really only had two janitorial staff but had increasing needs for more thorough and intensive cleaning. Along with this, it takes time to hire additional clinical staff. We want to hire additional trained nurses and support staff to help meet increased needs. We are going to have to take more time with each patient. Increased needs for testing. Our biggest hurdle is ramping up on staffing."

- Listening session 2 participant

Staff contact with confirmed or suspected COVID-19 positive persons at work and in their personal lives was an issue, especially for facilities with already small staff sizes.

"Staff members who travel out of state and that puts them at high risk for exposure."

- Listening session 2 participant

Still, other staff who have chosen to leave the workforce, not return out of fear or concern for themselves or family members, or were not allowed to return because of potential risk cause additional strain on the UIO workforce.

Some staff were considered essential but were scared and wanted to remain home. Some staff telecommuted, some stayed home, and those considered high-risk were sent home.

- Listening session 4 participant

Lack of standardization of training, concerns about ongoing compliance by some individual staff members, and rapidly changing protocols or procedures were consistent themes identified across all listening sessions.

"We definitely do run into problems with people being resistant to change, not wanting to make a change, change for a while, and then revert back to the way things always were. That's our biggest challenge."

- Listening session 2 participant

Several examples of UIOs that had developed proactive, responsive, and robust systems for training and monitoring IPC procedures were shared. While 74% of listening session respondents who responded indicated their UIO currently provided some type of IPC training, available training sources and program requirements varied widely. Broadly, there was a desire for more training, including more staff (not just clinical), that was timely and included ongoing follow-up for compliance.

This [standardized training] was not required. There was no standardized, formal introduction and training; regarding what PPE looks like and the benefits, structure, and process. She hopes that they can have formal training.

- Listening session 5 participant

Finally, participants in multiple sessions identified a range of **social determinants of health** that they believe disproportionately impact the Native clients seen at their UIO. These issues, which predated COVID-19, have further exacerbated challenges for providing care and services during the pandemic. According to the CDC, "social determinants of health are conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of-life risks and outcomes" Centers for Disease Control Prevention (2020). Participants most frequently discussed the lack of insurance or underinsurance. Additional social determinants of health identified by participants included

- Lack of internet access hampers the ability for patients to use telehealth services
- Disruptions in the clinic and public transportation systems for patients who have no other transportation alternatives
- Lack of running water or electricity for sanitation
- No access to masks or ability to clean reusable masks
- Community resources shut down due to COVID-19 or limited service hours
- Increased number of homeless and those facing food insecurity
- Lack of access to basic hygiene supplies like hand soap.

Two participants noted a shift in UIO patient population demographics. One cited an increase in the number of homeless patients seeking services, and the second noted an increase in the number of formerly incarcerated patients. Furthermore, both respondents said those clients had no other option for formal health services at that time beyond the UIO.

Cultural Aspects of UIO Work

Most UIOs see clients of all races and ethnicities. UIO Native patients come from many different tribes and represent various cultural practices and customs. One participant noted his work with 90 different tribes from their UIO service area. Participants shared examples of UIO cultural services that have included Sun Dances, sweat lodges, sage and sweetgrass for smudging, traditional healers, traditional medicine, and cultural leaders who lead prayers for both staff and patients. Culturally appropriate services bring value to both the communities served and staff who themselves may be Native American.

"It's kind of hard to explain. I've always lived in two different worlds. My cultural side was at home, with my family. Work was work. So, I turned that side off. Here [at the UIO] everything is put together. I'm learning how to bring out the one side now, and I don't have to shut part of myself off."

- Listening session 2 participant

However, COVID-19 has dramatically disrupted both clinical and cultural practices for UIOs and the communities they serve. Additionally, participants note there is some skepticism about the disease among community members.

"They are strong spiritual people who believe this COVID-19 is not natural.... There has been much stubbornness where some people feel like they are immune."

- Listening session 4 participant

Within the urban setting, traditional practices are still occurring, and funerals still occur, but they [UIOs] are trying to implement prevention measures. As it relates to the sweat lodge ceremony, they are trying to put precautions out there. While in the clinic, it becomes challenging when the response is, "...not our disease".

- Listening session 4 participant

A follow-up discussion on preliminary findings (part of member checking) included several UIO staff from the original listening

sessions from different parts of the country. These participants concluded that what was identified as 'skepticism' in preliminary coding and quotes is sometimes manifested as overt "denial" by some community members. One participant reflected on an elderly Native patient who personally experienced severe illness due to COVID-19, yet commented that it was not their [Indigenous people's] disease. The group postulated that skepticism or denial was potentially a root cause of behaviors that put others at risk, contributing to patient resistance to practices such as wearing masks, social distancing, or foregoing cultural ceremonies to protect themselves or their families. Native perceptions of infectious diseases (e.g., smallpox or AIDS), chronic diseases such as diabetes, and even cancer as "white man's" diseases have been discussed in research and health literature (Jones, 2006; McLaughlin, 2010; Desjarlait, 2017; Pfeiffer and Gilley, 2017). The origins of these diseases relative to the white man have been described as punishment for sin or immorality with roots in religion, human-made biologics, disruption of traditional Native ways caused by adopting the white man's lifestyle, or conspiracy by the government to perpetrate genocide. In virtually all cases, these perceptions and beliefs are often complex, deep-seated, and are an obstacle to care and treatment until overcome (Jones, 2006; McLaughlin, 2010; Desjarlait, 2017; Pfeiffer and Gilley, 2017).

Trust is a critical issue in Native communities. Although UIO healthcare staff generally referenced the CDC as a trusted source of information (65% of listening session participants who responded agreed), they indicated that their community members would be far less likely to trust the CDC. However, participants stated that their community members trusted UIO staff and ultimately would trust UIO guidance even if it originated from the CDC. There was also consensus that (1) broad community outreach and awareness on infection prevention and control training (2) through trusted sources (such as UIOs) to Native people living in urban communities (3) done in a culturally competent manner, and (4) accompanied by needed resources was a high priority. Participants provided several examples of culturally centered practices being explored and employed at their UIOs since the start of the pandemic.

In their staff meeting, her staff members discuss the cultural medicines that could be useful along with current practices. She also shared that on-site was a cultural person who shared this information. Her center also provides an area with sage and sweetgrass so that people can smudge themselves (if they choose) when they come in for appointments.

- Listening session 4 participant

DISCUSSION

The COVID-19 pandemic has at times overwhelmed virtually every component of the U.S. health system, resulting in shortages of staff, supplies, and infrastructure, as well as rationing and triage of care (McGuire et al., 2020), and UIOs are no exception. Native people served by UIOs and other tribal health providers suffer disproportionate rates of infection owing to a backdrop

of significant mental health and health disparities, disparities in social determinants of health, and significant structural inequities (Dorn et al., 2020; Hatcher et al., 2020; Tai et al., 2020; Kakol et al., 2021). UIO listening session participants provided novel insights into staff perceptions and experiences directly from the frontlines of care five months after the first COVID-19 case was diagnosed in the U.S. Though conversations were framed in the context of IPC practices and programs and designed to inform related training resources and protocols, the findings have relevance beyond training needs. At the same time, they preserve UIO healthcare workers' experiences at a unique moment in history. The four major themes generated from discussions included **adaptation** in the context of resilience, **responsibility** and duty to protect, **mental** and **emotional** issues for UIO staff, and **challenges** in the context of COVID-19. Multiple challenges were identified by participants, many that are perhaps not unique to the UIO setting. Significant disparities in **social determinants of health** create a unique, stark divide for the Native and non-Native populations served by UIOs relative to other mainstream healthcare providers' patient populations. According to listening session participants, the diverse array of tribal cultural values and traditions of the people and communities served by UIOs serve as facilitators and barriers to care, awareness, and uptake of infectious disease public health practices.

It is vital to consider findings and recommendations within the context of documented historical trauma and losses experienced by Native peoples in the U.S. Genocide, colonization, forced removal, efforts at assimilation via boarding schools or relocation programs, and other recurrent attempts to eliminate traditions and cultures of U.S. indigenous populations have resulted in government and institutional distrust (U.S. Commission on Civil Rights, 2018). Emerging research indicates perceptions of historical trauma and losses have increased mental health sequelae among American Indian people during the COVID-19 pandemic (John-Henderson and Ginty, 2020). Historical trauma and heightened stress mingled with mixed messages from various government entities as a result of continued learning about the virus likely lead to confusion and further foster the sense of distrust among Native communities.

Comparison With Existing Literature

Many findings identified in UIO listening sessions are reflected in the recent scientific literature. Several themes resonate with results from Liu and colleagues' (Liu et al., 2020) study of hospital-based healthcare provider experiences during the early stages of the COVID-19 crisis in China. A duty to patients and community (responsibility), challenges unique to COVID-19, and resilience amid these challenges emerged as three primary themes from their interviews with 14 nurses and physicians in the Hubei province. Additional commonalities were embedded in the article narrative. Themes that parallel experiences of UIO staff included adaptation in work environments, facilities, workflow, roles, and responsibilities; communication challenges; continually evolving protocols; increased stress, fatigue, grief, and fear of infection for themselves, colleagues, or family; and concerns about adequate PPE, supplies, and staffing. Unique to the Hubei study, their providers identified multiple forms

of support that offset their experiences of powerlessness, grief, stress, and physical and mental fatigue that culminated in a phenomenon labeled "transcendence." Systems of support for the Chinese healthcare workers included hospitals that provided logistical resources (PPE, food, and accommodations), ongoing IPC training and support to enhance feelings of safety and group connectedness, and provision of counseling services, in addition to vast social support networks that included colleagues, family, and community. Healthcare workers employed in the Hubei acute care settings presented with relative advantages compared to UIO staff regarding access to resources. Resource abundance on the part of Chinese workers was a significant divergence in findings from UIO staff experiences. Though mental health issues were also common among UIO listening session participants, there was little discussion of systematic approaches to psychological support or resources to address these concerns.

There is also marked congruence in findings from the UIO listening sessions with Houghton et al. (2020) review of barriers and facilitators to healthcare workers' adherence to IPC guidelines for respiratory infectious diseases. Of twenty studies included in the final sample, only one was U.S.-based. Most sampled studies (15) were situated in hospitals, with two non-U.S. studies based in primary care or family practice settings. Several new themes emerged in the current analysis of UIO experiences relative to the systematic review. These differences may be attributed to the setting (primary care vs. acute care), unique characteristics of the population served by UIOs, or perhaps the sustained impact of the COVID-19 pandemic on the U.S. population. See **Table 4** for a comparison of findings, including themes identified among UIO participants not identified in the review. Specific to the theme of mental health issues, even though neither mental health, psychological issues, nor stress was explicitly identified as one of the 26 key findings, narrative excerpts in the Houghton et al. review contained several associated terms including fear, frustration, fatigue, and emotional distress (2020).

The mental health impact of COVID-19 on healthcare workers is a growing concern across the U.S. and the subject of a rapidly expanding body of scientific literature. A subsequent scan of the literature returned nearly 200 journal articles that primarily originated outside of the U.S. In the aftermath of the 2003 SARS outbreak, DiGiovanni et al. (2004) write that healthcare workers suffered from a range of issues that ultimately affected their mental health such as fear, the inconsistency of measures between information distributors, lack of logistical support, psychological stress, and poor communication to the public. Brooks et al. (2020) identify the psychological impacts of quarantining, including for healthcare staff, who reported deteriorating work performance as a result. Notably, Brooks et al. (2020) identified no strong evidence of any demographic factors linked with poor psychological outcomes after quarantine. Two recent rapid systematic reviews aimed to assess epidemics and pandemics' psychological impact on healthcare workers' mental health (Preti et al., 2020; Stuijzand et al., 2020). Post-traumatic stress disorder (PTSD), depression, anxiety, burnout, and a host of other psychological symptoms were found to

TABLE 4 | Comparison of UIO listening session findings to systematic review of barriers and facilitators to infection prevention control.

Findings from Houghton et al. (2020) Review that Aligned with UIO Listening Session Findings	Findings from Houghton et al. (2020) Review Not Identified in UIO Listening Session Findings	Findings Unique to UIO Listening Sessions
Long, ambiguous, or conflicting guidelines created uncertainty	Adherence influenced by the support received from the management team	Mental health issues for UIO staff with possible implications for IPC practices
Frequently changing guidelines caused healthcare workers to feel overwhelmed	Guidelines workers perceived as impractical were hard to implement	The implication of telehealth on clinical and IPC practices
Fatigue and increased workload from IPC practices a barrier to adherence	Multiple methods and platforms for communications useful to ensure staff are kept up to date	Staffing issues (vacancies due to risk, exposures, and increased work demands)
Clear communication and sharing updated information within organizations critical to success	Frontline healthcare workers have difficulty balancing role as IPC trainer with clinical duties	Role of social determinants of health and need for UIO patients
Lack of training on specific infection information and PPE needs contributed to poor implementation	Access to handwashing facilities and surface cleaning supplies identified as key factors in adherence to IPC measures	Implications of culture for the Native population served by UIOs for modifications in traditional practices and medicine, provision of care, and public health practices
Lack of mandatory training and accompanying skills assessments contributed to lack of adherence	Personal knowledge of patient or colleague infection facilitated adherence to IPC guidance	
Healthcare facility with sufficient space to isolate patients viewed as a key to adherence to IPC methods	Workers recognize the responsibility to increase knowledge but must have evidence, rationale, and support to do so	
Adequate ventilation, isolation rooms, anterooms, and shower facilities are required to achieve adequate IPC measures	Workers had to value the importance of IPC to increase adherence and incorporate IPC into routine practice	
Patient/workflow measures, e.g., minimize overcrowding, route control, fast-tracking infected patients, and other measures to reduce risk seen as essential tools to protect staff and patients	Face masks could be perceived as frightening, cause isolation, or stigmatizing for patients and may reduce the use	
Inadequate supplies of appropriate PPE perceived as a serious concern	Discomfort wearing PPE may reduce adherence; ensuring proper fit may help	
Need for PPE increases as outbreaks intensify; requires attention to increasing PPE supply line needs as the outbreak continues		
Knowledge limitations among specific team members can be a barrier to overall ability to adhere to IPC guidelines		
Use of PPE, particularly masks, not always seen as important for healthcare workers		
Fear of infecting self or others facilitated adherence to IPC guidelines		
Workplace culture and colleagues can act as a barrier or a facilitator to adherence		
Healthcare workers felt a duty to care for their patients		

affect healthcare workers up to 3 years after epidemics and pandemics in both reviews. Resilience, perceived organizational support, confidence in protective measures, training, and trust in IPC measures instituted by organizations reduced adverse psychological outcomes.

Conversely, inadequate training, exposure to high-risk environments or perceived personal risk, low organizational or personal social support, and limited coping mechanisms increase the risk of psychological sequelae. A limited selection of evidence-based interventions was identified (Preti et al., 2020; Stuijzand et al., 2020). Beyond the personal impact of UIO staff endorsements of feelings of fear, fatigue, stress, and other mental health issues, one UIO staff participant shared an anecdote detailing the direct negative impact of long-term mental fatigue on IPC practices, specifically reduced care and attention in donning and doffing PPE. Research identifying a direct

causal relationship between fatigue, psychological symptoms, or emotional issues and lapses in IPC was not identified in the literature search. However, there is a substantial body of literature documenting the link between fatigue and risks to personal safety, patient safety, and adverse events (The Joint Commission, 2018). Thus, the hypothetical assumption that UIO staff experiencing these issues are at increased risk of exposure to SARS-CoV-2 due to lapses in practice is plausible.

Recommendations for Practice, Policy, and Research

Practice Recommendations

There are implications from the findings for practice, policy, and research. Given the grounding of this work in frontline UIO healthcare workers' experiences, there are clear and actionable implications for practice that are further supported by recent

research. Consistent across the literature are recommendations for providing sufficient access to PPE and protective measures, and enhanced knowledge of IPC and training, with evidence to support the positive short and long term mental health implications of addressing these needs (Houghton et al., 2020; Liu et al., 2020; Preti et al., 2020; Stuijzand et al., 2020). Houghton et al. (2020) identified additional facilitators that included the importance of how guideline content is communicated, manager support, the culture of the workplace, physical space, duty to provide care, and also noted the need to be inclusive of all facility staff in training (not just healthcare providers). Enhanced education and communication approaches can reduce fear and uncertainty and increase trust by enhancing IPC skills mastery and providing personnel responsible for continuous training, monitoring, and supervision of IPC practices. Organizations can reduce anxiety and other concerns related to virus transmission to family members and staff with training, enhanced safety practices and procedures, supportive conversations, and education about best practices surrounding mitigation and risk reduction for returning home after work (Liu et al., 2020).

Also, the following consolidated set of recommendations derived from the two systematic mental health reviews for supporting healthcare workers during a pandemic is offered for consideration:

- Support and enhance resilience and coping strategies through primary preventive strategies, including consideration for computer-assisted resilience training with interactive, reflective exercises
- Develop and deliver online support services
- Establish a mental health support team for healthcare staff
- Implement widespread staff screenings for perceived safety risks during the outbreak
- For staff with identified concerns, consider multi-phased intervention inclusive of psychological first aid, psychoeducation, and cognitive-behavioral therapy (CBT)
- Managers should foster peer support programs, implement programs to demonstrate organizational support, and routinely provide updated information
- Allow healthcare staff to volunteer for high-risk assignments, rather than impose a requirement
- Implement mental health screenings after the outbreak and at long term intervals.

UIO services and the Native and non-Native populations served are diverse, as are the individual organizations and communities' strengths and weaknesses. Findings from this publication and the literature may provide a framework and starting point for a systematic assessment of a UIO's organizational needs and capacities regarding IPC practices and policies.

Policy Recommendations

Policy recommendations are multidimensional. There are both minor policy considerations, meaning organizational rules and practices, and major policy needs, including federal and state policies (Eyler et al., 2016). Within the adaptation theme specifically and throughout discussions, UIO staff acknowledged the importance of organizational policies to their perception of

an adequate (or inadequate) response to the unfolding pandemic. UIOs with strong, existing, up-to-date policies and procedures and the infrastructure to rapidly create, review, and deploy policies were better positioned than those who did not have this capacity. Standardized IPC training is needed to support UIOs systematically across the country. As healthcare providers, in a time of scarce resource allocation, UIOs should be prioritized for PPE and other resource allocation at the local, state, and federal levels. UIOs have great diversity in size, scale, and operational capacity. They need comprehensive *support* to update and maintain facilities and operations. Although additional funding to address PPE and other essential supply and resource shortages is an important step, it does not provide a legitimate solution to significant resource shortages, and critical gaps remain regarding healthcare worker safety and training. For instance, funding can allow UIOs to make purchases or new hires. However, when local, regional, or state supply chains are depleted, and resources are being diverted to larger or resource-rich systems or communities, PPE may still be unavailable due to high costs—or it may even be entirely unavailable for purchase through suppliers, or staff may not be willing to work out of concern for personal safety. Principles of health equity, access to national and state stockpiles, and justice and mitigation of health inequities (National Academies of Sciences Engineering Medicine, 2020) in resource allocation strategies (similar to those recommended for vaccines) are needed to facilitate the return to normal or near-normal operations. Federal and state policies must recognize the crucial role of UIOs and other safety net providers, prioritize and address the most at-risk populations' needs.

Research Recommendations

There are significant research gaps, which are too often not inclusive of Native populations and community needs. These gaps exist across the spectrum of scientific and medical topics. Infectious disease, epidemic, outbreak, and healthcare workforce-focused literature reviewed for the present article historically and at present primarily originates outside of the U.S. However, within the body of research identified from the U.S., there is a particularly noticeable absence of Native American population representation. The present special collection and future-focused special collections are a significant contribution. It is plausible that the scarcity of publications results from the dearth of research conducted in tribal and urban settings. Unfortunately, case studies and experiences may not be enough to attract and compel policymakers to action. Until research barriers can be identified and removed within these communities and among Native-serving health organizations, creative solutions to fill the void in published literature must be identified. For example, data gathered from systematic assessments and evaluations conducted as part of projects and programs, such as the current project, should be published to serve as a foundation for future research. When research data is available, researchers must make the publication of findings a priority. The full spectrum of topics discussed in the present article represents gaps in the research literature. There is limited or no research originating in tribal

or urban Native communities on essential topics related to COVID-19, including:

- Infectious diseases, outbreaks, or epidemics involving the I/T/U healthcare workforce
- Effective IPC practices or programs
- Cultural facilitators or barriers to preventive public health practices among Native patients
- Patient and community conceptualization of COVID-19 as a “white man’s” disease
- Risk and protective factors for transmission or infection specific to Native American communities
- Role of social determinants of health
- Utility of social vulnerability indices created by the CDC in identification and prioritization of pandemic response efforts.

In fact, each theme or challenge in the present publication reflects an unexplored domain for health research among tribal healthcare workers or Native patients in virtually every health care setting and geographic location they may be served.

STRENGTHS AND LIMITATIONS

This paper is, to the authors’ knowledge, the first to employ rigorous qualitative methodologies to explore and publish the perceptions and experiences of frontline UIO healthcare workers or any healthcare staff who care for Native American people during the COVID-19 pandemic. A brief structured search of peer-reviewed literature identified no research studies that have assessed outpatient provider (e.g., primary care, family practice, outpatient provider) experiences with COVID-19 in the U.S. at the time of submission. Conversations with UIO staff touched on a diverse array of topics from culture to care patterns. Although these conversations are thought to represent the spectrum of holistic care provided by UIOs, they are seldom discussed in the context of one study or publication. The sessions included participants from multiple disciplines and professions. They all indicated that IPC practices and procedures are now a dominant reality in their work at the UIO. This new reality calls for a richer understanding of the implications of COVID-19 for the entirety of the UIO workforce, which this publication offers. The direct translation of findings to facilitate training, assist with policy development relative to COVID-19, and provide resources inclusive of UIO healthcare workers’ needs is a significant and relevant strength. Enhancing the knowledge of a healthcare workforce informed by those on the frontlines during a pandemic has the potential for immediate patient and community benefit.

There were several limitations associated with the approaches employed for the project. As noted, this project was not a research study; instead, the primary aim was to gather information to inform the training and education needs of the UIO staff during the present pandemic. The findings presented here are meant to contextualize understanding specific to the UIO staff experiences with IPC during the COVID-19 pandemic and are not generalizable. Not all UIOs were represented among the volunteer participants. Due to over-encumbered frontline staff at many facilities, there was likely

selection bias. Facilities that have a larger workforce may have been more likely to participate in sessions. However, based on the variety of professions, facility types, and facility sizes observed in the listening sessions, this seems unlikely. Limited demographic information for participants was available. Sessions were virtual, and as a result, this may have impacted the ability to build rapport with participants. The semi-structured interview guide, which was not piloted, was designed to elicit specific feedback on training needs and potentially influenced responses (e.g., participants’ terminology). While minor, interview guide revisions took several sessions to achieve maximal discussion with the least amount of facilitator intervention. The wording on questions changed slightly over the sessions, which may have led to variation in responses from the first to the last session.

CONCLUSIONS

UIOs, like other healthcare facilities around the country, are facing an unprecedented time in healthcare. UIO workers understand the unique contexts they occupy in terms of health equity, culture, and education. Listening session participants voiced a desire for a standardized IPC training program, policies, and procedures that acknowledge the unique cultural and tribal contexts in which they operate, specific to the I/T/U healthcare system. While identifying training needs was the core purpose of sessions, we were compelled to give voice to issues identified by UIO participants in discussions of their experiences during the COVID-19 pandemic, including a wide range of ongoing challenges related to resources, infrastructure, and available staff. Because unjust social determinants already affect urban Native populations disproportionately, special attention must be given to enhancing the fragile systems of services for these at-risk populations, and resources must be provided to address the most significant of these issues. Already under-resourced and over-burdened, UIO staff have adapted virtually every facet of their work at an intense and unrelenting pace, showing a degree of resilience reflective of the Native populations they serve. UIO staff in all roles are experiencing fatigue from the increased difficulty in conducting their jobs with increased responsibility, increased risk, and fewer resources. Mental health issues among staff are emerging and, in some cases, worsening and very few UIOs have the capacity to address these needs on top of other problems. Although UIO staff are attempting to adapt to a wide range of changes, their burden may be reduced by creating more efficient and streamlined communication channels and information dissemination internally and externally. Utilizing UIO staff as trusted community partners for outreach and community education could ensure receptivity and help eliminate doubts stemming from having received conflicting information from social media and other sources of misinformation.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusions of this article are not publicly available to protect participant confidentiality.

ETHICS STATEMENT

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

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AUTHOR CONTRIBUTIONS

NC, JC, JI-A, and DA were all present for the listening sessions. NC served as primary facilitator throughout all listening sessions. JC served as a secondary facilitator. DA served as a notetaker. JI-A managed the chat and video functions while ongoing. NC and JC performed initial coding, data analysis and drafted the manuscript and report. JI-A contributed as an editor toward the finalization of the manuscript. All authors contributed to the article and approved the original submitted version.

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Health Sciences Interprofessional Collaborative: A Perspective on Migration, COVID-19, and the Impact on Indigenous Communities

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At the United States-Mexico border, the impacts of immigration policy are dynamic with political, humanitarian, and health outcomes. This article highlights the experiences at the Casa Alitas migrant shelter in Tucson, Arizona. Casa Alitas aims to meet the needs of the im/migrants it serves, including the unique needs of indigenous asylum-seekers from Central America. We highlight the importance of community-based humanitarian response to support asylum-seekers in a way that acknowledges our shared humanity and implements specific approaches (e.g., language justice and trauma informed care). The effort at Casa Alitas is unique because in addition to other partnerships, Casa Alitas established an interprofessional collaboration between the University of Arizona Health Sciences Colleges and the Arizona State University School of Social Work. The interprofessional collaboration encourages mutual education amongst our professions and the use of our extended networks to meet the needs of im/migrants and asylum seekers in our community and the United States. We recommend the development of best practices in asylum health care, the importance of creating border-wide networks to build on local resources, and highlight the importance of exposing future health practitioners to trauma informed and culturally and linguistically appropriate care.

Keywords: indigenous, migration, asylum, border health, interprofessional

INTRODUCTION

The number of individuals seeking asylum in the United States skyrocketed over the past 2 years, increasing from 55,584 credible fear claims in 2017 to 146,660 in 2019 (U.S. Customs and Border Protection, 2020). During that same period, over 20,000 individuals came through the Casa Alitas Welcome Center, a shelter serving asylum seekers in Tucson, Arizona. These steep increases are a direct result of historic policy changes implemented under the Trump administration. The interaction of these policies with deteriorating socio-economic, political and climate conditions in Central America have served to exacerbate this migration trend. Indigenous populations from the Northern Triangle (Guatemala, El Salvador and Honduras) are disproportionately displaced by these external factors and have increased their migration in recent years (National Immigration Forum, 2019b; Meyer, Peter and Maureen Taft Morales, 2019). Among asylum-seekers at Casa Alitas, approximately one in every six identified as indigenous, and this is likely an undercount of the true numbers (Ama Consultants, 2020).

Casa Alitas is part of a network of migrant shelters and humanitarian aid groups on both sides of the United States-Mexico border working to meet the needs of im/migrants and asylum-seekers and serve as a counterpoint to the harsh shifts in immigration policy, enforcement, and political messaging over the past several years (Associated Press, 2019; Foster-Frau, 2019; Neri, 2019; Stone 2019; Prendergrast, 2020).

This article will address the response to this humanitarian crisis from the perspective of an interprofessional team from the University of Arizona Health Sciences and Arizona State University based at Casa Alitas. We will focus on our experiences and efforts to address the healthcare needs of asylum-seekers, particularly indigenous, in our community, beginning with the increase of asylum-seekers in 2018 and examining the repercussions associated with the COVID-19 pandemic of 2020. This work was done with the intent to provide trauma-informed care focusing on language justice and cultural humility. Based on our experience we offer an account of one community's response and potential practice recommendations to build a comprehensive, collaborative approach to the care of asylum seekers.

Internationally, we recognize the status of both refugees and asylum-seekers. Refugees, however are afforded both visas and certain health and humanitarian aid benefits while asylum-seekers are in a more tenuous position. In the United States, asylum-seekers live with humanitarian parole, a vulnerable status where they are in constant threat of being detained, and are without explicit access to medical care (Frelick, 2005; Siskin, 2009; American Civil Liberties Union, 2020). In order to address the complex nature of the factors influencing the health of migrant families, a multilateral and interprofessional approach is needed to provide holistic and comprehensive care.

This need became apparent during the response to the rapid influx of migrants into the Tucson community in fall 2018. Faculty and students from the individual health sciences colleges at the University of Arizona (Public Health, Nursing, Pharmacy, and Medicine) recognized that each college was separately mobilizing a response to the urgent needs of the arriving asylum-seekers, and that it would be more effective and serve everyone better to collectively coordinate and build on each college's work and expertise.

We want to recognize that we are not the center of this experience. We respect the experiences, decisions, and journey of the people we serve and recognize that our ethical duty extends beyond service to ameliorating harmful immigration policies in the United States.

IMPACT OF ASYLUM POLICIES ON THE UNITED STATES-MEXICO BORDER

Asylum can be requested from within the United States or at a port of entry (National Immigration Forum, 2019a). At the United States-Mexico border, individuals seeking asylum can also cross into the United States outside of a formal point of entry and present to Border Patrol agents (Miroff, 2018). Prior to 2018, following a credible fear interview, asylum-seekers could be

subject to civil detention or released to sponsors in the United States (National Immigration Forum, 2019a). Casa Alitas originated out of a need to support the individuals who were reuniting with sponsors in the United States.

Changes to immigration policy implemented after 2018 created new risks for asylum seekers. These changes included metering, Migrant Protection Protocols (MPP)/"Remain in Mexico", the asylum transit ban, and the Prompt Asylum Case Review (PACR) program. The MPP policy required asylum-seekers to remain in, or return to, Mexico for the duration of their asylum proceedings (American Immigration Council, 2020a; American Immigration Council, 2020b), and expelled over 60,000 migrants including at least 16,000 children and 500 infants. (Miller et al., 2020). The informal refugee camps for asylum-seekers in Mexico often lack access to clean water, food, safe places to sleep, bathrooms and other essential infrastructure including very limited health services (Miller et al., 2020). This contributes to the spread of illnesses such as COVID-19 and can increase the risk of violence (Human Rights Watch, 2020). Asylum-seekers in these camps reported over 816 incidents of rape, kidnapping, torture and other attacks in 2019 alone (Human Rights Watch, 2020).

Indigenous im/migrants from Central America are especially vulnerable as they are more likely to speak an indigenous language and have limited Spanish. This poses a challenge to navigating the camp environment, accessing health resources, engaging in the limited legal assistance available, and navigating the asylum hearing process. Additionally, members of indigenous cultures are at higher risk of persecution in Mexico (Ahtone, 2018; Long and Sawyer, 2019).

The conditions in the refugee camps under MPP were exacerbated with the onset of the COVID-19 pandemic. In early 2020, the Trump administration effectively closed the United States-Mexico border to asylum seekers, and allowed for the immediate expulsion of noncitizens, including children, arriving at the border (Miller et al., 2020). The administration has since extended this policy indefinitely although the decision has been criticized by public health professionals and was opposed by officials at the Centers for Disease Control (Alvarez, 2020; Centers for Disease Control and Prevention, 2020; Columbia University Mailman School of Public Health, 2020; Guttentag and Bertozzi, 2020). This policy led to the removal of 204,000 individuals between April and October 2020 and worsened the already dangerous conditions in the make-shift camps (Miller et al., 2020; Montoya-Galvez, 2020a). Journalists have reported that CBP used the policy to justify the expulsion of United States infants without their United States citizenship paperwork (Srikrishan, 2020; De La Hoz, 2021). Due to COVID-19, many immigration courts have closed and MPP proceedings were halted. These delays prolong stays in refugee camps. The Trump administration also continued to deport immigrants, with numerous deportees testing positive for COVID-19 immediately on arrival in their home countries (Mohammed et al., 2020). At one point, at least 23% of cases in Guatemala could be traced to returned detainees (Montoya-Galvez, 2020b). Indigenous populations are disproportionately impacted by COVID-19, and the pandemic has exacerbated racism and

stigma toward these groups, blaming them for higher rates of infection (Pan American Health Organization, 2020).

CASA ALITAS

Since 2014, Casa Alitas has provided food, health care, short-term housing, clean clothing, and travel support for asylum-seekers. Partnership with community organizations and with local jurisdictions have supported the shelter's services. The 2018 increase in asylum seekers created a renewed imperative to provide equitable and culturally sensitive humanitarian support. In the spring of 2019, the shelter served over 400 individuals at any one time, with more than 200 asylum-seekers arriving daily. In response, Casa Alitas partnered with secular and religious organizations to open pop-up shelters in the community. This network included hundreds of individuals from the Tucson community volunteering their time and expertise.

The asylum-seekers served by Casa Alitas represent vulnerable groups, including many indigenous people from Central America. Prior to the COVID-19 pandemic, nearly all were families—usually a parent with children, and the remainder were single adults with health conditions requiring significant attention which precluded them from remaining in detention due to the documented substandard medical care and dangerous health conditions in civil immigration detention facilities (Siskin, 2009; Long and Meng, 2017). Under the Trump Administrations' use of MPP and other policies to shut-down the asylum process, Casa Alitas experienced a decrease in activity toward the end of 2019. However, with the COVID-19 pandemic, Casa Alitas has renewed services, meeting a need for support and care for im/migrants who are released from long-term detention facilities or are exempt from the MPP due to medical conditions such as pregnancy, end-stage renal disease, diabetes or other respiratory diseases with higher-risk for COVID-19.

In order to most effectively serve these vulnerable people and ensure equitable care, Casa Alitas volunteers work to identify individuals needing specialized attention, specifically: those separated from their families, indigenous language speakers in need of interpretation services, or those with severe or immediate health needs.

Factors Impacting Indigenous Asylum-Seekers at Casa Alitas

Mirroring national im/migration trends, Casa Alitas has observed a change in demographics of asylum-seekers, with increases in those arriving from indigenous communities in Central America. Program records indicate that 60% of those served were from Guatemala. Within Guatemala, there are over 20 indigenous languages and dialects, and 21% of Casa Alitas guests reported speaking an indigenous language as their primary language. The most common self-identified indigenous languages spoken by migrants at the shelter were: Mam (42%), Q'eqchi' (14%), K'iche (10%), and Q'anjob'al (10%).

These language barriers create vulnerabilities across multiple settings including within the informal camps in Mexico, where, as

mentioned indigenous experience higher incidence of persecution, and within the United States legal system where the inability to offer adequate interpretation jeopardizes asylum cases (Jawetz and Scott, 2019; Medina, 2019; Nolan, 2019).

Indigenous groups in Central America, much like those in the United States, faced persistent barriers (e.g., discrimination in language, education, and health access) and historical trauma related to violence and displacement. During the initial arrival of asylum-seekers at the Casa Alitas shelter, many individuals did not volunteer their indigenous primary language or their immediate health concerns. This resulted in delays in communication and care. Additionally, the self-identified reporting of indigenous language described above is likely an underestimate due to this hesitancy to volunteer such information. Casa Alitas recognized this phenomenon early on and worked closely with indigenous language specialists to address these delays and mitigate the language barriers contributing to the perpetuation of health disparities.

In response to the numbers of Guatemalans who have come through the shelter, and the desire to provide equitable assistance, Casa Alitas established a relationship with the Guatemalan Consulate. This relationship expedited the process of arranging legal, travel, and language services and reuniting family members. Casa Alitas also worked to address the issue of language access, by creating and maintaining a network of peer interpreters. These are individuals who are fluent in an indigenous language as well as either Spanish or English, who were willing to serve as on-call phone or in-person interpreters. While many lacked formal training; they had passed through the shelter themselves and their dedication bridged the gaps for those following in their footsteps. The peer interpreters demonstrated compassion and commitment that continues to benefit those in their direct service and the broader community. Additionally, the repeated need to use appropriate and culturally sensitive interpreters has increased local provider and volunteer awareness, along with improving cultural humility in healthcare and social services practice.

Despite efforts to mitigate the substantial barriers that asylum-seekers faced, it is clear that many experienced additional challenges in their journeys. These included persistent language and sociocultural barriers. Indeed, this vulnerable population may often seem invisible in communities unprepared to deliver the support that they require. These individuals and families often experience continued persecution and fear of the immigration processes. While these barriers exist for all migrants, they are especially pronounced for indigenous groups.

Medical and Interprofessional Response at Alitas

Individuals seeking asylum, im/migrating, or arriving as refugees often present with histories of trauma incurred pre-departure, during their migration journey, after arrival and during detention, and while assimilating into their new communities (The Center for Victims of Torture, 2005). This is certainly true for those arriving at Casa Alitas. After making the difficult decision to leave their home countries, many experience

arduous trips through Central America and Mexico. They may be persecuted or extorted by the cartels, and experience further trauma upon arrival at the United States-Mexico border.

At the United States-Mexico border many waited days, if not months, to be allowed to seek asylum. Others crossed through treacherous routes in the desert, only to then be detained and held in “hieleras” or “ice-boxes” by CBP (Garcia Bochenek, 2018; National Immigration Forum, 2019a; National Immigration Law Center, 2020). This mistreatment at the hands of the United States Government and others are efforts to diminish dignity. Asylum-seekers arrive at the shelter with ID bracelets from CBP but without their shoelaces, hair ties, necessary medicines, and sometimes missing personal belongings. Casa Alitas attempts to restore some of that dignity.

A team of doctors, NPs, PAs, nurses, pharmacists, public health professionals and social workers formed to address the trauma and health needs of the guests arriving at the shelter. As mentioned, there is precedent for formally integrating refugees into our health system and society, with pre-departure screenings, post-arrival clinic visits, and agencies with dedicated staff to accompany individuals through the arrival process. There is no parallel system for those seeking asylum. The experiences of those arriving at the shelter demonstrated the need for a community-based and interprofessional response to meet their health needs. The Casa Alitas healthcare team and its interprofessional composition have, as a result, formed an external support system and network that has served as a bridge to the existing infrastructure both in Tucson and in the communities where these individuals settle. This has included partnerships with the local public health department and universities to provide more comprehensive services including flu vaccines, well-child visits, and varicella and flu treatment and prophylaxis.

At Casa Alitas, the medical team screens all asylum-seekers on arrival at the shelter. They are assessed for urgent, serious, or infectious conditions and triaged appropriately. Following the initial screening, asylum-seekers have access to medical care on an as-needed basis, with an on-call provider available 24 h a day both to triage and address immediate health needs and accompany those who need higher levels of care at local clinics or hospitals. Nearly all presented with some level of dehydration and malnutrition. They reported gastrointestinal symptoms from poor quality food and hesitancy to drink while in detention exacerbating dehydration and food scarcity from their journeys. Internal project records show that pre-COVID, one in ten reported severe or acute medical conditions on arrival such as diabetes, hypertension, or even cancer or HIV, and approximately 4% were pregnant. After MPP and COVID-19, fewer guests arrived, but those arriving required significantly increased medical attention. Many of those released from detention facilities were directly exposed to COVID-19, with some testing positive, and requiring hospitalization. Many others had pre-existing chronic conditions that put them in high-risk categories and needed higher levels of medical care.

Of those coming directly from the border, some of those with serious conditions were treated during their brief detentions by ICE or CBP. Many others, however, reported that their

medications were confiscated during their detention. Others reported recent surgeries or stays at local hospitals, but often arrived without discharge information, medications, or follow-up plans. Due to crowded conditions on the journey and in detention, many arrived with infections such as flu, varicella, scabies, and hand-foot-mouth disease. In the shelter setting, it is important to identify and treat such infections prior to further outbreaks. This became even more essential following the onset of the COVID-19 pandemic. Other asylum-seekers experienced rape or sexual assault during their journey or prior to leaving their home countries. Still others had visible signs of Post-Traumatic Stress Disorder (PTSD) and manifestations of torture that occurred during or prior to their journeys.

In addition to direct medical care, there was a need for a more comprehensive and interprofessional approach to address the complex needs of the migrants. To this end, we formed a standing interprofessional working group of faculty and staff from University of Arizona Health Science colleges and the Arizona State University School of Social Work. This group has partnered with community organizations and has allowed us to be dynamic and adaptable to the unfolding needs of families welcomed at the shelter. The group lends academic support to the ongoing crisis and integrates students into the volunteer teams. In partnership with SEAHEC (Southeast Arizona Area Health Education Center), we created an interprofessional service-learning course, Migration Interprofessional Leading to Action and Growth (MILAGRO), to provide first-hand experience with the realities of humanitarian care, and expertise in building sustainable, community-engaged responses. Students work in interprofessional teams to learn about the root causes and impacts of migration and the realities and challenges migrants and asylum-seekers face, preparing students for a more culturally informed, interprofessional approach to their future practices. Projects have ranged from creating videos on how to navigate travel across the United States using the bus system, to in-person instruction on recovering from dehydration and malnutrition. This model of an academic-community partnership, based in interprofessionalism, is one that we want to share with our communities, nationally and internationally, as they seek to be responsive to the urgent health issues in their own communities and nations.

DISCUSSION

With this paper, we aimed to share our experiences responding to the humanitarian crisis caused by punitive immigration policies with a focus on addressing the needs of indigenous people who are migrating to the United States. As an interprofessional group, we have witnessed the devastating effects of policy changes on the individuals seeking asylum and, on their families, and communities. The interprofessional nature of our partnership allowed us to view the complexity of the issues facing asylum-seekers from a diversity of perspectives and develop a robust and evolving response as aspects of the crisis changed in response to COVID-19. Sharing information within our group and with the participating students has led to increased knowledge and

improved practices in the areas of cultural humility, language justice, trauma informed care, and healthcare.

The medical needs of asylum-seekers that we observed among those released from detention underscore the need for the development of best practices on integrating asylum healthcare into community-based health care. Our experiences caring for im/migrants confirm the extensive reporting on the inadequacy of care in CBP and civil detention settings. Humanitarian workers must be prepared to assess and respond to chronic conditions that have been exacerbated by the journey. Given the substantial expertise and medical resources needed to provide a comprehensive response in a given community, further development of networks across communities and binationally is warranted.

Lack of access to adequate interpretation services perpetuates the inequalities faced by all im/migrants. Indigenous asylum-seekers face language and cultural barriers that compound these challenging situations. While it is, or should be, protocol for individuals to be offered formal interpretation services both in medical and legal settings, we found that the reality is more complicated. Many indigenous im/migrants hesitate to disclose their language preferences for fear of discrimination. In the best of scenarios it is still difficult to obtain accurate interpretation or translation of resources into the dialects of numerous indigenous languages (Gentry, 2015). Numerous national organizations are working toward addressing linguistic justice and addressing adequate interpretation services for indigenous migrants in legal and medical settings. Supporting and connecting with these organizations and using technology across communities receiving asylum-seekers could aid this effort. Further, we recommend the creation of a cadre of paid professional interpreters working in legal and health care settings to ensure linguistic justice. Awareness of the language and other barriers faced by indigenous im/migrants and asylum seekers is an important starting point but it is insufficient to meet the standards of ethical care.

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While this article focuses on the experiences and lessons learned from one community shelter, further studies and attention are needed to understand how im/migrants, and particularly indigenous migrants, are integrating into their destination communities, and how to better support them and their communities in this process. In Tucson, the community came together, with hundreds of volunteers working with community organizations like Casas Alitas and complemented by partnerships with local governmental agencies, other non-profits, and the resources and infrastructure of an academic partnership. This dynamic partnership has helped to address the crisis created by immigration policy focused on restriction and enforcement and that refuses to engage or address the human consequences of such policies.

Our experience recommends the creation of interprofessional networks for humanitarian responses in order to ensure ongoing sharing of experiences, failures and successes, and to identify strategies for improvement. Additionally, we have an opportunity and obligation to train future medical, social, public health and legal providers in a more inclusive, interprofessional, comprehensive, compassionate, and culturally humble manner. This will ensure trauma-informed care that is team-based and culturally and linguistically appropriate.

DATA AVAILABILITY STATEMENT

The raw data supporting the conclusion of this article will be made available by the authors, without undue reservation.

AUTHOR CONTRIBUTIONS

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

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