

Caring for Native Americans
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FROM THE EDITOR IN CHIEF

Health of the First Americans

Audiey C. Kao, MD, PhD

Today, the place along Lake Michigan I call home sits on ancestral lands of Indigenous peoples, including the Ojibwe, Odawa, and Potawatomi nations.¹

During middle school, I was taught that Indigenous peoples of the Americas first arrived some 13 000 years ago by crossing a land bridge that connected Siberian Asia with Alaska.² The history that was imparted to me and my classmates seemed to be a straightforward one: a single wave of southbound migration populated the entire Western Hemisphere. Analyses of ancient DNA have since revealed that there were many complex and unexpected migrations taken by the First Americans.³ As with much of the past accounted for in textbooks, what has long been told can be oversimplified, incomplete, and wrong.

While in middle and high school, I was not taught about the US government's dispossession of First Americans' land and property and the means by which they nourished their bodies and spirits. This forced impoverishment rendered their age-old agricultural and stewardship practices useless and with no surviving expression, leaving so many Pima and Tohono O'odham Indians dependent on a federal supply of canned and other processed foods of such poor nutritional quality that they now possibly have the highest rates of type 2 diabetes in the world.⁴ I was not taught about the Trail of Tears and other forced relocations that led to thousands of deaths⁵; I did not learn about the many treaties signed by Indigenous tribal nations that were violated by the US government.⁶ I was not taught that these dispossessions, terminated family lineages, forced dependencies, and betrayals were sources of **transgenerational trauma**, loss, and grief for so many First Americans.

I never understood or appreciated that these nations had thriving cultures before the first Europeans arrived in 1492.⁷ It is estimated that in the pre-Columbian era, more than 100 million Indigenous people were living in the Americas, with about 10% living north of the Rio Grande river.⁸ Regardless of the actual population numbers, archaeological evidence reveals the on-the-ground reality of densely populated lands and not, as the 19th-century George Bancroft claimed, "an unproductive waste ... its only inhabitants were a few scattered tribes of feeble barbarians."⁹ Indigenous peoples of those times established communities and created cultures that equaled the diversity and richness of those of modern-day societies.¹⁰

According to the 2010 US Census, 5.2 million people identified as American Indian and Alaska Native.¹¹ If we simply compare the numbers of Indigenous peoples living in the past and in the present, the well-being of Indigenous peoples would seem to be in great peril. Yet these raw numbers don't tell the full story. Life expectancy of American Indians and Alaska Natives is 5.5 years less than that of the overall US population, as they die at a rate that is 1.1 times higher for heart disease, 3.2 higher for diabetes, and 4.6 times higher for chronic liver disease.¹² American Indian and Alaska Native youth also have the highest suicide rate—2.5 times higher than the national average for young people.¹³

These dismal health statistics are disturbing but wholly predictable in light of the **socioeconomic condition** of Indigenous peoples. For example, the 2017 median household income for American Indians and Alaska Natives was \$40 315 compared to \$57 652 for the country.¹⁴ That disparity translates to almost 6 times as many American Indians and Alaska Natives living in poverty.¹⁴ Only 17% of this population pursue any **post-high school education** compared to 60% of people in the United States as a whole.¹⁵ American Indians and Alaska Natives also have the lowest rate of reported “perfect” attendance among 8th graders.¹⁶ One of the reasons seen as contributing to increased school absenteeism is poor infrastructure, with more than three-quarters of all existing roads on tribal lands that qualify for federal funding being unpaved.¹⁷

The COVID-19 pandemic has dramatically exposed and further amplified large **health disparities** in our society, as communities of color are suffering and dying at much higher rates. The true toll of this pandemic on Indigenous peoples is still not known because race and ethnicity data either are not collected or are inaccurate—particularly in tribal nations, where data reporting is not required.¹⁸ I hope this issue of the *AMA Journal of Ethics* not only provides readers with some necessary illumination on the health of First Americans and the breadth and depth of Indigenous persons' and communities' strength and resilience, but also serves to draw us together in productive, respectful, and well-informed partnerships.

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CASE AND COMMENTARY

How Should Allopathic Physicians Respond to Native American Patients Hesitant About Allopathic Medicine?

Madison L. Esposito and Michelle Kahn-John, PhD, RN

Abstract

American Indian (AI) and Indigenous peoples utilize traditional medicine/healing (TM/H) for health and well-being. Allopathic health care practitioners (HCPs) receive minimal training and education on TM/H and its application and integration into health care settings. Lack of knowledge and practice guidelines on how to navigate these 2 health care perspectives (allopathic and traditional) creates uncertainties in the treatment of AI and Indigenous peoples. Such conflicts can undermine patient autonomy and result in culturally incongruent practice. This article presents a case study showcasing suggestions for how HCPs can direct clinical decision making when working with AI/Indigenous patients who utilize TM/H. The article argues that health professions education institutions and HCPs must dedicate effort to expanding awareness of and education about TM/H to enhance the delivery of evidence-based and integrated clinical treatment for AI/Indigenous patients.

Case

Ms Q is a 72-year-old Navajo woman seeing Dr S, a new physician at an Indian Health Service (IHS) unit in New Mexico. Ms Q reports 5 months of weight loss, fatigue, epigastric pain, and jaundice. She lives in a remote community on the Navajo Nation, and her granddaughter drove 2 hours to bring her to the IHS clinic, insisting that Ms Q's symptoms should be evaluated by an allopathic physician. Traditional Navajo healing practices and customs are important aspects of Ms Q's life. Although she does not routinely visit the IHS clinic, Ms Q is open to being evaluated by Dr S.

In a follow-up visit, Dr S discusses test results with Ms Q. Based on laboratory evidence of obstructive jaundice and a computed tomography scan revealing a solid mass in the head of Ms Q's pancreas, Dr S suspects that Ms Q has pancreatic cancer and recommends endoscopic retrograde cholangiopancreatography (ERCP), a procedure that enables examination of the liver and pancreas ducts, with endoscopic ultrasound (EUS) to confirm the diagnosis. Ms Q feels hesitant to pursue ERCP with EUS and the required travel and requests to see her medicine man to discuss her symptoms and Dr S's recommendations. Unfamiliar with traditional Navajo healing, Dr S wonders how to respond.

Commentary

To provide an adequate response to this clinical case, some knowledge of traditional medicine and healing (TM/H) is required. An in-depth definition of TM/H developed with input from American Indian (AI) traditional medicine healer-practitioners (TH/Ps) follows.^{1,2} TM/H is broadly defined as the interrelational therapeutic processes involved in the application of sacred, mysterious, and spiritually informed AI/Indigenous cultural knowledge systems and healing practices that are passed down from one generation to the next. TM/H is used to diagnose and treat physical, spiritual, mental, and emotional imbalances that result in illness and distress. The exact practices of TM/H are wide-ranging, vary widely between tribal nations, and include specialized ceremonies that range from short, diagnostic ceremonies to larger, more comprehensive ceremonies that span several days. Sweatlodge ceremonies, all night chant ceremonies, Native American Church ceremonies, purification ceremonies, and the use of herbal remedies are just a few examples of tribe-specific AI/Indigenous ceremonial practices. Characteristics of TM/H include trust between the patient and TH/P, recognition of the sacred nature of TM/H, and incorporation of prayer, ceremony, ritual, or the use of herbal therapies. AI/Indigenous ceremonies, stories, and cultural wisdom are privileged and private information; therefore, details of the interventions may be intentionally restricted for purposes of safeguarding and ensuring the safekeeping and application of the TM/H intervention by a TH/P.

The authenticity of a TH/P is determined by the community that practitioner serves. TH/Ps are vetted by other TH/Ps, family, and the community to which the patient seeking TM/H care belongs. TM/H practice is commonly transferred across generational lineage, with each TH/P receiving years of training by an older relative or mentor prior to independent practice. Attributes of TH/Ps include kindness, respectfulness, humbleness, and self-sacrifice. In addition, TH/Ps are expected to convey love to all living and nonliving entities, are self-disciplined, practice self-care, have a sense of humor, and are spiritual. TH/Ps also possess in-depth cultural teachings, ceremonial knowledge, and tribe-specific wisdom and stories; awareness of sacred orders of time and space; and awareness of or skills in communication between the spiritual and physical worlds. Importantly, they have sacred relationships with self, others, animals, nature, and spiritual realms.^{1,2}

The role of the patient in seeking health and well-being through TM/H involves personal agency, preference, and intent. Based on personal preferences, cultural teachings, level of acculturation, and accessibility to healing and health care modalities, the patient may choose to pursue TM/H as the sole vehicle of care or may take an integrative approach by also seeking Western medicine as a secondary intervention or a concurrent intervention alongside TM/H. It is important to note that patients may not be forthcoming about their use of TM/H when discussing their health with Western health care professionals due to the distrust that some AI/Indigenous peoples have of non-Native interventions or interventions delivered by government agencies.

Practice Challenges

In a discussion of challenges associated with navigating the delivery of allopathic medicine alongside TM/H, it's important to include challenges perceived or experienced by health care practitioners (HCPs) as well as patients.

Health care practitioner challenges. HCPs rely on scientific evidence as the basis of practice standards. They employ this evidence to support assessment, clinical

reasoning, patient autonomy, and treatment recommendations. Contemplating the integration of a **complementary or alternative approach**, such as TM/H, and evidence-based clinical practice may contribute to HCPs' practice uncertainty due to the incongruence between science-based knowledge and cultural and spiritual-based knowledge. Another challenge HCPs may experience is respecting patient autonomy by allowing patients to choose and prioritize the health and wellness interventions they feel best fit their physical, mental, emotional, and spiritual needs—especially when patients prefer complementary or alternative approaches. These are valid HCP concerns and must be considered, discussed, and further explored to maintain optimal health and safety of patients.

Safe delivery of TM/H alongside allopathic care requires openness, safe communication, and all practitioners' understanding of the recommended treatment options. Not all ceremonial interventions are safe for all patients, and the final decision on whether a patient should participate in a physically demanding TM/H ceremony should be reached only after collaborative discussions among all practitioners serving the patient have occurred. For example, a sweatlodge ceremony could be taxing for an acutely ill or frail patient due to the physically demanding aspects of the ceremony. Collaborative and informed approaches allow the patient, TH/Ps, and HCPs an opportunity to discuss safe strategies, which may include a recommendation to proceed, cancel or postpone the ceremony, consider safer approaches, or modify the treatment, thereby reducing associated risks.

Education and training are critical factors in addressing these concerns. HCPs are likely unaware of TM/H and may have received little or no education or training on practices, safety, and health outcomes related to TM/H. This situation is gradually changing, as some medical and nursing schools have become increasingly informed about safe, culturally congruent, and evidence-based alternative, complementary, and integrative approaches to health care delivery.^{3,4,5,6,7,8,9,10}

Patient challenges. TM/H is critical to the identity and culture of tribal nations and the ways that they relate to the world around them.^{11,12,13} Two studies from the 1990s indicate that 62% of Navajo had utilized TM/H interventions at some point in their lives,^{14,15} while 39% received TM/H interventions on a regular basis as a component of their overall health and wellness practices.¹⁵ Another study based on an intertribal sample of 30 tribal affiliations found that 38% of patients used TM/H healers and 86% of those who did not use TM/H healers would be open to seeking consultation from a TM/H healer.¹⁶ Failure of HCPs to recognize TM/H as a core component of self-identity and wellness for AI/Indigenous patients may be perceived as culturally insensitive, thereby eroding the patient's autonomy and hindering the development of trust between the HCP and patient. Without the foundation of trust, **respect for patient autonomy**, and provision of culturally sensitive or congruent care in their relationships with patients, clinicians risk unintentionally harming and disrespecting AI/Indigenous patients. These patients may then begin to distrust, and become unwilling to participate in, allopathic care.¹⁷ By contrast, an HCP's ability to recognize the importance of TM/H to the overall well-being of an AI/Indigenous patient creates opportunities to optimize patient health outcomes through intentional consideration—and sometimes integration—of both healing paradigms.¹⁸

Suggestions for Enhancing TM/H Education

TM/H education is necessary and beneficial for HCPs. However, several challenges exist for HCPs who want to learn more about TM/H:

- TM/H is considered sacred knowledge and is sometimes restricted and not shared with individuals outside of the tribal community.
- The diversity of TM/H across tribes creates challenges to learn about the wide array of tribe-specific as well as shared (intertribal) TM/H approaches and specialties.

The lack of training in TM/H is at the core of the dilemma faced by Dr S in this case. Without a solid understanding of TM/H, Dr S does not have the knowledge to accurately evaluate and offer a clinically informed response to Ms Q's request to seek council with her medicine man. If Dr S were to deny Ms Q's request and recommend immediate treatment, Dr S might be perceived by the patient and her family as culturally insensitive and disrespecting of patient autonomy. As a result, the patient and her family might be hesitant to engage in an integrated treatment plan or Western health care interventions.

For all HCPs, training in TM/H and in strategies for navigating allopathic medicine and TM/H is imperative to providing comprehensive, culturally inclusive, and effective care to AI/Indigenous patients. TM/H education should be integrated on several levels of allopathic training, including standard medical and nursing training, continuing education, and personal study. Although some courses exist, widely available, robust educational instruction on TM/H may still be far off in development, and personal study may be the most accessible avenue for individual training in TM/H for most HCPs.

3,4,5,6,7,8,9,10

Recommendations for HCPs to expand their understanding of TM/H include engaging in TM/H learning opportunities and advocating for the transformation of health sciences (medicine, nursing, and pharmacy) curriculums through **partnerships** between academic health centers and tribal communities.^{3,4,5} These starting points will encourage trust building among all stakeholders and enhance capacity to address the health inequities experienced in AI/Indigenous communities. We recommend navigating each case in a thoughtful manner while tailoring the approach to the needs of all involved in the health of the patient, including the patient. Although it is challenging to propose practice guidelines, we offer the following suggestions for Dr S:

- Extend gratitude to Ms Q for her trust and for her willingness to share—and her openness in sharing—her preference to seek advice from her TM/H practitioner.
- Seek out relevant facts and safety considerations about TM/H practices that are common in Ms Q's tribal community.
- If Ms Q is willing, respectfully encourage her to share details of the TM/H interventions that she is seeking, which would allow for assessment of safety concerns or contraindications. If she declines to share, an understanding and accepting response is recommended.
- If appropriate, request a collaborative discussion with Ms Q, her family, and the TH/P as a means to co-create and prioritize a safe, comprehensive, culturally sensitive or congruent, integrative, and medically necessary treatment plan. Such meetings should be approached with respect for both Western and

traditional health care approaches. A component of this respect includes recognition that some TM/H is sacred and may not be shared.

- If appropriate, invite local cultural experts or TH/Ps to offer regular in-service presentations or consultations on aspects of common TM/H practices. Subjects may include etiquette in discussing TM/H, off-limit topics for discussion, and medically relevant elements of and safety precautions in using TM/H.
- Visit an integrated care delivery site. Such institutes can offer valuable advice and strategies for integrating allopathic and traditional medicine.

This list is in no way exhaustive, but if Dr S were to participate in any of these strategies, he could navigate future encounters involving TM/H from a place of better understanding and respect. Such a change in practice delivery could result in mutually positive interactions, support for patient autonomy, and enhanced trust between himself and the patient.

Integrative Approach

Establishing and maintaining trust is crucial in developing therapeutic relationships with AI/Indigenous patients. The relationship between HCPs and AI/Indigenous peoples is stained with the grief and the losses that occurred in historical traumatic events. This history presents a major hurdle for allopathic HCPs to overcome in building trust with AI/Indigenous patients. Building trust is more challenging when HCPs are unfamiliar with the cultural and traditional practices of their patients, highlighting the need for an informed integrative approach. Creating times and spaces to discuss integration of TM/H and allopathic medicine must be prioritized and realized.

Themes intended to guide HCPs, TH/Ps, and national organizations as they embark on the safe integration of TM/H within Western health care settings were generated from discussion among TH/Ps and HCPs in 2010 and at the Traditional Medicine Summit of 2019.^{1,2} The themes identified include perception (spirituality), translation (humility), protection (sustainability), and contribution (accountability).² These themes (drawn directly from discussions led by TH/Ps) align directly with discussion points in this article on the sacredness of TM/H, the integral and cultural importance of TM/H to Indigenous peoples, the importance of increasing TM/H education and training for HCPs and agencies that serve Indigenous populations, and developing safe integrative practices across health care settings, education, and research.

Across the globe, we are seeing much-needed changes to health care delivery that are inclusive of AI/Indigenous TM/H approaches. The state of Arizona has a model of reimbursement for the delivery of culturally congruent, safe, and evidence-based health care services for American Indians.¹⁹ Further evidence of change is the Traditional Medicine Summit of 2019, which was hosted by national health care delivery organizations (the National Institutes of Health, the Centers for Disease Control and Prevention, and the Center for Complementary and Integrative Health) and which demonstrated national and global support for tailored, integrated, and culturally congruent health care delivery approaches for our diverse nation—specifically, AI/Indigenous populations.^{2,20}

Conclusion

Lack of familiarity with TM/H and lack of practice guidelines for clinical decisions involving safe integration of TM/H are just 2 of the obstacles faced by HCPs and Indigenous patients as they collaborate in allopathic health care services. Although it is

unreasonable to request that HCPs gain a comprehensive understanding of TM/H, there are certainly areas in which basic TM/H education is possible. In addition, HCPs who demonstrate understanding of TM/H and respect for patient autonomy by supporting patients if and when they express a preference either for TM/H or an integrated approach to achieve health and wellness can strengthen the patient-practitioner relationship. Cultivating knowledge of TM/H, recognizing TM/H as an integral component of some Indigenous people's identity, and creating space to integrate allopathic care and TM/H can lead to significantly better care. The case study presents the complexities involved in the clinical decision-making process, and we hope it sheds light on the breadth of awareness and further education required to effectively navigate practice dilemmas of this type, which are often encountered by HCPs serving AI/Indigenous patients.

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Editor's Note

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.

CASE AND COMMENTARY

What Should Physicians Consider About American Indian/Alaska Native Women's Reproductive Freedom?

Felina Cordova-Marks, DrPH, MPH, Nikki Fennimore, MD, Amanda Bruegl, MD, and Jennifer Erdrich, MD, MPH

Abstract

Historically, American Indians and Alaska Natives (AI/AN) have been subjected to a lack of control over various aspects of their lives, including their reproductive health. In discussions of family planning with AI/AN patients, clinicians must consider past violations of reproductive rights and the need for transparent consent. This article explores the following questions: What were historical violations of AI/AN women's reproductive rights? How should physicians express respect for this history and for the autonomy of AI/AN female patients regarding surgical sterilization procedures today?

Case

Greg's ob-gyn rotation during medical school was at an Urban Indian Health Program (UIHP) clinic that served American Indian and Alaska Native (AI/AN) patients who lived on a nearby reservation. He had learned little about Indigenous populations throughout his undergraduate and medical education, and he was looking forward to learning more about how to care for different populations. On his first day, he accompanied Dr Smith to meet Ms Davis, an AI patient with bipolar disorder in the 34th week of her sixth pregnancy. Ms Davis had had no prenatal care until she presented to the emergency department with suicidal thoughts the week before. At that time, her drug screen was positive for amphetamines. Prior to entering the exam room, Dr Smith turned to Greg and said, "We need to make sure she has a reliable form of birth control after delivery."

Ms Davis came to her appointment alone. When asked what she wanted to talk about at this visit, she said that she wanted to make sure that her baby was healthy, and she wanted to be a good mother. She revealed that she did not have custody of her other children. Dr Smith stated, "Thank you for coming to clinic today. Along with making sure you and your baby are healthy, I want to ensure you have good birth control after your upcoming delivery. You've had vaginal deliveries and one C-section in the past. If you get a C-section this time, we can tie your tubes then. Or, if you have a vaginal delivery, we can do it shortly after the birth. I think this would be a good option for you." Ms Davis looked surprised but did not respond. She cast her eyes to the floor. Dr Smith continued

to measure her belly and listen to the fetal heartbeat without discussing the topic further.

Greg never saw the patient again, but he ran into Dr Smith in the labor and delivery unit at the local hospital near the UIHP clinic. Dr Smith mentioned to Greg that Ms Davis presented to the hospital 4 weeks later with no prenatal care in the interim and had a precipitous vaginal delivery. She had a bilateral tubal ligation by Dr Smith the next day. Greg wondered how the conversation about consent for the bilateral tubal ligation proceeded and whether it was what the patient wanted, as she seemed so unsure about it during her first prenatal visit.

Commentary

Coercion or the lack of true informed consent for reproductive surgical procedures, such as tubal ligation and hysterectomy, can lead to forced sterilization. In the case of Ms Davis, the historical forced sterilization of AI/AN women needs to be taken into consideration, as it informs AI/AN women's perceptions of modern health care (including potentially Ms Davis'). To decrease the occurrence of forced sterilization, we not only discuss the history of forced sterilization of AI/AN women but also offer guidance for physicians on appropriate interactions with AI/AN patients when discussing reproductive health.

A History of Forced Sterilization and Coercion

American Indians/Alaska Natives have been subjected to paternalism since the arrival of European settlers. Colonial contact separated American Indians/Alaska Natives from their land, culture, and children and eroded their self-determination to manage their own affairs as sovereign nations. Forced removal of AI/AN children from their families to boarding schools or foster homes—a practice that began in the 1860s and expanded in the mid-20th century under the US Boarding School Policy and the Latter Day Saints' Indian Student Placement Program—continued until 1978, when the Indian Child Welfare Act was passed—and all of this history remains in the minds of American Indians/Alaska Natives to this day.^{1,2,3,4} Historically, AI/AN women have been threatened with removal of their children by social services when seeking and receiving medical services.^{4,5} The forced removal of children has continued into contemporary times by physicians taking away AI/AN women's reproductive rights to make decisions over their own family planning.

An inadequate consent process, due to either lack of procedural explanation or absence of consent, leads to coerced or **forced surgical sterilization** (hysterectomy or tubal ligation) and loss of reproductive freedom. All of these violations have been experienced by AI/AN women.⁴ Coercion can occur when women feel they do not have a choice when it comes to being surgically sterilized. There have been cases of sterilizations being performed on vulnerable AI/AN women not capable of providing consent. Between 1973 and 1976, 36 AI/AN women who were judged mentally incompetent or who were less than 20 years of age were sterilized.⁴ In addition to experiencing coercion, AI/AN women have undergone surgeries for which the physician has not provided surgical explanations or disclosed surgical consequences⁴—as modeled by Dr Smith not discussing the procedure or outcomes in the scenario. In some cases, surgeons have given AI/AN women no information on the medical procedure that they were to undergo and false information on its consequences when they learned of it. It has been reported that in the mid-20th century and within multiple AI/AN communities, it was not infrequent for physicians to perform a discussed procedure, such as appendectomy,

that would include a sterilization procedure that had not been clearly discussed or properly consented.^{6,7} When AI/AN women awoke to learn of the incidental tubal ligation or hysterectomy that had been performed, they were often told that it was reversible.⁶ Ms Davis undergoing a tubal ligation the day after giving birth evokes remembrance of how other AI/AN women have been coerced into giving consent for sterilization during labor and delivery.⁷ Understandably, the physical and mental stress associated with childbirth can compromise a person's decisional capacity, and, in the early 1970s, this vulnerability was often taken advantage of by physicians who would gain consent for sterilization immediately after childbirth, if consent was obtained at all.⁸

In this way, a moratorium on performing sterilizations on those under 21 and **guidelines on informed consent** put in place by the US Department of Health, Education, and Welfare (HEW) in 1973 and 1974 were violated,^{4,9} as were court orders, such as a key protective order passed by a US district judge in 1974 that required oral notification to patients that they could refuse surgical sterilization without loss of federal benefits.⁶ It is estimated that 25% of AI/AN women of reproductive age were sterilized between 1970 and 1976, with cases going back to 1962.^{5,6,10} The number of sterilizations is greatly underestimated, however, as other AI/AN women who had been surgically sterilized might not have reported it due to feelings of shame and fear of losing government benefits, health and nonhealth related.⁷ Although the Hippocratic Oath includes doing no harm, many physicians have greatly harmed AI/AN female patients within recent medical history. Reasons cited for medical professionals performing these sterilizations have included accelerated certification for subspecialty practice, disengagement due to placement at Indian Health Service (IHS) hospitals via drafts or owed service, and discrimination.^{4,5}

Honoring AI/AN Female Reproductive Freedom

In 2016, the American College of Obstetricians and Gynecologists (ACOG) stated that “Obstetrician-gynecologists are discouraged in the strongest possible terms from the use of duress, manipulation, coercion, physical force, or threats, including threats to involve the courts or child protective services, to motivate women toward a specific clinical decision.¹¹” This guidance should be adhered to when consulting with AI/AN patients on their reproductive surgical options. ACOG has stated that, in addition to its being a legal requirement, consenting patients is an ethical process and requirement.¹² Portions of the ACOG consent process include respecting patient autonomy, including patients in their health care decisions, communicating in an effective manner, and identifying a surrogate as needed.¹²

These pieces of the ACOG consent process, seen through an AI/AN lens, would include respecting reproductive freedom by doing the following:

1. Fully informing AI/AN women, such as Ms Davis, of the procedure they are to undergo.
 - a. Offering an interpreter to patients who primarily speaks their Indigenous language since communication is the cornerstone of consent.¹⁰
 - b. Allowing the patient time to discuss their choice with their family when requested and providing information and materials to the family members the patient identifies.
2. Explaining to patients that they will not be penalized or lose any government benefits if they choose not to have the surgical procedure and assuring them that their reproductive autonomy is safeguarded as part of including patients as

partners in their own decision making and discussing each individual patient's desires for their own family planning.

3. Fully disclosing what female family planning procedures are not reversible and stating in clear and commonly understood terms that, after irreversible procedures (eg, hysterectomy), the patient will not be able to have any children postprocedure. Tubal ligations may be reversible, although various factors affect postreversal pregnancy success.^{13,14} It should further be disclosed that access to reversal procedures might not be widely covered even if the individual has access to insurance. (IHS does not cover tubal ligation reversal.)
4. Finally, as the American Medical Association advises on consent for all patient groups, there must be a discussion of the alternatives, including nonsurgical methods, as well as risks, benefits, steps of the procedure, and rationale for the type of surgery to be performed.¹² In addition to proper consenting processes, we advocate for implementing cultural competency training that includes local tribal input on how to successfully interact with AI/AN patients.

AI/AN people live with historical trauma that they have experienced personally or that has been experienced by family and community members. Some of these violations have occurred within the health care system charged with the task of protecting their health and well-being, and it must be remembered that this history is more recent than many physicians realize and that it has a pervasive influence over what AI/AN patients bring to their medical encounters. The topic of reproductive rights is particularly sensitive because of recent forced sterilization practices and should be remembered and respected by physicians when discussing family planning with AI/AN women. Transparency in the consent process is a universal requirement, but there are additional considerations in consenting AI/AN patients, as outlined above, that are critical not only for preventing their being coerced into any surgical procedure but also for promoting informed, shared decision making.

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.



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MEDICAL EDUCATION

How Should Health Professions Schools Partner With AI/AN Communities?

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Abstract

Many health professions education institutions exist on land once inhabited by American Indians and Alaska Natives (AI/AN). Land acknowledgment by these academic organizations is helpful, but collaborative support of AI/AN health is also needed. Because tribal-university partnerships in education are fewer than in research but just as important, this article considers health professions schools' responsibilities to offer students clinical rotations on tribal lands and to recruit AI/AN students. Such investment expands student educational opportunity, diversifies clinical workforces, and helps tribes improve health infrastructure and sustainability. This article also offers an adaptable roadmap for building such partnerships.

Case

After months of processing paperwork and permissions between the medical school and tribal health facility, NZ and KY, 2 medical students, finally start a surgery clerkship on tribal land. In prior weeks, they attended seminars to learn some of the history and culture of this area of the Southwestern United States. NZ grew up on the Navajo reservation and KY grew up in Ohio and has never been on a reservation. Both students are interested in rural health and hope this clerkship will help them make career decisions.

The site director instructed KY to do a preoperative history and physical for a 77-year-old woman, Ms B, who was diagnosed with a left-sided colon mass after coming to the emergency department with a painful obstruction. During the examination, Ms B informed KY that she needs to see a traditional medicine person for a ceremony before her operation. KY's review of Ms B's lab values and imaging suggests that Ms B's operation needs to happen soon to minimize her risk for perforation. Unsure what to do, KY found NZ and asked why Ms B needs a healer. NZ explained the value of the ceremony to KY and worked with staff to locate a traditional healer.

Commentary

The majority of university-tribal work has centered on research, and, unfortunately, there is a long-standing history of exploitation with sweeping negative consequences.^{1,2,3,4,5}

Community-based participatory research (CBPR) is changing the paradigm of “helicopter research” by drawing upon community members’ skills and by more equitably distributing risks and benefits of research. Uptake of CBPR principles demonstrates a much-needed institutional makeover of tribal research engagement. Just as university researchers are reformulating how to conduct responsible research, so university clinical educators have an obligation to reframe the health sciences curriculum and ensure that the tribal health facilities are equal partners in its implementation.

Since 1997, the College of Medicine at the University of Arizona has run the Rural Health Professions Program (RHPP, directed by the second author) to prepare a culturally competent workforce for practice in Arizona’s underserved communities. The RHPP has graduated many students, Native and non-Native alike, who have become practicing clinicians at partner tribal facilities. Outstanding feedback from students, preceptors, and tribal members has helped the program thrive for more than 20 years.

Although numerous publications share recommendations on how to conduct tribal-university relationships for research,^{1,5,6,7} we could find none that outline how to build a responsible tribal-university educational partnership. Here we consider the 3 key principles that have fostered the program’s success: (1) the development of relationships rooted in trust and equality, (2) the commitment to a rigorous educational experience, and (3) the investment of resources by the academic institution.

Trust and Equality

Relationship building with tribes involves historical and political challenges that take an immense amount of **trust and time** to overcome.³ The RHPP has relied upon general guiding mechanisms to confront these challenges. In particular, by personalizing communication and travel and endorsing a collaborative approach to management, the program has built relationships infused with trust and equality.

Travel and communication. Working with AI/AN partners often requires rural, remote travel.^{1,2,4} Academic institutions should plan for extended timelines and dedicated, frequent personal communication.^{1,2,5} The RHPP director visits partner sites, which sometimes entails a full day of travel, at least once a year to maintain the personal relationship with each partner. Email and teleconferencing maintain interim communication, but tribes greatly value the person-to-person relationship.

Collaborative management. Too often, tribal entities have not been viewed as full partners in tribal-university partnerships.¹ This antiquated thinking hinders any enterprise, as university-tribal interactions only succeed when each partner functions as an equal. Tribes are sovereign nations with the autonomy to make their own decisions. The RHPP respects tribal sovereignty by allowing the partner tribal health services facility to set up the process for student entry. Each site has its own established protocol and its own requirements for background checks, fingerprinting, and vaccination records that the RHPP helps the students complete because it supports the tribe’s autonomy to vet who works with tribal members. We recognize that tribes want clinical education that protects and benefits their patients just as much as the university wants to provide rich educational opportunities for its students. This sense of reciprocity is similar to a tenet that a growing number of universities hold for research.^{3,4} With equal participation in the relationship comes **mutual benefit**.

Rigorous Education and Training

The RHPP is under obligation to make the rotation at the tribal facility equal to the home campus rotation. These rotations are neither “vacations” for students nor a chance for them to cross “red tape” and practice above their level. We believe that several key components have made the program academically rigorous and thereby fruitful for both partners:

- *The RHPP is competitive.* The rotations with AI/AN communities are not mandatory, and there are a limited number of available assignments. Currently, there are only 28 positions for a class of 120 students. RHPP students go through an application process to rotate at tribal facilities. This process leads to a self-selected group of students who are highly motivated to conduct their training with the AI/AN community.
- *Students are sent for clerkship rotations.* These rotations are not electives. Students must obtain the same educational experience, hours, and case volume as if they were at the main campus institution. They are evaluated under the exact same rubric as the university hospital sites. The tribal facility preceptors have just as much import for their grades as any campus faculty. This arrangement leaves no room to slack and helps the students arrive on site with the same learning goals and respect that they bring to the rest of their academic curriculum.
- *The students undergo extended preparation.* They participate in a 16-week seminar series on issues in rural health with dedicated AI/AN topics. Upon arrival, each tribal facility runs a self-designed orientation to provide tribal-specific history, sensitivity training, structure, and advice on how to work with their patients. This kind of preparation helps students like KY in the scenario manage cross-cultural conflicts between Western and traditional medicine and integrates philosophical teaching into hands-on practice. As representatives of the academic institution, students like KY then show tribal members a favorable impression of visiting clinicians, which is important for the restoration of medical trust.
- *Rotations are controlled by the tribal facility.* We recognize that clinical teaching demands a major investment by the clinical instructors at the tribal facility, many of whom are overworked and dealing with stressors unique to their patient population. We structure the student rotations such that no one site is overburdened, and at each site there are gaps between student rotations as a way for preceptors to recuperate. By controlling when and how often students rotate, the preceptors can maintain a higher level of enthusiasm and investment in the students.
- *The RHPP is a blend of AI/AN and ethnic-majority students.* This mix allows the students to be peer teachers and collaborative colleagues. As seen in the scenario, NZ’s knowledge benefits her classmate and their patients and additionally demonstrates the value of enrolling AI/AN students in medical school.

Institutional Commitment

Academic institutions with health professions educational programs have a duty to invest in tribal health care infrastructure and sustainability. Each level of medical training and every health discipline should participate. We have described the RHPP, which functions at the medical student level. Two residency programs (Family Medicine and Surgery) at the University of Arizona College of Medicine have rotations with tribal facilities as well. Several other institutions have also recently developed programs that

place fellows in clinical positions at tribal facilities.⁸ Since there is a physician vacancy rate of over 25% in AI/AN communities, these continuity models are intended to reduce local physician staffing gaps.⁸ There are nursing student equivalents of these immersion programs as well.⁶ These programs represent several institutions' commitment to building the workforce of clinicians who know how to navigate the range of culturally sensitive issues and to narrow AI/AN health disparities.⁸ These institutions have allowed their faculty the time it takes to engage tribal entities in the provision of education and clinical care.^{6,8} They have also prioritized recruitment of AI/AN students and provided additional support for retention so that they can complete their education and enter practice.⁸

Tribal-university research infrastructure requires substantial time and resources, and the same is true of clinical educational infrastructure.³ There are financial resources that the university pledges in these partnerships. The university has to support a faculty member with adequate full-time employees to devote to a tribal-university educational program.¹ Salary support must be allocated to a program coordinator, as the coordinator is instrumental in managing the nuanced logistics at each tribal site. The university must also account for student expenses and be prepared to reimburse the tribe for housing and transportation.

The university investment is not simply financial. Expertise and technical assistance are fundamental to program success. It is the responsibility of the university, usually by way of the program director and staff, to verify that the doctors on site want to teach and can maintain high standards, to be selective of the students that are sent, to properly prepare and evaluate students, and to conduct program evaluation by soliciting feedback from all stakeholders.

Conclusion

A health professions educational relationship can flourish between tribes and academic institutions when it starts with true relationship building so that the partnership is collaborative and equal. The educational curriculum should be held to a high standard so that academic rigor is preserved and AI/AN patients receive culturally sensitive, quality care. The academic institution must invest financial resources and technical assistance to build sustainable infrastructure. These 3 principles—of relationship building, rigorous education and training, and institutional commitment—can generate a partnership that enhances health professions education, fills gaps in clinical care, fosters the AI/AN clinical pipeline from student to clinician, and builds a diverse workforce dedicated to improving the health of AI/AN communities.

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MEDICAL EDUCATION

Three Levels of Autonomy and One Long-Term Solution for Native American Health Care

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Abstract

Native Americans have twice the poverty rate of the general US population, suffer significant health inequity, and are chronically underrepresented, at only 0.08%, in the US physician workforce. The COVID-19 pandemic has illuminated key ethical, clinical, and economic complexities in health decision making among Native patients. This article discusses 3 levels of autonomy relevant to health decisions, including taking care of our own by increasing numbers of Native medical students.

Introduction

The COVID-19 pandemic illuminates key complexities of Native Americans' health decisions. Three levels of autonomy—individual, tribal, and health professional—will be considered here to introduce our proposal of a single, long-term solution to oppressions that have undermined Native Americans' expressions of their agency and autonomy.

Three Levels of Autonomy

Individual, familial. The first level of autonomy for health care decisions among Native Americans—the individual level—is more complex than most appreciate. Historical trauma casts a long shadow over Native Americans' health care interactions today. For instance, in the 1970s, about one-third of Native children were removed from their families and tribes and taken to boarding schools or “adopted out” to White families before passage of the Indian Child Welfare Act of 1978, which ended forcible government-sanctioned removal of Native children from their families and tribes.¹ Even more disturbing, approximately 3000 Native women were **involuntarily sterilized** by a federally funded program.¹ Non-Native health care workers might think they are giving a compliment when saying, “What an adorable baby! I could just take him home with me.” But to Native parents whose autonomy was undermined by federal child-removal policies, that remark can be threatening and retraumatizing.

Tribal. The second level of autonomy in health care decision making among Native Americans is the tribal level. A test of this type of autonomy arose in 2020: *Does a US*

tribe, cautious about reservation visitors' potential to introduce the SARS-CoV-2 virus to members of their at-risk population who have access to only suboptimal health care, have legal authority to stop that visitor? This question about Native sovereignty arose in South Dakota, where the Cheyenne River Sioux Tribe established checkpoints. Harold Frazier, the tribal chair, summarized why: "The nearest health facility is a three-hour drive in Rapid City, SD, for critical care. And our health facility... only [has] eight beds. You know, there's probably over 10,000 residents. So if we were to have a massive outbreak [of COVID-19] ... where are they going to go?"² The state's governor demanded the checkpoints' removal, yet no legal action has been taken.³

Perhaps this standoff arose because federally recognized tribes have a form of autonomy no other US population has. Ratified in the 1800s with the US Department of War negotiating on behalf of the federal government, treaties conferred status on tribes as domestic dependent nations that maintain **sovereignty over their lands** and, perhaps surprisingly, included health care provisions.⁴ During westward expansion in the United States, epidemics spread easily, so the federal government used treaties as a legal basis for quarantining Native people during outbreaks.⁵ In 2020, tribal autonomy is still being tested.

Self-sufficiency. There is a third level of autonomy in Native health decision making: providing care for your own. Although patient-clinician concordance—defined as a shared identity between patients and clinicians—has not been studied in Native populations, its significant benefits have been documented in other minoritized communities.⁶ Thus, we regard "taking care of your own" as an important expression of Native self-sufficiency and autonomy. Native self-sufficiency was boosted by Public Law 93-638, the Indian Self-Determination and Education Assistance Act of 1975.⁷ Commonly referred to as 638, this law allows tribes to take over administration of their health care from or to contract with the Indian Health Service (IHS), which is chronically underfunded.

One Long-Term Solution

Writing this article in the wake of George Floyd's 2020 murder, we are struck by the rapid evolution of race relation discussions. Drastic measures are being considered, such as the Minneapolis City Council unanimously voting to disband its police department in favor of a community-led model.⁸ In this time of America's unprecedented willingness to discuss systemic racial issues, we focus on one long-term solution to boosting Native workforce capacity to provide care for our own: addressing the chronically low number of Native physicians.

The Association of American Medical Colleges (AAMC) administers the required medical school entrance and Step exams and coordinates application processes for most medical schools and residency programs. Alarmed by data documenting low numbers of Native students in medical school classes, the AAMC collaborated with the Association of American Indian Physicians (AAIP) to generate and release a report in 2018.⁹ Over the past decade (ending in academic year 2017-2018), the number of single-race Native applicants to medical school ranged from 150 to 200, despite steady increases in US medical school matriculants (totaling about 21 000 per year). The report states: "We must view this issue as a national crisis facing not just American Indian-Alaskan Native (AI-AN) communities, but all medical schools and teaching hospitals."⁹ In 91% of US medical schools, there are few, if any, Native American students: in 2016-2017, only 9% of US medical schools had 4 or more Native medical students, 48% had 1 to 3, and 43% had none.⁹

Indian Country is at a disadvantage in preparing Native students to face the academic and financial challenges of pursuing a medical degree. A 2013 American Community Survey found that 82% of Native Americans ages 25 and older had at least a high school degree or equivalent compared to 86% of the overall US population and that 18% had a bachelor's degree or higher compared to 29% of the overall US population.¹⁰ The survey also found that the median household income of single-race American Indian and Alaska Native households was \$36 252 compared to an overall US median income of \$52 176, with 29% of single-race American Indian and Alaska Natives living in poverty compared to 16% of the overall US population.¹⁰ Moreover, a US Department of Housing and Urban Development study found that 16% of Native American households in tribal areas were affected by overcrowding compared to 2% of all US households.¹¹ In Indian Country, 17% of households had one or more people residing therein because they had nowhere else to go.¹¹

The AAMC-AAIP report is important because it explains why Native physicians make up only 0.08% of the overall US physician workforce. By contrast, Native physicians make up 10% to 15% of the IHS workforce (M. Toedt, oral communication, 2018), but the IHS is significantly understaffed, with an average clinician vacancy rate of 25%.¹² Despite that Native physicians are already helping care for their own, an obligation remains to increase Native representation in medicine.

National Collaboration

The AAMC, AAIP, American Medical Association, and many medical schools met in 2018 and 2019 to collaborate on how to increase medical school enrollment among Natives and agreed upon 5 priorities¹³:

1. *Reach students at a younger age.* Initiate and maintain Native children's interest in medicine. Outreach and mentorship programs with Native health care workers could illuminate multiple career paths and allow for one-on-one guidance and networking.
2. *Centralize information sources about higher education.* Tribal and federal agencies should collaborate to create a centralized online information source to facilitate college and medical school applications, canvass scholarship and financial aid opportunities for Native students, and provide "ambassador kits" for counselors and advisers to offer Native students seeking information about higher education and health professions education opportunities.
3. *Expand financing options.* Scholarships are vital to increasing educational opportunity, since 33% of Native American children live in poverty, according to the 2017 American Community Survey.¹⁴ Yet scholarships available to Native students are limited and competitive. Expanding financing options at public and private institutions should be a priority, particularly since the economic consequences of COVID-19 are likely to disproportionately affect Native Americans.
4. *Improve academic preparation.* Education quality in largely Native communities must be improved to better prepare Native students to meet higher education and health professions education demands. Secondary school STEM programs, test preparation, outreach partnerships between universities and Native community schools (eg, the Massachusetts General Hospital partnership with the Rosebud Sioux Tribe in South Dakota), integration of Native culture into

medical training (eg, exposure to healers, sweatlodges, and clean-earth living) and addressing Native recruitment resistance should be priorities.

5. *Address social determinants of health.* Colleges and medical schools should provide culturally informed preventative health and mental and behavioral health support for Native students navigating intergenerational trauma from colonization, massacres, and boarding schools.

In sum, these priorities' purpose is to improve matriculation, retention, teaching and learning, and student performance.

Conclusion

Other important educational considerations include structural racism and how to respond to overt and subtle racist acts in health care contexts. Native clinicians and patients have many personal experiences with racial discrimination. For instance, when the first author (S.W.) was regularly on call with a White male classmate, she would be asked, "Are you the translator?" Many clinicians caring for AI-AN patients are not Native, so formal opportunities to cultivate cultural awareness and investigations of racism's root causes must be robustly integrated into health professions training. Despite being the only race with a legal right to health care in the US,¹⁰ Native Americans suffer some of the worst health inequity in the nation,^{15,16} an injustice stemming from a lack of recognition of Native individual and tribal autonomy and the inadequacy of the current health system to meet individual and tribal health needs.

Taking care of our own—as our ancestors did for thousands of years before first contact—and increasing Native representation in medicine are much needed. The two of us beat the odds to become Native physicians. Our painful experiences in medical school and clinical training have galvanized our determination to eliminate systemic barriers keeping other bright Native students from earning medical degrees. Native physicians and their allies in the AAMC have already laid the groundwork for change through national collaboration. Although the severe economic consequences of COVID-19 make implementation of the 5 priorities more challenging, there are more reasons than ever to boost the number of Native American physicians caring for their own.

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HEALTH LAW

Effects of Substance Use Disorder Criminalization on American Indian Pregnant Individuals

Rachel Simon, MD, Jennifer Giroux, MD, MPH, and Julie Chor, MD, MPH

Abstract

Individuals with substance use disorders (SUDs) are at markedly elevated risk of involvement in the criminal legal system. Over the past 30 years, substance use during pregnancy has been criminalized through laws on the federal, state, and tribal level. American Indian (AI) individuals are disproportionately affected by these laws due to their race, socioeconomic status, and limited access to SUD treatment. This article aims to educate readers on laws criminalizing substance use during pregnancy and on how AI individuals are disproportionately affected by these laws. It also discusses how these laws conflict with the ethical principles of autonomy, nonmaleficence, and justice. Finally, this article recommends that clinicians advocate for the decriminalization of SUDs during pregnancy and for improvement in access to comprehensive, evidence-based SUDs care.

Criminalization of Substance Use Disorder in Pregnancy

Approximately 1 in 10 individuals in the United States will develop a substance use disorder (SUD).¹ Between 1999 and 2016, drug overdoses increased dramatically,² and, in 2017, overdose was the leading cause of accidental death in the United States.² American Indians (AIs) have been hit particularly hard, with a prevalence of SUD exceeding that of other racial and ethnic groups in the United States.³ Tribes across the country have declared treatment of SUD a public health priority.⁴

The nation's drug laws place individuals with SUD at high risk of involvement with the criminal legal system. It is estimated that over 65% of individuals under correctional supervision meet criteria for SUD.⁵ Pregnant people with SUD face prosecution, given state laws that specifically criminalize drug use during pregnancy.⁶⁻⁸ Pregnant AI individuals are disproportionately affected by these laws due not only to their race and gender, but also their lower socioeconomic status and the compounded **government surveillance** under federal, state and tribal laws.

In the 1980s, during the "war on drugs," the US government focused on crack cocaine, demonizing people of color who used this drug while pregnant and laying the foundation for federal, state, and tribal laws **criminalizing substance use during pregnancy**.⁹ The

Child Abuse Prevention and Treatment Act of 1974, for example, requires states that accept federal grant funding to have policies and procedures for notifying child protective services agencies of infants who are identified as being affected by maternal substance use.¹⁰

States have passed a variety of laws criminalizing substance use during pregnancy. Twenty-three states and the District of Columbia have laws proclaiming that drug exposure during pregnancy constitutes child abuse.¹¹ Twenty-five states and the District of Columbia require health professionals to report suspected prenatal drug use, with 8 requiring testing for and reporting of prenatal drug exposure if they suspect drug use.¹¹ Some states have also passed laws related to “fetal personhood,” “fetal assault,” and “chemical endangerment” and used these laws to prosecute people who use drugs during pregnancy.¹² In Tennessee, for instance, a fetal assault law makes giving birth to a newborn showing signs of prenatal exposure to illicit substances a crime punishable by imprisonment.¹³

Tribes have their own legal approaches to substance use during pregnancy. Each of the 573 federally recognized tribes has its own laws, court systems, and facilities to detain tribal members convicted of certain offenses within reservations.¹⁴ Because of their nationhood status, tribes have a government-to-government relationship with the United States. On Indian reservations, AIs are typically subject to tribal and federal law only, not state laws. However, as US citizens, AIs are additionally subject to state law when outside of a reservation and on state land.¹⁵ For tribes whose laws were available for review, substance use during pregnancy is consistently criminalized, with varying levels of punishment. Some tribes (Navajo Nation, White Earth Nation) mandate substance use treatment programs, while others (Little River Band of Ottawa Indians, Standing Rock Sioux Tribe) identify substance use during pregnancy as child abuse and require child protective services involvement.^{16,17,18,19}

The number of pregnant people who have been criminalized for substance use is unknown. One report documented 413 arrests, detentions, forced medical interventions, and separations of newborns and mothers between 1973 and 2005 for pregnant people of all races and ethnicities, the majority (84%) of which involved substance use during pregnancy.²⁰ Given the difficulty in identifying cases, the authors suspect hundreds, if not thousands, were missed.²⁰

American Indian Vulnerability to Criminalization in Pregnancy

AI individuals are particularly vulnerable to criminalization during pregnancy for several reasons.

First and foremost is the impact of racism. AI women are jailed and imprisoned at higher rates than their white counterparts relative to their share of the general population.²¹ In South Dakota, of the 558 women in custody in January 2020, more than 50% (297) were AI, although AIs constitute 8% of the state population.²² Racism also has a significant impact within health care. One national survey showed that 23% of AIs reported experiencing discrimination in a health care setting.²³ Numerous studies document how racial and ethnic minorities receive less access to and lower quality of health care and have worse health outcomes.^{24,25} For pregnant people of color, discrimination is acutely evident. Black people are 1.5 times more likely to get tested for drug use during pregnancy than other people,²⁶ and, if they test positive, 10 times more likely to get a positive result reported to child protective services.²⁷ AI individuals are

often overlooked in public health and policy research, largely because of their small population and frequent racial misclassification. While more research is needed, it is clear that AI individuals are not exempt from racism and likely experience its hardships uniquely.

Second, AIs are one of the most impoverished populations in the country, increasing their vulnerability to criminalization during pregnancy. They are more likely to be involved with state-sponsored public health and social services programs²⁸ and subsequently more likely to be subject to public reporting. Additionally, when AI people on tribal land become pregnant, they're often shuttled between the **Indian Health Service** (IHS) and state-funded agencies, including state hospitals and social services, because the IHS has limited obstetric capacity. Shuffling between health care settings on and off reservations results in exposure to rules and regulations of tribal, state, and federal jurisdictions and the potential to be prosecuted under the authority of all three.

Finally, AI people are particularly affected by the criminalization of substance use during pregnancy because of their minimal access to SUD treatment, due largely to shortages and limited resources of reservation-based treatment programs, stigma associated with SUD, and lack of SUD training among health care professionals who work on reservations, especially among those working with pregnant patients.² In particular, the IHS is perilously underfunded; despite the high disease burden in AI communities, the agency receives less funding per person than Medicare or Medicaid, making it difficult to establish and strengthen SUD treatment.²⁹ With limited access to care, AI individuals with SUD often are not treated for their disease and remain at high risk of ongoing drug use during pregnancy.

Ethical Considerations

Legal, political, and medical structures that create disparate risk for AI individuals seeking pregnancy care undermine core ethical principles. By adversely affecting pregnant AI individuals seeking prenatal care, these structures are unjust. Furthermore, in preventing pregnant people from controlling their health information and in violating their confidentiality, laws mandating clinician reporting of substance use violate the ethical principle of respect for autonomy.

Numerous professional medical associations, including the American College of Obstetricians and Gynecologists,³⁰ have recognized SUD as a chronic, relapsing disease. However, SUD remains highly stigmatized. Instead of receiving treatment, people with SUD—particularly those who are pregnant—are treated as moral failures by society and criminalized, with severe health consequences. Individuals who use drugs are understandably fearful of seeking health care because of risk of arrest, imprisonment, or loss of child custody if their health care professional suspects or concludes that they are using illicit drugs. Fear of punishment decreases participation in health care, particularly prenatal care, and erodes trust in physicians.^{31,32} The documented harm from these laws violates the ethical principle of nonmaleficence.

Laws criminalizing drug use during pregnancy place physicians in the untenable position of being legally required to help enforce these laws. Health care professionals, whose professional and ethical priority is to provide competent, compassionate care, are mandated to abide by laws that are detrimental to their patients' health. These circumstances necessitate that health care professionals advocate for decriminalization

of substance use during pregnancy and for increased access to comprehensive, evidence-based treatment for SUD.

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STATE OF THE ART AND SCIENCE

Using OCAP and IQ as Frameworks to Address a History of Trauma in Indigenous Health Research

Angela Mashford-Pringle, PhD and Kira Pavagadhi, MPH

Abstract

Indigenous people have been studied at great length. To counter deficit-based research that can reinforce stereotypes, the National Aboriginal Health Organization introduced principles of ownership, control, access, and possession (OCAP®) to reduce historical trauma to individuals, families, and communities from research and reporting of findings. A further step in promoting culturally safe and responsible research with Indigenous peoples is to incorporate the Inuit Qaujimagatunqangit, traditional laws and principles that guide a way of life and of knowing. Based on these 2 guides, researchers and scholars should be working with Indigenous peoples to *co-develop* research rather than merely conducting research on Indigenous populations. By working collaboratively with researchers, Indigenous people can provide input to ensure that a project respects Indigenous culture, language, and knowledges and does not re-ignite or exacerbate historical trauma or further current colonial policies that marginalize and oppress Indigenous peoples.

Research as Trauma

Indigenous people in Canada have been the objects of colonial research that has harmed individuals and communities for generations. Much of this research was conducted without informed consent and with the investigators' knowledge that the research itself would put those involved in the study at serious risk.^{1,2,3} Problems with Indigenous health research are ongoing and extensive, including Indigenous people's forced participation; analysis, interpretation, and distribution of their data without their permission; and devaluation of their culture and erasure of colonialism's impact on their lived experience.^{2,4} Deficit-based research, which shows Indigenous groups in Canada comparing poorly to non-Indigenous Canadians, has directly harmed Indigenous individuals, families, communities, and nations.⁵ Such research has inflicted trauma on Indigenous people through physical injury, psychological distress, and cultural harm, in addition to creating **distrust of research** among larger communities affected by the research.^{6,7} Further maltreatment has been inflicted through researchers interpreting and using the resulting data in ways that can be misconstrued and that are problematic for the subjects of the research. Primary and secondary trauma that has resulted from

research on Indigenous people as subjects rather than as active, consenting collaborators has created a legacy of intra- and intergenerational trauma.

To avoid perpetuating historical trauma brought about by colonial research, Indigenous research must be conducted in collaboration with Indigenous communities and in adherence to strict ethical guidelines. Principles of ownership, control, access, and possession (OCAP®) created by First Nations,⁸ along with traditional *Inuit Qaujimagatuqangit* (IQ),⁹ can inform culturally safe and responsible research with Indigenous communities. These guides place Indigenous people at the center of the research process, drawing on their cultural values and promoting sovereignty to mediate harms of colonial violence. This article explores how Indigenous-led research frameworks can mitigate harms of research and promote self-determination and well-being among Indigenous people overall.

Colonial Assumptions as Harm

One of the most well-known examples of harmful research in Canada occurred as a result of the James Bay Survey of the Attawapiskat and Rupert's House Cree First Nations. Following the survey, Lionel Pett, director of the Nutrition Services Division, with guidance from the Indian Affairs Branch Superintendent of Medical Services, Percy Moore, carried out nutrition experiments at 6 residential schools from 1948 to 1952.¹⁰ Interested in the capacity of nutritional supplements and vitamins to remediate effects of malnutrition, Moore and Pett maintained the diets of already malnourished children in the control group and supplemented the diets of children in the experimental group without consent from their caregivers. The results were catastrophic. The interventions were not only ineffective but caused greater harm to children-subjects than malnutrition alone, leaving them with anemia and severe dental decay.¹⁰ Additionally, we now know that chronic malnutrition experienced in residential schools is linked to type 2 diabetes and adulthood obesity, conditions unknown to Indigenous people until the 1940s and now more prevalent among Indigenous people than in the general population.¹¹

The impact of **colonial research** has been pervasive throughout Canada's history. In 1933, the residents of the Qu'Appelle reserves in southern Saskatchewan were identified as a trial population for the bacille Calmette-Guérin (BCG) vaccine against tuberculosis (TB).¹² Indigenous people in Canada are at a higher risk for TB and many other illnesses' morbidities as a result of colonization. And such was the case for residents of the Qu'Appelle reserves, where limited resources and food, along with poor living conditions, affected and continue to affect¹³ health and well-being. The research did not acknowledge the impact of colonialism on Indigenous people's health but instead was rooted in the racist assumption that Indigenous people's "primitive" nature made them vulnerable to TB.¹² The dissemination of research findings on the vaccine's efficacy thus failed to improve public understanding of how existing disparities between Indigenous and non-Indigenous groups—in living conditions and access to health care services, for example—contribute to TB's transmissibility.

These examples underscore how social determinants of health are historically situated and are ethically fraught for a number of reasons. Studies like the nutritional experiments in Canadian residential schools and the Qu'Appelle BCG vaccine trials illustrate how colonial research frames Indigenous people as "objects" of study for the benefit of non-Indigenous people; non-Indigenous academicians who research Indigenous people benefit in their careers, but Indigenous people do not necessarily benefit. Moreover, findings of deficit-based research that assume Indigenous inferiority

can reinforce colonial ideals and false negative stereotypes by being absorbed into mainstream knowledge.

Nothing About Us Without Us

A framework at the forefront of First Nations research ethics is OCAP.⁸ OCAP was first formally introduced in 2002 by the National Aboriginal Health Organization's First Nations Centre to improve First Nations research. OCAP is a set of principles: ownership, control, access, and possession of data within a collaborative relationship between the researcher(s) and First Nations people and communities.⁸ OCAP can serve as a framework for research that prioritizes self-determination of First Nations and their people's authority to decide why, how, and by whom research will be done and, consequently, with whom, which, and how data and resulting knowledge can be shared.⁴ Properly applying OCAP results in First Nations communities being able to use knowledge generated by research, which can improve First Nations members' health.

Inuit communities have derived a similar research ethics framework from IQ, translated from Inuit traditional knowledge. IQ guides research with Inuit people in ways that uphold 8 core values, presented in the table below.¹⁴ IQ is widely implemented to promote respect for Inuit people's autonomy, and it ensures that researchers approach research in a culturally safe and respectful manner.¹⁵ Every research project conducted with Inuit people is expected to engage elders, knowledge keepers, and community representatives before it is initiated.

Table. Eight Core Values of Inuit Qaujimaqatuqangit

Value	Translation
Inuuqatigiitsiarniq	Respect for other people
Tunnganarniq	Openness
Pijitsirniq	Acts of service
Aajiiqatigiinni	Decision making through discussion and consensus
Pilimmaksarniq	Development of skills
Ikajuqtiigiinni	Working together for a common goal
Qanuqtuurniq	Being innovative and resourceful
Avatittinnik Kamatsiarniq	Respect for the land

Ethical Indigenous Research

OCAP and IQ are important guidelines for helping researchers work collaboratively with Indigenous people to promote self-determination; to incorporate Indigenous voices into knowledge acquisition, translation, and dissemination; and to benefit Indigenous communities. These guidelines also promote strengths-based research, which follows many Indigenous teachings and empowers the community by drawing attention to Indigenous strengths.

Nevertheless, building relationships, which is the first step in Indigenous research, is often a challenge to researchers, as it takes time; what is important to relationship building is not simply a set of emails or phone calls, but rather attending ceremonies

and feasts.^{16,17,18} Many researchers have not encountered this approach to engaging the participants or subject they wish to examine. In academic settings, relationships with participants can be built quickly and thus do not “cost” time, effort, or possibly money.

Another challenge to ethical Indigenous research is that funding sources, like the federally funded Tri-Council (Social Sciences and Humanities Research Council, Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council) in Canada, establish parameters for grant opportunities that might not align well with an Indigenous community’s current realities or needs. Many Indigenous worldviews are centered on the **interconnectivity** of all in creation, including different aspects of self (physical, mental, spiritual, and emotional).^{19,20,21,22,23} Previous research has shown that concepts of Indigenous health and education are interconnected and should be examined holistically, not as separate or unique variables.^{20,24} As such, funding cannot be siloed and should encompass health, humanities, social sciences, and physical and life sciences. Funding opportunities that do not allow for this diversity of approaches present a challenge to researchers who rely on grants as part of their academic metrics showcasing their productivity. These funding opportunities continue to rely on researchers predetermining their research agendas at the cost of excluding Indigenous communities’ input, which in turn limits the usefulness of the results or, worse, causes further harm by reinforcing false negative stereotypes.

Future Directions

OCAP and IQ are salient to Indigenous health research because they put guiding principles of Indigenous ethics into practice; however, they are not prescriptive. Creators of both OCAP and IQ rightfully acknowledge their respective frameworks are not all-encompassing and that their application might differ among nations. However, the utility of both frameworks is their ability to guide research in an ethical and safe way. Employed in American Indian health research settings, frameworks like OCAP and IQ can mitigate harm and uphold autonomy and jurisdiction among American Indian people. In fact, the way that Indigenous ethical frameworks such as OCAP and IQ accommodate the variability and uniqueness of Indigenous communities is one of their strengths.

Researchers who seek to improve their efforts at inclusiveness must familiarize themselves with nonviolent ways to approach research with Indigenous communities, build relationships, and consult Indigenous people about how to best apply Indigenous ethical research principles in individual projects. OCAP and IQ can contribute to international improvements in well-being for Indigenous peoples and promote safe, meaningful, collaborative research with Indigenous communities.

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Racialization as a Barrier to Achieving Health Equity for Native Americans

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Abstract

Racial identity is a complex idea, particularly for American Indian and Alaska Native (AI/AN) populations. The idea of a single AI/AN race developed from a European-American view of phenotypic and cultural differences. It continues to have significant consequences for AI/AN populations within the clinical-medical context. For clinicians, using this flawed category in medical decision making poses ethical challenges and has implications for patient autonomy and justice. This article briefly traces the development of the idea of an AI/AN race, the concerns raised in using this identity marker, and the ethical implications of employing the categorization.

I really feel that identity is a very complicated mixture, of what you grow up with, what you find out about yourself. I didn't want to add any confusion to it. It wouldn't do me any harm, but when I asked my extended family about this—and I did go to everyone—I was told, "It's not yours to give, Louise."¹

Racial Categorization in Medicine

Racial categories are ubiquitous in modern medicine, particularly in research, health professions education, public health efforts, and clinical practice. Although race as a biological category has been disavowed by professional societies, including the American Public Health Association,² the American Sociological Association,³ the American Anthropological Association,⁴ and the American Association of Physical Anthropologists,⁵ clinicians often invoke biological differences based on racial or ethnic identity—and often a conflation of the 2 categories—to structure diagnostic and treatment approaches to a wide range of conditions, from sickle cell anemia to mental health illnesses.^{6,7,8,9}

In this article, we explore racialization of American Indian and Alaska Native (AI/AN) identity within clinical contexts, tracing the history and development of Native identity as a sociocultural-political identity that continues to affect clinicians' presumptions about

patients' biologically based disease risk. We then consider ethical implications of using race as a category in clinical practice.

History of Native Identity and AI/AN Racialization

Development of a Native identity predates the current concept of an American Indian "race." Promulgation of the idea that significant biological and behavioral differences existed between Indigenous peoples and Europeans began at first contact in the Americas. Columbus noted in his journals how cultural practices of the Arawak of the modern-day Bahamas, such as giving whatever they had when asked, differed significantly from Europeans' transactional gift giving. He interpreted this difference as a kind of inferiority, and concluded that Natives would ultimately make excellent subjects and slaves.¹⁰ Over time, such beliefs about the cultural and biological inferiority of Indigenous peoples were coupled with religious ideas and now-debunked social Darwinist theories to justify ensuing genocide and settlement of Indigenous peoples' lands throughout the period of colonization both in the United States and globally.¹¹

The United States continued an unrelenting expansionist policy that both was justified by the putative underlying biological inferiority of native peoples and justified their continued management. In the United States, Indigenous populations were forcibly removed from their homelands and relocated to distant reservations or coerced into signing treaties that often exploited their ancestral lands.¹² A constructed Native identity became more important from a governance standpoint and, in some ways, more *biologically real* to the US government during the late 19th and early 20th centuries. Indeed, the US government increasingly sought to identify which individuals could be granted (or denied) access to Native lands based on their ancestral ties and family lineage.¹³

In its bid to eliminate Indigenous presence and open Indigenous lands to further colonization and exploitation, the United States passed the Dawes Act of 1887, which allowed for allotment of reservation land.¹³ More specifically, the law allowed the federal government to determine which individuals would have access to reservation land, based on a blood quantum of at least one quarter Native. As a result, some communities' land was legally reduced because many Natives did not meet the minimum threshold, allowing the federal government to distribute land to more "competent" individuals who could sell it to homesteaders and others.¹³ Although blood quanta criteria developed during this period to establish tribal affiliation were not intended to represent heredity, such hereditarian ideas pervade modern analyses of associations between ancestry and genetics.¹⁴ Blood quanta became fundamental to federal policy determining Native identity, and such socially constructed categories have contributed significantly to perceptions of race as hereditary.¹⁵

Contemporary conceptions of Indian identity were further cemented after the Indian Reorganization Act of 1934. Federally recognized tribes used a minimum quantum of "Indian blood" to affirm an individual's tribal enrollment, an important determination that allowed individuals access to federal benefits, including access to health services.¹⁵ Issues of the relation of blood quanta to identity and tribal affiliation have emerged as real, everyday problems for Native peoples, something Louise Erdrich literally embodied. Her dilemma was whether being culturally Ojibwe was enough for her or whether she should possibly alter her own family's understanding of their kinship through DNA analysis and possibly claim certain rights based on blood quanta.

During the mid-20th century, the federal government “terminated” numerous tribes by depriving them of recognized status and benefits and imposed relocation policies on Native communities in an effort to assimilate members of recognized tribes.^{13,15} Such policies have not only resulted in loss of tribal identity for individuals but also taken a generational toll since, without a minimum blood quantum, one’s ancestral lineage to a tribal nation can be severed both politically and culturally. Faced with the daunting challenge of diminishing populations, many tribes have restructured tribal citizenship criteria to include lineal descent. For many tribes, providing evidence of lineal descent ensures tribal citizenship without individuals having to provide evidence of a minimum blood quantum. Tribal citizenship is complicated, however, considering that many self-identified AI/AN are affiliated formally or informally with tribes that do not have federal or state recognition yet feel they are tribal citizens or compose a distinct cultural group living within the United States.

The racialized identity of AI/AN peoples developed to a large extent according to European-American conceptions of race.¹⁴ The AI/AN race was formulated based on federal policies intended to identify individuals who could access federal benefits; modern conceptions of DNA and genetics did not play a significant role in the development of an AI/AN race.¹⁴ Accordingly, racial categorization is still used to study and articulate social and structural inequities that lead to poor health outcomes and ongoing disparities for Native populations.¹⁶ Similarly, **medical education** has long perpetuated the idea of race as an important biological marker that could explain increased risk for illness.^{6,17} Moreover, significant research conducted by academics as well as by pharmaceutical companies continues to focus on identifying links between genetics, race, and therapeutics.^{18,19}

Racializing and Clinical Decision Making

Clinical decision-making processes are complex and have been studied extensively. Fundamentally, clinicians integrate research, training, and intuition developed through clinical practice to make judgments about clinical course, diagnosis, and treatment of their patients.^{20,21} To make such decisions, clinicians often rely on racialized information.^{20,21,22} Using racialized identity, particularly in treating AI/AN patients, raises significant concerns about the accuracy of racial categorizations.

Racial misclassification of participants in research studies is common due to individual, systemic, and policy-level factors.¹⁵ Such misclassification produces wildly varying estimates of outcomes in various studies; in many cases, however, misclassification leads to an underreporting of mortality and morbidity in AI/AN populations and can lead to worsening health disparities.²³ Even when misclassification does not affect outcomes in studies using racial categories, the use of racialized identity, whether in large state or national studies or in case-based research, can **oversimplify experiences** of vastly different tribes or individuals by grouping them into a single category. For example, fetal alcohol spectrum disorder (FASD) has often been racialized and medicalized as a Native problem in Canada because researchers do not account for particular historical, political, or sociocultural factors that lead to FASD.⁹

A second concern is the use of race as a proxy for genetic heritage in studies and research proposals arguing that there are genetic differences in risk of illness or in protective factors against certain illnesses. For example, although research on alcohol and drug use disorders has identified numerous nonbiological risk factors,²¹ some studies still seek to establish a genetic link for such disorders.²² These studies identify

participants as “Native American” or “American Indian,” based on their enrollment in a tribe. Participant selection based on tribal enrollment does not account for the complexities of race and instead relies on race to study potential genetic predisposition.^{24,25}

Clinical decision making and education in recent years has begun to emphasize reducing risk of illness or mortality in addition to treatment of disease.²⁶ Many clinicians, particularly those treating AI/AN patients, make clinical decisions based on studies that use racial categorizations. However, this use of race has important limitations, particularly for AI/AN populations, as racial categories can form a “weak and ambiguous basis” for making clinical decisions.²⁶ The consequences for medical decision making based on such categories are significant: in any given case, clinicians might overestimate or underestimate the patient’s real disease risk and offer treatment based on incomplete or inaccurate data. Moreover, clinicians might use data that classifies significantly diverse populations as a single racial group.²⁷ Such concerns have important ethical implications.

Ethical Implications

As clinicians and educators concerned about autonomy and justice for AI/AN populations, we evaluate the ethical implications of racializing AI/AN health from these perspectives. Paternalistic attitudes based on the putative racial, religious, and cultural superiority of White Americans fundamentally shaped the experiences of Indigenous people.²⁸ This history still affects patient-clinician relationships by undermining respect for patient autonomy; as such, it becomes particularly important to empower Native patients and to ensure that their autonomy is respected during the clinician-patient encounter. Fundamentally, autonomy is subject to an individual’s ability to use accurate, complete information. Given studies’ racial classification errors and the potential conflation of heredity, genetics, and sociopolitical identity, clinicians’ medical information can be inaccurate or inadequate. Physicians are often left with little choice but to use such data in helping their patients make decisions about their risk of illness and the potential benefit of appropriate treatment. The inability of patients and their physicians to make truly informed decisions results in reduced autonomy and at times less than optimal treatment. As such, the use of racialized criteria in treating AI/AN patients presents unique challenges in improving patient outcomes while upholding patient autonomy.^{29,30}

Similarly, achieving justice is difficult when using racialized data. Contractarian theories of justice require redistribution of resources to correct social inequities, especially when those inequities exist in the setting of historical and ongoing oppression of a group of people.³¹ A practical redistribution of resources that would correct inequities requires us to identify groups or individuals, as well as their specific needs. Our inability to use data to clearly identify individuals, groups, or the social determinants of health that result in poor outcomes and to make the appropriate clinical decisions based on such information necessarily makes the task of achieving justice for disparate groups and individuals incredibly difficult. Consider the example of alcohol use disorder: using race as a proxy for a biological basis of illness could result in the determination that all AI/AN individuals are at high risk for alcohol use disorder because of genetic predisposition, although it has been shown that numerous, nonbiological criteria affect the prevalence of alcohol use disorder in such communities.³² Similarly, a utilitarian theory of justice would note that an inability to identify the needs of particular groups would impede the task of maximizing benefits and providing resources to achieve the best outcome

possible. Justice, according to both contractarian and utilitarian models, would be difficult to achieve in such circumstances.

Conclusion

The racialization of health can be traced to the historical and colonial need for identifying, dehumanizing, and marginalizing the other. Race developed into an important and de facto category for differentiating human groups within state and federal government policies, and the use of racial categorization was later extended to the practice of medicine. The convenience of uncritically using race as a category perpetuates the misunderstanding that there are significant differences between human groups based on biology. A single category of AI/AN race also eliminates (or erases) the important sociopolitical and historical differences between and among Native peoples. Clinicians who engage with and treat Native peoples understand the complex role that race plays in their patients' everyday lives. Nevertheless, race and racism continue to affect everyday hospital and clinical practices—from mental health treatment to pain management. As such, the concept of race must continuously be interrogated as a medical, legal, and **everyday category of difference**. Racializing health continues to have both practical and ethical consequences, limiting medicine's ability to achieve health equity for AI/AN populations as well as impeding communication in clinical encounters and significantly eroding patient autonomy.³³ Moreover, racializing health outcomes results in an inadequate assessment of the social determinants of health. Accurate assessment of and optimal care for the patient requires thorough and continuous review of the social determinants of health and structural inequities affecting Native peoples' everyday lives.

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MEDICINE AND SOCIETY

Holding Space for All of Us

Julie E. Lucero, PhD, MPH and Yvette Roubideaux, MD, MPH

Abstract

Negative experiences and misunderstanding are common in tribal-academic research partnerships. The Holding Space: A Guide for Partners in Tribal Research draws on the concepts of *governance*, *trust*, and *culture* to strengthen relationships, honor tribal sovereignty, counter histories of opportunistic research, and recognize all ways of knowing. We apply the Holding Space toolkit concepts to the All of Us Research Program and call on all research studies funded by the federal government to honor governance, trust, and culture in research partnerships with tribal nations.

Need for Tribal-Academic Partnerships

While social and health research has addressed some health challenges in American Indian and Alaska Native (AI/AN) communities,^{1,2} health disparities persist³ and are not easily resolved.^{2,4} For example, diabetes prevention and control require strategy implementation at the individual, family, and community level.⁵ Additionally, many AI/ANs and tribal nations have long-standing mistrust of research and research policies shaped by interactions with opportunistic academic researchers doing federally funded work without tribal input or benefit sharing.^{4,6,7}

Participatory or **community-engaged research** is one approach to reducing mistrust and ensuring tribal communities' equal partnership in research.^{8,9} Strong **tribal-academic research partnerships** that adhere to principles of participatory research can play a key role in developing the multilevel and contextualized solutions required to achieve health equity for AI/ANs.^{9,10} The National Institutes of Health (NIH) and Patient-Centered Outcomes Research Institute acknowledge the scientific value of inclusive, partnered research,^{11,12} and the Common Rule requires federally funded researchers to comply with state, local, and tribal laws.¹³ However, theory-practice gaps—manifest in discounting tribal sovereignty, paying little attention to cultural protocols, or minimizing community concerns raised by research—can cause or reintroduce mistrust and exacerbate disparities. For example, one recent research incident with the Havasupai Tribe demonstrates the need for meaningful tribal-academic partnerships in genetics research.¹⁴

Researchers and federal agencies interested in partnering with tribal nations often lack not only knowledge of tribal sovereignty and tribal nations' past negative experiences with research but also skills for building successful research partnerships.^{8,10,14} To respond to these knowledge and skill gaps, the National Congress of American Indians (NCAI) and the University of Nevada, Reno developed the Holding Space: A Guide for Partners in Tribal Research¹⁵ (Holding Space toolkit) to provide education to tribal and academic research partners on the importance of applying the concepts of governance, trust, and culture in their research partnerships.⁹ This article examines how these Holding Space toolkit concepts can be applied to the NIH All of Us Research Program's tribal outreach efforts and data collection plans.

NIH All of Us Research Program

The NIH All of Us Research Program was developed as part of the Precision Medicine Initiative announced by President Obama in 2015.¹⁶ Its aims are to enroll a large number of participants reflective of the diverse US adult population, collect biospecimens (ie, blood, saliva) and health data (ie, from a survey, medical records, physical measurements, and digital tracking), deidentify individual responses and publicly share the data (via cloud-based storage), and enable research on health conditions and development of targeted therapies. NIH funding, released in 2016, enabled creation of the All of Us recruitment network, which, in 2018, began enrolling participants who are diverse in terms of race, ethnicity, age, sex, ability, and health conditions.¹⁶ However, active recruitment of AI/ANs is currently on hold pending meaningful consultation and partnership with tribal nations. Tribal nations have expressed significant concerns about initial plans for the NIH All of Us Research Program's planned research and data sharing activities. These initial concerns include lack of tribal consultation prior to program initiation, questions about how AI/AN participants' data (including their tribal affiliation information) will be shared and used, and lack of information about tribal roles in research review and partnership.^{17,18} The main concepts from the Holding Space toolkit could help address these concerns and questions.

Holding Space Concepts

Governance. The NIH All of Us Research Program appeared to have misunderstood requirements to consult with tribal nations. In 2017, it formed a Tribal Collaboration Working Group and described the group's formation as one of its "engagement activities."¹⁹ But tribal consultation is not community engagement. Tribal consultation must be treated formally, according to established federal-tribal policies. Tribal sovereignty must be understood and respected during any partnership with tribal nations, which are responsible for stewarding tribal resources and promoting well-being among tribal members, citizens, and lands. Many tribal laws govern human subjects research beyond federal institutional review board (IRB) **requirements for human subjects research**. Tribal nations have a right to government-to-government relationships with the federal government and may invoke their own processes of research review and apply their own guiding principles to making decisions about initiatives that affect them.^{20,21} For 2 years, important partnership decisions, meaningful recruitment activities, and opportunities for AI/ANs were postponed until the NIH initiated a formal tribal consultation on the All of Us Research Program in 2019 after considerable input from tribal nations and advocates.^{17,19} Some outstanding concerns remain, particularly about data access, ownership, and the rights of tribal nations. The tribal consultation process is ongoing.

Trust. Trust is foundational to partnership success. Given the federal trust responsibility to provide health services in exchange for lands that were taken, tribal-federal partnerships are more likely to be successful when based on functional trust, or trust characterized by agreed-upon and clearly articulated roles and responsibilities.^{9,22} Despite efforts to build functional trust, mistrust or suspicion can still be present. Although tribal nations understand precision health's benefits for individuals, due to a history of negative experiences with and suspicion of population research, tribal nations see citizen protection as a primary function.⁶ AI/AN inclusion in the All of Us Research Program—a population research program—requires tribal belief that the research's potential benefits outweigh its potential harms.⁷

In 2015, the All of Us Research Program conducted a survey to gauge attitudes toward and potential concerns about precision medicine research and to measure support for such a study.²³ Unfortunately, the published report did not include AI/AN responses. It is not clear whether AI/AN individuals did not participate or if their responses were combined with those of other groups, a common practice. What is known, however, is that distrust and conflict between tribal nations and the federal government persisted for 2 years until the All of Us Research Program heard the calls for tribal consultation and initiated it in 2019.²⁴ A lesson from the Holding Space toolkit is that developing meaningful partnerships in order to conduct investigations that are useful for all stakeholders requires that researchers work with tribes early in the research process and recognize the types of trust and strategies that can help reduce conflict.

Culture. Human subjects research is not culturally neutral and neither are its topics, questions, and processes.^{9,15,25} Both research institutions and tribal nations have their own cultures and traditions, which sometimes result in unnecessary struggle over whose culture will prevail. For example, ethical and regulatory guidelines applied by IRBs tend to focus on reducing an *individual* subject's risk of harm. For tribal nations, however, risk is assessed most often in terms of *community* impact, and individualistic ethical frameworks might inadvertently exacerbate community risk.²⁶ This difference between tribal communities' and academic researchers' assessment of risk can cause delays in the research process. For example, focus on speed and efficiency is yet another value in individualistic ethical frameworks. By contrast, in community-based approaches, time is regarded more as a requirement for careful, deliberate tribal stewardship. The Holding Space toolkit promotes cultural humility as a virtue and value in weighing potential benefits against risks of harm. Understanding the differing cultures present in tribal-academic research partnerships can lead to a better path forward for the research.

Conclusion

The Holding Space toolkit concepts^{9,15} can be applied to strengthen tribal-federal research partnerships, including those needed to fund and support meaningful consultation and common research goals for the All of Us Research Program. Consulting with tribal nations and understanding the critical role of tribal governance, trust, and culture in research can facilitate improved individual and community health outcomes. We all have much to contribute, and we all have much to learn and gain by holding space for each other.

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MEDICINE AND SOCIETY

Policy, Wellness, and Native American Survivorship

Em Loerzel, MSW

Abstract

Native American women and femme-identifying individuals are twice as likely to be sexually assaulted as members of the general population. Given the high prevalence of violence experienced by members of this community, health care professionals and support staff must better understand social determinants of violence, barriers those experiencing violence face when seeking health care, and actions they can take to promote and implement change within systems that improve services.

Violence and Native Femme Bodies

There is a high prevalence of sexual violence among Native American women. A recent study found that 94% of homeless women residing in Seattle who self-identified as Native American reported experiencing coercive sex or rape during their lifetime.¹ In a nation-wide survey of American Indian women, 34% reported being raped during their lifetime,² confirming that this is not a localized phenomenon specific to the Pacific Northwest. Overall, Native American women are roughly 3 times more likely to be raped or sexually assaulted than the general population of women in the United States.³

With increased exposure to violence comes increased health complications stemming from it: Native victims of intimate partner violence and family violence are more likely to be injured and hospitalized than other victims of such violence in the United States.⁴ Abuse and violence can also leave scars not visible to the naked eye, with many studies reporting higher rates of posttraumatic stress disorder (PTSD) in American Indians and Alaska Natives than in Whites.⁵ PTSD influences not only mental health but also physical health, with patients reporting increased substance use, physical pain, and other general health conditions comorbid with the disorder.⁵ Trauma can also leave a more insidious mark on Native families in the form of **historical trauma**, which can be defined as “a source of intergenerational trauma responses” caused by long-term and ongoing distress and abuse within communities and families.⁶ To better understand historical trauma and its impact on violence in Native communities, we must first understand the relevant history and current-day impact of colonization and settler-colonial policy.

Colonization and Historical Trauma

Michele De Cuneo, a shipmate of Christopher Columbus, aptly summarizes how colonizers of the Americas treated Indigenous women from the beginning in a diary entry dated 1495:

I took a beautiful Cannibal girl and the admiral gave her to me. Having her in my room and she being naked as is their custom, I began to want to amuse myself with her. Since I wanted to have my way with her and she was not willing, she worked me over so badly with her nails that I wished I had never begun. To get to the end of the story, seeing how things were going, I got a rope and tied her up so tightly that she made unheard of cries which you wouldn't have believed. At the end, we got along so well that, let me tell you, it seemed she had studied at a school for whores.⁷

This diary entry clearly manifests the theme of colonizers treating Indigenous women as nothing more than sexual objects for their pleasure, to be ultimately disposed of as if some novel toy. Ultimately, the destruction and violation of Indigenous bodies and lives are rooted in colonization. Colonization can be defined as settlers coming in and taking control of people or resources that they are not indigenous to and inserting structures that maintain the continuous control over the Indigenous resources or people.⁸ This process often has a toxic impact on Indigenous peoples that includes cultural or physical erasure, genocide, forced assimilation, and disenfranchisement, be it through outright or structural violence.

In 1978, the federal case of *Oliphant v Suquamish* ruled that tribes could not prosecute cases in which non-Indian persons were involved, even if the case involved a tribal member or tribal descendent on tribal grounds.⁹ This ruling created a unique policy gap that made it impossible for tribal police to investigate and prosecute violence perpetrated by non-Native people on Native people. It is reported that as many as 88% of abusers of Native women are non-Native themselves,⁹ which puts the majority of perpetrators out of reach of tribal jurisdiction.¹⁰ In a retelling of a story of a Native woman attempting to flee her abusive non-Native husband, it was related that the woman attempted to go to the tribal police, who told her that there was nothing they could do because of their lack of jurisdiction in cases involving non-Native people and that she would have to report the abuse to the federal government.¹⁰

With a historical distrust of the federal government, many Native women do not feel comfortable reporting—or want to report—crimes to the federal government. If Native women do build up the courage to report, the crime often goes uninvestigated. Of sexual assault—including rape—cases involving tribal members on reservations that were referred during fiscal years 2005 to 2009, the federal government only investigated a third.¹⁰ If tribes could not investigate these cases and the federal government underinvestigated cases, how does violence against Native women get addressed?

There were approximately 35 years during which tribes could not prosecute non-Native offenders of violence; this legal “loophole” incentivized violence against Native women and disempowered tribal jurisdictions to protect their citizens. Given that 3 of 4 Native women experience violence or abuse³ and 1 of 3 Native women is raped during her lifetime,³ *Oliphant v Suquamish* left a particularly vulnerable community even more so by creating an environment in which it is unlikely that women could get help or prosecute their perpetrator, as tribal police could not take action and the federal government would likely not investigate the matter.

Violence Against Women Reauthorization Act

In 2013, the Violence Against Women Reauthorization Act (VAWA 2013) attempted to address the gap in policy that prevented the prosecution of non-Native persons who perpetrated violence against Native women. Under Title IX of VAWA 2013, tribal court-issued orders of protection were now recognized outside of reservation lands, increased funding was given for the development of resources to address violence in communities, and tribes were given back limited jurisdiction to prosecute perpetrators in dating violence cases that involved a known non-Indian partner.⁴ However, these new policy additions are not fully comprehensive and fail to include child victims or victims of human trafficking.

While VAWA 2013 adds protections for Native women against abuse and violence, tribal courts lacked jurisdiction for prosecuting crimes against children and “violence against women committed by a non-Native stranger.”¹¹ VAWA 2013 only allows tribes to prosecute a non-Indian status person if that person has sufficient ties to the reservation, such as working or living on it.¹¹ While a major loophole was closed and some tribal autonomy was restored by the act, this rigid and specific set of guidelines left out many situations and perpetrators that could potentially be prosecutable. If perpetrators of violence against Native American women know that they are essentially legally invisible and bulletproof from prosecution, what is stopping them from specifically targeting Native women for assault, coercion or, in the most extreme cases, murder? Would a tribe consider an acquaintance a stranger, or would the acquaintance be considered as having sufficient ties to the tribe for prosecution? The act left a large legal gray space that could be negatively interpreted and reduce tribal ability to prosecute.¹¹

Furthermore, the underfunding of health programs does not fully empower tribal communities to take action. For example, the **Indian Health Service** has in some years been underfunded by nearly 50% and cannot fully provide adequate support services to Native victims of violence and sexual assault.¹² Underfunding limits access to care that could aid in the prosecution of the assaulter (ie, rape kits or training for medical staff on sexual assault protocol or kit administration) and limits access to healing resources, such as medical assistance for physical trauma and therapeutic services for mental trauma.

Underfunding health programs should be considered structural violence and oppression because a policy can influence the health and wellness of our nation’s most vulnerable and marginalized communities. Looking at the historical context of the relationship that the federal government has had with Native peoples, especially women, it can be argued that the lack of comprehensive funding, programming, or awareness to address violence against Native women, as well as the existence of legal loopholes, reflects the ideology of a Euro-settler narrative that has been present since first contact: Native women are less than human, and the only good Indian is a dead Indian.

Going Forward

Several things can be done to improve VAWA 2013 and its social impact on the health and wellness of Native American women. First, the stipulation that tribes must conform to the standards set by the settler-state nation for court process requirements must be rescinded. To be autonomous, tribes must be able to decide how legal recourse should take place on tribal land. Many of the issues that Native people currently face directly stem from colonization and abuses from the US government and its policies.¹² Second, there are still large gaps in the legislation that leave Native people vulnerable to

violence. VAWA 2013 needs to include child abuse and remove the stipulation that tribes must be able to prove that the perpetrator has “ties to the tribe.”¹¹

These improvements would allow Native women greater access to existing resources and funding reserved for victims of violence and increased resources to be allocated to caring for Native survivors of violence. However, with the recent US Supreme Court decision in *McGirt v Oklahoma* upholding federal criminal jurisdiction for crimes involving Native Americans on Muskogee tribal lands,¹³ it is uncertain how Oklahoma tribal entities’ ability and resources to enact VAWA 2013 will be affected,^{14,15} making it ever more urgent to support tribal sovereignty and resources. Past and present policies are woven together, much like thorns, to prevent and deter survivors from getting the much-needed help and healing that they deserve. As health care professionals, we must understand how these policies leave lasting legacies of oppression and how we can best advocate for our patients to promote the healing and wellness of Native peoples and the future of their communities.

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ART OF MEDICINE

Paintings From Spain's COVID-19 Pandemic

Teófila Vicente Herrero, MD

Abstract

Artist Francisca Lita Sáez considers experience of physicians during Spain's COVID-19 pandemic. Three acrylic and pastel paintings convey defenseless human beings' confrontations with the novel SARS-CoV-2 virus, which is not yet controlled, leaving suffering and death in its wake. A physician-artist collaboration offers a visual representation of the clinical and ethical magnitude of the pandemic and humanity's fight for survival.

Views From Spain

Artist Francisca Lita Sáez and physician Teófila Vicente Herrero, like many of us, endured a long period of **quarantine** in Spain. Their collaboration informs art's capacity to help us find our way when medicine is overwhelmed and when science and its resources are outmatched. The series *COVID-19* includes 7 acrylic and pastel paintings, 3 of which are below. An image of the SARS-CoV-2 virus is represented in each; Lita Sáez's characteristic uses of color and human and nonhuman animal (especially insect) anatomy invite a viewer to consider, perhaps, feelings of abandonment and defenselessness in our collective and individual **struggles to survive**.

The SARS-CoV-2 virus emerged in Wuhan, China and spread rapidly around the world. There is currently no available clinically approved antiviral drug or vaccine, so **need for research** and discovery is urgent.¹ The World Health Organization has encouraged researchers and clinicians to think in innovative ways to reduce risk for individuals and mitigate spread in communities across the world.² Art-based ways of thinking can motivate innovation and have, for example, long been used to help humanity make sense of illness and death experiences during bubonic plague or the 1918 (Spanish) flu outbreaks, which are referenced in the 3 paintings^{3,4,5,6} and have informed our understandings of and responses to disease.⁷ Lita Sáez's paintings are situated in this tradition and have also served therapeutic purposes.

Vicarious Art Therapy

Art therapy draws on creation to facilitate psychological and emotional expression to complement verbal, linguistic expressions.⁸ The British Association of Art Therapists defines art therapy as "a form of psychotherapy that uses art media as its primary mode of expression and communication."⁹ The American Art Therapy Association also defines

art therapy as a valuable complement to clinical psychological approaches to psychotherapeutic healing.¹⁰ Lita Sáez's paintings invite, perhaps, a viewer to contemplate communicating among our own and others' experiences of the reality that humanity is not currently up to the fight against the SARS-CoV-2 virus. The paintings propose the value of vicarious art therapy as a possible pandemic intervention.^{11,12,13,14}

In *The Threat*, figures at right respond to attack by the SARS-CoV-2 virus at center. Like the Furies from Greco-Roman mythology—and like clinicians—these figures try to protect the cosmos from chaos and infection.

Figure 1. *The Threat*, 2020, by Francisca Lita Sáez

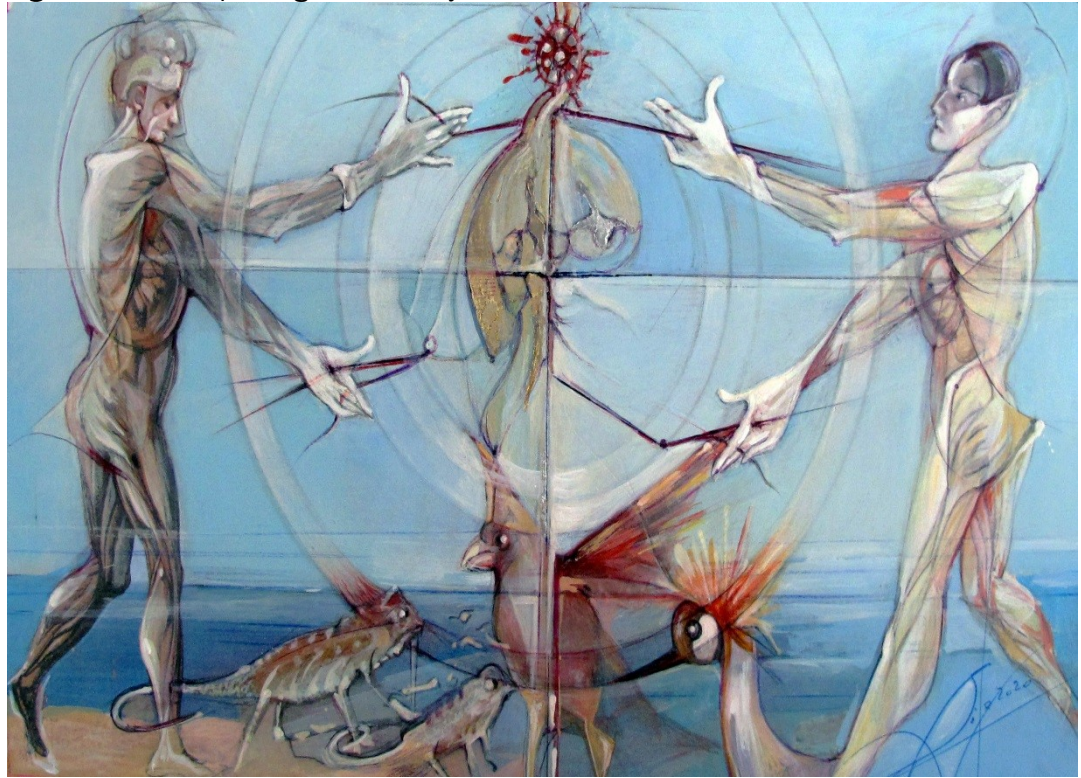


Media

Acrylic and pastels, 18" x 25".

In *An Unequal Fight*, 2 figures try to protect human and nonhuman organs from viral invasion. In both paintings, red suggests the novel virus's malignancy, against which we have inadequate immunity.

Figure 2. *An Unequal Fight*, 2020, by Francisca Lita Sáez

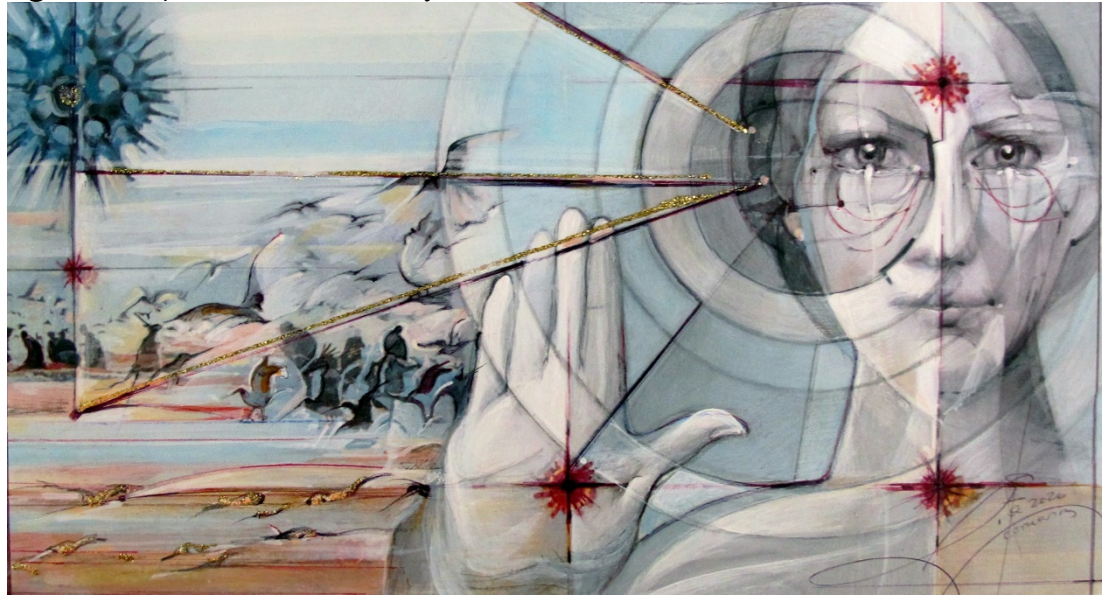


Media

Acrylic and pastels, 18" x 25".

In *Stop Pandemic*, a well-defined individual suffers infection despite a hand raised in a plea to stop the virus' blows, symbolized in red as direct hits. Other figures, less defined in shape and color, flee, suggesting capitulation to illness, despite our pleas and despite our fight.

Figure 3. *Stop Pandemic*, 2020, by Francisca Lita Sáez



Media

Acrylic and pastels, 18" x 25".

Lita Sáez's paintings portray the SARS-CoV-2 virus' global trail of death, but they suggest that hope might yet spring from collaboration between art and medicine and the therapeutic capacity of both.

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ART OF MEDICINE

Indigenous Apocalypse and Transgenerational Trauma

Sam Ramos, MFA

Abstract

The disproportionate negative impact of the COVID-19 pandemic on Native communities is a result of transgenerational traumas—mental and physical—which have been ongoing and developing for centuries. This article considers 19th-century American visual and narrative representations of Native experiences of and responses to transgenerational trauma. This article also suggests ethical implications for Native American health of interpreting those representations and suggests an obligation to look on 19th-century White American artists' romanticizations of Native experiences with humility.

Origins of the “Ghost Dance”

The year 1890 is frequently listed as the last—or penultimate—year on timelines documenting genocide of Indigenous people, often described as the “American Indian Wars.” After a year of continued violence and oppression, especially the forced confinement of Indigenous tribes on reservations, Sitting Bull, a great resistance leader of the era, was killed by Indian police on Standing Rock Indian Reservation in South Dakota.¹ Only a few days later, up to 300 of the 350 Lakota men, women, and children gathered near Wounded Knee Creek were killed by US troops.²

Ralph Albert Blakelock painted *Ghost Dance (the Vision of Life)* between 1895 and 1897. The image refers to a communal dance known to have accompanied the teachings of a Numu healer named Wovoka, who, in 1889, claimed to have had a vision prophesying removal of Whites from tribal lands, the rising of Numu dead, and the restoration of a once-thriving Indigenous America.³

Figure 1. *Ghost Dance (the Vision of Life)*, 1895-1897, by Ralph Albert Blakelock. The Art Institute of Chicago®. This information, which is available on the object page for each work, is also made available under Creative Commons Zero (CC0).



The Art Institute of Chicago, Charles H. and Mary F. S. Worcester Collection.

Wovoka's prophecy grew into a spiritual movement that spread beyond his own community to other tribes, who found hope in the seer's vision. The movement itself took on the name of the Ghost Dance, a ceremonial practice central to this new belief system. The Ghost Dance was accompanied by song (versions of which can be heard [here](#)) and was performed in a circle. As the song sped up, some participants entered a trance and separated to dance at the circle's edge.⁴

Regalia of Resistance and Healing

Some tribes read warlike resistance into the Ghost Dance. This interpretation, inspired by the aggression and violence of tribal encounters with US soldiers, led many followers of the Ghost Dance movement to wear white shirts, known as Ghost Shirts, said to guard wearers from bullets.² Dramatizations of people donning Ghost Shirts, and the Ghost Dance itself, appeared in newspapers and magazines⁵ and inflamed fear among Whites, who responded by pressuring the US military to suppress the Ghost Dance, to prosecute its Indigenous performers with new and brutal vigor,² and to use hyperbolic rhetoric, both in text and image, to narratively and visually amplify White nationalist expansion that resulted in the killing of Sitting Bull, the Massacre at Wounded Knee, and so many atrocities of empire. Focused eradication of Native resistance came bloodily and swiftly in the 19th century but had begun centuries earlier when European traders first arrived on "American" shores. By 1890, genocidal eradication was fully expressing manifest destiny. It should come as no surprise that civilizations crushed by gun and cannon fire, industrialization, colonization, and infectious disease would have found solace in a spiritual dance of healing.

Today, writer Julian Brave NoiseCat describes Native Americans as "a postapocalyptic people."⁶ He states: "[I]n a society built atop our graves, survival has become an act of resistance."⁶ During the COVID-19 pandemic, Brave NoiseCat emphasizes that tribal nations have been hit especially hard. The Navajo Nation, which at one point had the highest per capita SARS-CoV-2 (the virus that causes COVID-19) infection rate in the

United States, lacks running water and, like other impoverished and marginalized communities, suffers disproportionately from preconditions that make residents especially vulnerable to the virus and other illnesses.⁷ Legacies of poverty resulting from the forced migration, segregation, “reeducation,” disposition and resettlement, and other kinds of oppression prompted Wovoka and Sitting Bull to resist in the late 19th century, a time Brave NoiseCat calls “the last time Native life seemed on the brink of apocalypse.”⁶

Romanticized Remembrance

Wovoka was a healer, so it is appropriate to consider the Ghost Dance a healing practice that medicine generated—in shared dance among bodies, minds, individuals, and identities shaped in multiple Plains tribal cultures—perhaps as a means of ongoing recovery from transgenerational trauma. Trauma experienced by past and present Native peoples can be considered from both ethical and aesthetic perspectives in American art of the 19th century. White artists’ narrative and visual representations of Native persons’ lived experiences, such as how Native people performed and developed the Ghost Dance and the spiritual movement it birthed, deserve careful consideration. This includes examining how these representations have contributed to romanticization of Native American spiritual and healing practices.

Blakelock himself, for example, probably never witnessed a Ghost Dance. When he painted *Ghost Dance (the Vision of Life)*, he had not been out West for 20 years. His vision of Native life in this image is nostalgic for spectral dancers from a lost world. It is ethically and aesthetically important to acknowledge Blakelock’s vision of Native life as a fantasy. Although a fantasy, in and of itself, might not be ethically fraught, its source must be acknowledged as one perspective among many. This kind of humility must be modeled in our interpretations of White representations of Native lives lost so that elegiac fantasy does not obscure, erase, or dominate perspectives of those still in need of time and space to process trauma and grieve ancestral losses of loved ones and lands. Notably, the dark, close landscape and squat trees of *Ghost Dance (the Vision of Life)* have more in common with Italian Renaissance painting than with the gold and green grasslands of the American Northern Plains. Whose world and whose vision are represented is not an ethically or aesthetically neutral feature of Blakelock’s art, nor is our viewing of it.

Narrative art also calls us to consider humility as an ethical and aesthetic value in narrative representation. Alvan Fisher’s *The Prairie on Fire* was completed in 1827. It features an elder Natty Bumppo, the fictional hero of James Fenimore Cooper’s *Leatherstocking Tales*, protecting a White family from a fire set by ruthless Native warriors. Natty Bumppo was a White man who grew up among Eastern tribes, living and fighting alongside them. In the final book in the series, from which Fisher’s painting takes its subject, Bumppo has come West to escape the sound of trees being cut down for industry. He wants to die among the pristine wildlands he loves.

Figure 2. *The Prairie on Fire*, 1827, by Alvan Fisher. The Art Institute of Chicago®. This information, which is available on the object page for each work, is also made available under Creative Commons Zero (CC0).



The Art Institute of Chicago through prior acquisition of the George F. Harding Fund; restricted gift of Jamee J. and Marshall Field; Americana Endowment Fund.

Like Natty Bumppo, Fisher, Cooper, and Blakelock were White men. Regardless of whether their stories and images are sympathetic or even rendered with sympathetic intention, their perspectives express desire to inhabit (exclusively) lands already inhabited and represent encroachment of White settlers, traders, thrill seekers, and military forces rather than the Indigenous communities who are these artists' subjects.

Humility as an Ethical and Aesthetic Virtue

We might most charitably view the narrative and visual works of White artists of the late 19th century as products of their time. We might recognize that they might not have seen their representations as romanticizations at all or, even if they did, that they might not have recognized their romantic visions as capable of erasure of perspectives of Native people whose lives, activities, and experiences they sought to represent. But those of us who live today are not products of the late 19th century. Too often, past and present voices of the oppressed are unheard, even when their own histories are at stake. In this way, those histories are at risk of becoming lost, obscured, dominated, or erased, and experiences of transgenerational trauma—a process that seems to persist even postapocalypse—are at risk of being rendered invisible or silent. We must fulfill our ethical and aesthetic obligations to look on American art of our recent past, especially art by artists representing Native Americans past and present, with humility about the very act of representing and humility about each subsequent act of looking at what is represented.

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Editor's Note

Visit the Art Institute of Chicago [website](#) or contact Sam Ramos at sramos@artic.edu to learn more about the museum's medicine and art programming. Browse the *AMA Journal of Ethics* [Art Gallery](#) for more Art of Medicine content and for more about the journal's partnership with the Art Institute of Chicago.

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ART OF MEDICINE

I Am Not Your Ballot

Arianna Victoria Ramirez

Abstract

This drawing considers masks' transformation from an evidence-based public health measure to a political symbol during the 2020 COVID-19 pandemic.

Figure. *I Am Not Your Ballot*



Media

Digital drawing with Procreate.

COVID-19 has played numerous roles in American social and cultural **polarization**. Politicization of masks, in particular, illuminates how a legitimate public health intervention has been transformed into a daily source of conflict about the appropriate nature and scope of individual persons' freedom to act (even when informed by false, dangerous health beliefs) and the appropriate nature and scope of collective government and institutional legitimacy and authority. Polls indicate a widening gap between Democrats and Republicans over masks use.¹ Just as the voter does in this drawing, so each of us uses a mask to signal our own stance on whether and how to confront a common, invisible enemy to which we are all, but not equally, vulnerable.

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