

Resilience as a Mediator for Cancer Prevention in American Indian and Alaska Native Communities

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Prepared in Collaboration by:

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INTRODUCTION

The National Association of Chronic Disease (NACDD) and the International Association for Indigenous Aging (IA2), in partnership with the Centers for Disease Control and Prevention (CDC), hosted two subject matter experts to highlight the role of resilience as a mediator for cancer prevention in American Indian (AI/AN) communities. The presenters shared how resilience can support both a traumainformed, as well as a culturally appropriate response to cancer prevention among this population. References are available in the presentations available at https://chronicdisease.org/page/cancerprog rams/cancer-prevention-across-thelifespan/ unless otherwise cited.

PRESENTER BIOS

Margaret P, Moss, PhD, JD, RN, FAAN (Mandan, Hidatsa, and Arikara Nation)



Director, First Nations House of Learning The University of British Columbia, The Long House

Dr. Margaret Moss, is an enrolled member of the Mandan, Hidatsa, and Arikara Nation in North Dakota. She has equal lineage in a Dakhóta First Nation. She is the first and only American Indian to hold both Nursing and Juris Doctorates. She has been a nurse for 34 years and an academic for 23 years across 4 universities, including the University of Minnesota, Yale University, SUNY Buffalo, and currently at the University of British Columbia (UBC), where she is a Professor in the Faculty of Applied Science, School of Nursing. She was recently Interim Associate Vice President of Equity & Inclusion at UBC and has now returned to be Director of the UBC First Nations House of Learning, a strategic Leadership position under the Provost. Dr. Moss was one of only two Indigenous women named to the inaugural Forbes 50 over 50 Impact List, 2021. She was elected to the American Academy of Nursing's Board in 2021 and has been elected a member of the National Academy of Medicine (NAM) (2022). She sits on a Board of the National Academies of Sciences, Engineering, and Medicine, and is currently on a NAM study to review Federal Policies that Contribute to Racial and Ethnic Health Inequities.

Catherine E. McKinley, PhD, LMSW



Associate Professor Tulane University

Dr. McKinley was drawn to health disparities research related to Indigenous Peoples (e.g. Native American, American Indian, Alaska Native, and/or Native Hawaiian in the U.S.) due to many of the distinct strengths demonstrated by these peoples as well as the high disparities related to violence, mental, and physical health. Her work began with an exploration on how a non-Indigenous person, such as herself could work as an ally to contribute toward culturally sensitive, beneficial, and ethical research with these peoples. After studying "how to conduct culturally sensitive research" she began working with tribes of the Southeast to address disparities in violence, mental health, substance abuse and health. Her work now extends cross-nationally. Given there has been a lack of culturally relevant frameworks to explain disparities, she has worked in collaboration with tribes to develop the ecological "Framework of Historical Oppression, Resilience, and Transcendence", which identifies and organizes culturally relevant risk and protective factors across community, family, and individual levels to understand how, despite experiencing centuries of historical oppression and trauma, Indigenous peoples recover from, demonstrate resilience in response to, and transcend oppression and other forms of adversity.

BACKGROUND AND BRIEF HISTORY

Being American Indian or Alaska Native (AI/AN) can mean different things to different people, such as one's culture and connection to a tribe or based on one's ancestry. Understanding who is AI/AN and the nuances of this is critical when providing care and other resources to this population. Over 400 treaties were involved in establishing the 574 federally recognized tribes, at present day. As an enrolled member of one of these tribes, this recognition permits access to various resources, such as healthcare through the Indian Health Service (IHS). Descendants of federally recognized tribes and members of the 66 state-recognized tribes may access resources through other programs; however, available resources vary by geographic location. Four hundred tribes and their descendants lack recognition by state and federal jurisdictions, so they cannot access any of these resources.

Enrolled members of federally recognized tribes are guaranteed the right to healthcare through the Indian Health Service. However, healthcare services lack adequate funding, and oftentimes services are hard to reach for the over 85% of AI/ANs living in cities and outside of tribal areas. (U.S. Census Bureau, 2021)

Resilience

Resilience is the capacity to withstand or recover quickly from difficulties. Resilience is often seen as an individual trait; however, things such as culture and spiritually can further bolster resilience (Moss, 2023).

Indigenous Resilience

Indigenous resilience encompasses ecological, systemic, and interrelated factors across cultural, familial, personal, and sociostructural levels. Protective factors for physical, mental, behavioral, and social risks tend to be more relational and span across the life course and include engagement with culture, spirituality, family, subsistence, and traditional foodway culture. Family tends to be the primary conduit for intergenerational cultural knowledge, including foodways (McKinley, 2023). AI/ANs have demonstrated resilience and "survivance" through their ingenuity, persistence, and commitment to place, humor, and spirit.

The Health of American Indians and Alaska Natives

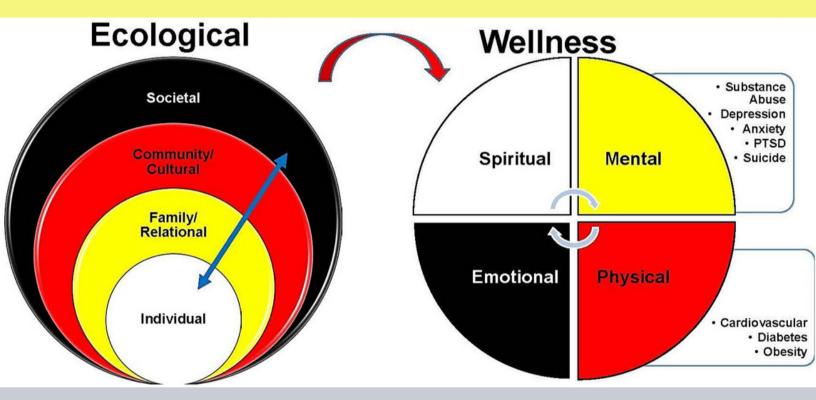
Chronic diseases are defined broadly as conditions that last three months or more, by the definition of the U.S. National Center for Health Statistics, and require ongoing medical attention or limit activities of daily living or both. Chronic diseases such as heart disease, cancer, and diabetes are among the leading causes of death and disability in the United States. Al/AN death rates from chronic disease can be as much as 520 percent greater than all races combined (Moss, 2023). Stress is a major factor in the high rates of chronic disease, including cancer, among Al/AN people. Stress can be positive (brief increases of heart rate, mild elevations in stress hormone levels), tolerable (serious, temporary stress responses, buffered by supportive relationships), or toxic (prolonged activation of stress response systems in the absence of protective relationships). Al/AN people have a history of toxic stress through profound events such as boarding schools, relocation, assimilation, and historical trauma. Contemporary trauma also continues to cause toxic stress today, such as missing and murdered Indigenous people. Contemporary trauma and toxic stress contribute to high death rates from chronic disease. While there are countless risk factors for poor health outcomes, there are also promoting factors that can lead to health equity for Al/AN.

THE MEDICINE WHEEL AND ECOLOGICAL MODEL

The Medicine Wheel is important to understand when working with AI/AN people, especially elders. Much of the AI/AN resilience is thought to come from the connection between spiritual, emotional, mental, and physical health. Connecting these four elements is critical for a culturally appropriate response to cancer prevention in the AI/AN population.

The ecological model allows for examining the interrelated protective and risk factors beyond an individual's wellness. In the Framework of Historical Oppression, Resilience, and Transcendence, there is recognition of historical and contemporary forms of oppression as well as resilience and transcendence of tribal members

(FHORT) (McKinley, Figley, Woodward, Liddell, Billiot, Comby, & Sanders, 2019)



Culture as a Mediator to Resilience

Culture is a protective factor for AI/AN people, young and old. Strength comes from culture, spirituality, shared values, a strong sense of identity, accountability, and responsibility for individual wellness, family, and even community wellness.

Culturally relevant protective factors include:

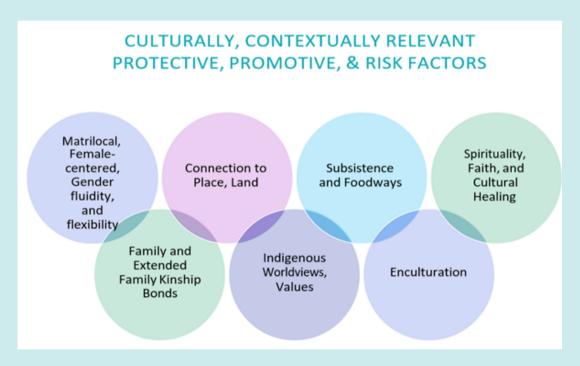
- Matrilocal gender arrangements
- Family and extended family kinship bonds
- Connection to place: subsistence and foodways
 - Cultural traditions
 - Spirituality, faith, and cultural healing

EXAMPLES

An Example: Chukka Auchaffi' Natana

Chukka Auchaffi' Natana (Choctaw), or Weaving Healthy Families (WHF), is a project done in collaboration with the Mississippi Band of Choctaw Indians. It seeks to promote family resilience and healthy living skills by focusing on improving communication, emotions, healthy relationships, and personal skills while aiming to prevent problems due to alcohol, tobacco, and other drugs, along with conflict and violence in families. It examines seven components listed below.

Participants reported an improvement in discrimination, communal mastery, parenting, alcohol and other drug use, and anxiety as a result of participation in the WHF program. Additionally, they reported an almost 3-times reduction in alcohol use after the program (McKinley, 2022).



Examples of culturally appropriate activities for programming to support AI/AN elders and encourage their participation include:

- Go out before dawn
- Touch the earth every day
 - Burn food offerings
 - Abstain from food
 - Pilgrimages
 - Dancing
 - Feed the Gods

RISK AND PROTECTIVE FACTORS FOR CANCER SURVIVORS

Factors that make cancer difficult for AI/AN populations include limited access to treatment (distance to travel, money for gas or transportation to treatment), changing service providers, discrimination, and mistreatment. Without access to care, many individuals forgo screening, and cancer survivors were unable to continue their surveillance and treatment plan. A safe environment needs to exist where traditional and alternative forms of medicine are available and safe to discuss, including for those that live away from tribal lands.

Promotive			Risk		
Structural	Culture	Family	Structural	Social	Health / Mental Health
Fluid Gender Roles	Spirituality, Ceremony	Matrilineal Gender Roles	Income	Violence	Mental Health
Sovereignty & Survivance	Foodways, Subsistence	Extended Family	Education	Incarceration	Physical Health
Connection to Place & Environment	Cultural Traditions	Connectedness	Employment	Maternal Child Health	Disability
			Environmental Justice		

Food For Thought:

How to introduce yourself as a person with a settler colonial background: We all live in a world structured by settler colonization: the heteropatriarchy/paternalism, white supremacy, capitalism, racism, sexism, positivism, and eurocentric perspective. Liberation from the colonial mindset requires:

- Dismantling ideologies of colonial superiority privileging Western European dominant approaches and thought.
- Taking time to understand that the Western European/Settler mindset varies greatly from the Indigenist mindset regarding knowledge, land/environment use, family and relationships, and individual versus collective mindsets.
- Acknowledging that colonization is ongoing today, it takes a different form.
- Taking the time to introduce yourself as a person with a settler colonial background acknowledges that your history and mindset come from this perspective rather than that of an indigenous one.
- Acknowledge the land you're on: It is important to recognize that the land you're currently on,
 wherever it is, is the ancestral homelands of indigenous people. Simply acknowledging those that
 lived there before raises awareness of the original stewards of the land and hopefully encourages
 others to acknowledge it as well.

Risk and Protective Factors for Cancer Survivors

Ecological <i>Risk</i> Factors for Cancer Survivors	Ecological <i>Protective</i> Factors for Cancer Survivors				
Systemic/Structural/Community/Cultural					
 Historical oppression undermining community support Unmet needs (institutional) Discrimination, internalized oppression, sub oppression Underutilized cancer screening (institutional) Stigma and confidentiality Poor care: needs/wishes are overlooked, lack of consistent care, inadequate access and infrastructure, poor quality care, misinformation, and pressure 	 Community support Cultural and culturally-based prevention and practices, engagement, and traditional healing is predictive of higher breast cancer screening Support groups and education Ceremonial and traditional practices 				
Family/Relational					
Adverse Childhood Experiences	 Instrumental and emotional intergenerational family and kinship support from grandparents, children, aunts, siblings, partners, and children Family and social support Health practitioners 				
Individual					
Changes in roles and identity as a cancer survivor	 Resilience and posttraumatic growth: stronger faith, relationships, gratitude, helping others, becoming healthier Integrative Two Eyed spiritual and religious coping Spiritual coping Keeping active Spending time outdoors Creative activities Optimism Finding meaning Cancer awareness and knowledge 				

LOOKING AHEAD

A trauma-informed approach to cancer prevention is critical, with the most important factor being safety, both individual and cultural safety. This is done through practicing cultural humility and respect for one's culture. The only way to ensure this is done is by allowing the patient to have a voice that lets others understand their history.

Services should be age and gender relevant and informed with an understanding of the available resources, such as through the Indian Health Service. Use culture to inform the solutions.

When working with AI/AN communities, make space for indigenous knowledge through community-based participatory research and ensure harmonization with respectful, reciprocal, and reflexive relations.

Going Beyond Resilience

- Decolonization: consider whose perspectives and worldviews get to count as knowledge and research for practice. Be considerate of traditional practices.
- Indigenization is a newly emerged term that means increasing the presence of Indigenous peoples and knowledge in traditionally Euro-Western institutions. It is the integration of AI/AN ways of knowing to guide practices and services.
- Reconciliation: the outcome of successful decolonization and indigenization, bringing the two sides together. It is an aspiration worth trying to achieve.
- Living Awake: a process to personal and collective liberation. While there might be some distress in raising one's consciousness, it will aid in the ability to look at the origins of the problem, not just the outcome of it.



Q & A WITH PRESENTERS

Using a trauma-informed approach, how can non-tribal communities and practitioners respectfully recognize historical and intergenerational trauma to promote AI/AN resilience in cancer prevention?

Al/AN history and realities from today have been wiped out, which was done by design. There were federal policy periods and informal periods, such as "get rid of the Indian problem" and "kill the Indian, save the man." Unfortunately, people may still be unfamiliar with this history. It goes beyond Christopher Columbus and Thanksgiving turkey. Take time to understand the Al/AN history, such as the Trail of Tears. You must seek out this information; you can't move forward until you have the truth. Al/ANs experienced genocide, not only cultural genocide but actual genocide, according to the World Health Organization. History, truth, healing.

How would you recommend applying your trauma-informed logic model where a public health risk reduction program effectively incorporated AI/AN cultural knowledge, practice, and resilience with cancer prevention?

Involve community stakeholders and self-determination of the community so they can drive the process. Allow indigenous people to lead and guide it locally and address things across the ecologic model. Understand the history of the practices we use today, such as eugenics. Work incrementally to shift this, and use the proactive factors to guide what to invest in.

How could funders better support the use of AI/AN collective resilience models to guide cancer risk reduction efforts?

Proposals should have an understanding of the history of the communities/regions. Make sure there are connections or collaborations with the AI/AN community or individuals to ensure this is wanted by the community. Have trust, time, and place by going into the community - funders should require that grantees show that they have done these things. Funders/ reviewers should also understand the fundamentals of what is important, such as community-based work, data sovereignty, culture, reciprocity, and sovereignty. Integration of these components in a good way should be considered when selecting who gets funding. Invest in localized community efforts to get more precise and relevant data and trust from the community. Value localized knowledge building versus a one-size-fits-all model.

Using a trauma-informed approach, how can non-tribal community practitioners respectfully recognize historical and intergenerational trauma to promote AI/AN resilience in cancer prevention?

You need to inform yourself of the historical and contemporary trauma. Currently, AI/AN have some of the highest suicide rates across age groups, and it is important to understand why, such as relocation programs, boarding schools, etc. Recognizing the connections and traumas that feed into chronic disease is important. Indigenous people have a unique and specific history.

Create cultural safety - this is a process of learning and listening. Listen, learn, and follow, do not lead. Understand that there are things that you might not recognize as relevant, so you need to open up your mind, build relationships, listen, and be immersed by listening to stories and letting people tell them in their own words. Be there to listen, follow, and uplift. Take a step back and recognize your privilege. Let the alternative stories come through - there are approaches out there; you just need to seek them out.

Resources

• American Indian Health and Nursing, Margaret P. Moss (available on Amazon)

Citations

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