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Aging In Minnesota: Forging A New Narrative

# Weaving Pathways: Walking With our Elders

Ginearosa Carbone, MS3, UMN Medical School  
Center of American Indian and Minority Health

# Introduction

Boozhoo nijj!

Although we are virtual/ on zoom - I personally am located in Saint Paul and want to take a moment to acknowledge that Minneapolis and Saint Paul have always been a gathering place for Indigenous peoples and acknowledge that we are on the ancestral lands of the Dakota, Ojibwe, Ho-Chunk, Cheyenne, Oto, Iowa, and Sauk and Maskawi people. We each need to recognize the enduring relationships between Indigenous peoples and their traditional homelands and express the gratitude for which we gather and are able to teach on days like today. It is important to respect Minnesota's indigenous peoples, the original stewards of this land and value the sovereign relationships that exist between tribal governments, state governments, and the federal government. Despite centuries of colonial theft and violence this is still, and will always be, Indigenous land. Indigenous peoples are still here and must be celebrated and uplifted.

Miigwetch!

# Background

What this presentation/ our paper is about:

- Here, we describe one model for initiating advanced care planning and dialogue to American Indian and Alaska Native (AIAN) communities.
- Honoring Choices of Minnesota approached the Center of American Indian and Minority Health (CAIMH), housed in the University of Minnesota Medical School, to participate in a project with the goal being to increase healthcare directives in AIAN communities.
- CAIMH assembled AIAN faculty, students, and community members to better elucidate and address barriers to healthcare directive finalization and conversations regarding end of life decisions.
- The project team embarked on a bidirectional approach: culturally knowledgeable provider training aligned with culturally pertinent community involvement.
- **Our goal was to empower AIAN to engage with healthcare providers on decisions influencing their care and to supplement the support of AIAN patients and their providers.**

# Approach

To understand the baseline status of EOL planning in AIAN communities CAIMH:

- recruited two Native American medical students to conduct a literature review.
  - The review identified several important barriers limiting completion of healthcare directives and impeding discussion of EOL care in AIAN communities.
    - Obstacles included the following: mistrust of healthcare systems; lack of relationships with healthcare staff; varying perceptions of death and dying within families and communities; lack of understanding by healthcare providers about cultural and historical concerns; misconception by providers about AIAN willingness to discuss the topics; language barriers; inaccessible paperwork; issues of jurisdiction; and lack of adequate care and services in rural communities.
  - CAIMH selected culturally-based and community-inclusive improvement methods: revise the *Honoring Choices* Advance Care documents and develop culturally-tailored communications within AIAN communities.
  - Located in Ojibwe country, CAIMH engaged local experts to help craft the communications and contribute to the revisions. CAIMH recruited a regional Tribal elder and an Ojibwe clinical social worker. CAIMH also invited an elders-focused lawyer from the Minnesota Legal Aid office to review the revisions.

# Rationale

- 30% of the population has completed an advance care directive
- Within ethnic and racial minority populations the percentage of completed advance care directives is considerably less
- Inadequate care at EOL traumatizes the patient and family, strains relationships between healthcare facilities and the community, and reinforces mistrust.
- Barriers to completion include mistrust by the patient, lack of access to care in rural communities, and misconceptions held by the healthcare providers.
- AIAN communities experience higher rates of chronic illness and early death, yet receive far less EOL care than the general population thus are at greater risk for unsatisfactory EOL, leading to undue physical, mental, spiritual, and economic hardships

# Pilot description

We began the project by culturally tailoring the *Honoring Choices* long form.

- addition of artwork created by a local Ojibwe artist.
- changed “Healthcare Agent” to “Healthcare Decision Maker” as seen in a previous study.
- addition of information about autopsies and post mortem care aligned with growth in the interest and practice of traditional EOL practices which require the body to remain intact.
- hosted community discussions led by a community elders with years of experience in EOL care.
  - As is customary for this tribal community, food was provided at all events. In addition to emphasizing the necessity for community involvement, our literature review revealed the need to educate and train health practitioners, particularly around misconceptions of death taboos and how to approach EOL topics

# Pilot description

## Continued

- With the staff of two tribal clinics, CAIMH organized workshops to familiarize the revised directive and identify ways to start conversations with patients and families using the revised resources.
- The community discussions and clinical workshops described the differences and uses of both the EOL directive and the POLST.

# Impact

Following the community discussions and clinical workshops, one tribal clinic has experienced an 18% increase in the number of healthcare directives and/or individuals with advance care documents on file. This encouraging increase reflects the community's desire for EOL discussions and EOL care. CAIMH will continue to work with the tribal clinic and community to monitor and sustain this trend.



# Conclusion

Sensitive discussions about EOL topics are more effective if delivered through relationship-centered events. While the literature review identified the relational aspects, the initial pilot approach involved larger meetings which did not result in sufficient community engagement. During the initial kick-off event, a participant suggested an improvement using the smaller and regularly-scheduled elders' group meetings. This pivot proved to be more engaging and foundational, expanding the network of relationships and leading to more suggestions for subsequent events.

expanded the discussions to more specific themes including patient autonomy, empowerment, and trust. During our discussions with elders and community members, CAIMH emphasized that documenting one's EOL wishes in an advance care directive makes them more likely to be followed and that the healthcare directive document is legal and binding. Still, changes can be made, so EOL documents can and should be revisited regularly.

The workshops for the health care providers covered a number of key points. Impressively, 92% of attendees with previous training about healthcare directives and EOL care considered the information to be new. Key points included the following:

# Conclusion continued

- Ask patients and their families for permission to initiate a discussion about EOL care rather than assuming the conversation is welcomed.
- If permission is not given at one visit, consider subsequent visits as opportunities to revisit the potential for discussing advance care decision making, recognizing that just because a patient doesn't want to talk about it at this time, doesn't mean they won't at another time.
- Approach the subject gently and be mindful of the person's condition and what else is going on. Further, recognize that EOL care planning can be a longitudinal conversation that doesn't need to happen all at once.
- Position the EOL topic in context. For instance, our clinical social worker often begins the conversation, "Our ancestors did not have to make these types of decisions." From experience, engaging the patient about ancestors and how they would approach the situation have been effective starting points.
- Emphasize that discussions about EOL care is about family and community. Directives support AIAN families and communities to exercise their sovereignty and take control of their healthcare.

# Next steps

Currently, CAIMH is developing an EOL toolkit for community members and practitioners. The EOL toolkit will include video resources and documents that will be accessible via hospital websites and the *Honoring Choices of Minnesota* website. Fundamentally, the toolkit can serve as a useful guide for each community to optimize a relationship-centered approach to EOL discussions to fit the specific needs and community resources.

New questions have emerged. For instance, how do we connect with younger generations to broaden the conversations? Ultimately, the goal is to empower the entire community. More empowerment can lead to more conversations among providers, patients, and families. More EOL conversations can ensure community members exercise their healthcare rights and wishes in EOL care.

# Acknowledgements

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