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Systematic Literature Review: Culturally Appropriate Approach to Advance Care Planning for
Ponca Tribe Elders

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ABSTRACT: Advance Care Planning is understudied in Native American and Alaskan Natives communities. There is a strong need for further research on culturally adapting advance care planning (ACP) for indigenous communities. Specifically, for the Ponca Tribe, culturally adapting the ACP used would ideally increase the acceptance of ACP in that community. This systematic literature resulted in identifying four themes other tribes have utilized to culturally adapt their ACP, advance directive, palliative and/or end-of-life processes in an effort to increase completion rates. The four themes were involving the elders with the adaptation process, increasing education efforts and awareness of ACP and ADs, adapting the language and imagery used in the educational materials used, and focusing on training the providers so that they feel more comfortable in addressing ACP with elders in a more culturally sensitive way. These approaches can serve as starting points that the Ponca Health Services can use to begin their cultural adaptations of their current ACP process to help increase ACP completion rates.

CHAPTER 1 – INTRODUCTION

There are 573 federally recognized Native American and Alaska Native Tribes in the United States (Indian Health Services [IHS], 2019). Each tribe has a distinct culture that helps shape their views of life, illness, and death (Whitesell et al., 2020). However, one aspect of their culture shared by most native cultures is the decreased level of health. The level of health disparities in native communities has impacted the native culture. Health disparities refer to life expectancy, disease morbidity, and quality of life matters (Stanley et al., 2017). Native Americans and Alaska Natives have faced and continue to face a lower health status than other racial and ethnic groups in the United States (Lillie et al. 2020). Native Americans and Alaska Natives have a life expectancy at birth that is seven years shorter than the average Non-Hispanic White individual (Arias & Xu, 2022). Compared to Non-Hispanic Asians, Hispanics, and Non-Hispanic Blacks, there is a difference in life expectancy of 13.8, 10.1, and 3 years respectively (Arias & Xu, 2022). The five leading causes of death for Native American and Alaska Native men are heart disease, cancer, unintentional injuries, diabetes, and chronic liver disease (Centers for Disease Control and Prevention [CDC], 2019 b). For Native American and Alaska Native women, they are cancer, heart disease, unintentional injuries, chronic lower respiratory disease, and diabetes (CDC, 2019 a).

Native American and Alaska Native individuals have long experienced worse health conditions than other groups of Americans (IHS, 2019). The burden of disease for this group is significant. It can be attributed to many social determinants of health, including experiencing higher poverty levels, discrimination/racism, lack of access to quality medical care (other health services), lower education levels, and a general lack of understanding of the cultural differences by the medical field (IHS, 2019). There is a strong need to begin working towards becoming

more aware of the need for culturally adapting various interventions in health to fit different patient populations (Purtzer & Thomas, 2019; Spero, 2019; Stanley et al., 2017; Zager, 2011).

Planning for the future, especially in medicine, is crucial for a population experiencing many health disparities that can lead to more illnesses and a lower life expectancy rate at birth (Stanley et al., 2017). Advance Care Planning (ACP) is a necessary process that helps an individual plan their medical wishes and preferences if they were to become incapacitated or unable to speak for themselves and make critical medical decisions on their own (Carney et al., 2021; U.S. Department of Health and Human Services [US DHHS], 2018). ACP involves creating an advance care directive (AD) in which the patient can list all their medical preferences in a legal document. This document would become active and go into effect if the patient becomes incapacitated or unable to make any decisions for themselves (Carney et al., 2021; US DHHS, 2018).

The Ponca Health Clinic in Omaha wants to increase the level of completion of advanced care planning by the clinic's elders. The Nebraska Geriatrics Workforce Enhancement Program (NGWEP) has also been aiding in these efforts. The Nebraska Geriatrics Workforce Enhancement Program (NGWEP) is a five-year partnership between the University of Nebraska Medical Center (UNMC) and primary care clinics in Omaha and 13 rural Nebraskan counties (UNMC, 2021). One of GWEP's main activities is transforming primary care clinics into 'age-friendly' clinics in Omaha and rural Nebraska to improve the healthcare and healthcare outcomes that Nebraska's older population receives (UNMC, 2021)

The Ponca Health Services operates two primary care clinics in Omaha and Norfolk, NE, and has recently opened a third clinic in Lincoln (Ponca Tribe of Nebraska, 2021). All three clinics offer medical, dental, pharmacy, behavioral health, and public health services (Ponca

Tribe of Nebraska, 2021). Currently, the Ponca Health Clinic is experiencing a low level of completion of its Five Wishes Advance Care Planning. The low levels might be due to a cultural difference in the population, making the current approach to advance care planning difficult for both providers and patients. Their patients are not engaging in advance care planning with their providers, and the providers do not feel comfortable addressing advance care planning with their patients during the annual checkups. One method Ponca Health utilizes to help increase ACP rates in their clinic is to have an attorney from Nebraska Legal Aid. Billy Boyd, an attorney from Nebraska Legal Aid, provides ACP legal services and support to the elders a few hours a week at a couple of the Ponca Health clinic locations. As of now, no evidence-based, culturally appropriate practice for ACP has been implemented at Ponca Health. There is a need to identify evidence-based, culturally appropriate practices to increase the rates of advanced care plans being completed at the Ponca Health Clinic by the patients and ensure that the providers feel more comfortable and capable of facilitating the discussion.

Advanced care planning for Native American individuals is an understudied area. Even less research has been done regarding culturally adapting ACP for Native American or Alaska Native individuals. This may explain, to some extent, the low adoption of ACP. (Kwak et al., 2019). The low rates of ACP completion by Native American and Alaska Native individuals is a significant issue considering that the Native American population experiences a disproportionately higher rate of health disparities and health conditions that can affect their end of life and life in general (Lillie et al., 2020; Purtzer & Thomas, 2018; Rumbaugh et al., 2018; Stanley et al., 2017). The deficiencies or gaps in ACP acceptance in Native American and Alaska Native populations highlight the importance and relevance of this Capstone project. This project intends to answer the research question, "How can we culturally adapt the advance care planning

(ACP) process with the Ponca Tribe to promote the completion of advance care planning by the elders and increases the providers' ability and confidence in addressing such a topic?". To help answer the thesis/question, this project's specific aims are (1) To synthesize current literature to understand the tribe's cultural beliefs around health and end-of-life through the literature review, (2) To find similar evidence-informed approaches in completing ACP in similar Native American and Native Alaskan populations and describing key components of those previous approaches, and (3) Adapt the previous approaches from Aim Two specifically to the Ponca Tribe through interviews with key stakeholders at Ponca Health and the Ponca community to increase their feasibility

Advance Care Planning is a very crucial process that allows an individual to have a higher level of care at the end-of-life (Sullivan & Dickerson, 2016; US DHHS, 2018). ACP has been shown to help improve communication between patients, providers, and their caregivers (Sullivan & Dickerson, 2016). It has also been shown to help reduce stress within those individuals by helping ensure that the patient's values, wishes, and desires are met during their end of life (Sullivan & Dickerson, 2016; US DHHS, 2018). According to Carr and Luth (2017), ACP is also "linked with greater use of palliative care among dying patients [and] lower medical expenditures at the end of life" (pg. 1). For a population who experience a high prevalence of serious disease and health conditions, it is imperative for them to have a plan in place that meets not only their medical needs at end of life, but also their cultural and spiritual ones as well (Lillie et al., 2020). Partaking in certain health related behaviors such as advance care planning, can also help ease the burden of making difficult decisions from the elder's family (US DHHS, 2018). Advance care planning helps ensure that the elder receives the type of care they want at their end of life, decrease their worries about their end of life, and also remove the burden off the

elder's family and community to make those difficult decisions when the time comes (Lillie et al., 2020; Sullivan & Dickerson, 2016; US DHHS, 2018)

CHAPTER 2 – BACKGROUND (Description of the health Problem)

Nationally, it is estimated that about one in every three adults completes advanced care planning in the United States (Yadav et al., 2017). A systematic review study conducted by Kuldeep N. Yadav and colleagues (2017) highlighted that, of the 795,909 individuals included in the 150 studies between 2011 and 2016, about 36.7 percent had completed an advanced care directive. This percentage is estimated to be lower by Sullivan and Dickerson (2016), who reported the rate of advanced care planning at 15%. A study by Kwak and colleagues (2019) concluded that American Indian older adults were significantly less likely to partake in advanced care planning than their White counterparts. In the study containing 436 White and 200 American Indian older adults, Kwak and colleagues (2019) discovered that only 43.5% of the American Indian individuals in the study had completed a durable power of attorney for health care (DPAHC) and only 29% had completed a living will. This is compared to 63.8% and 58.9%, respectively, for the White individuals (pg. 38).

Lower rates of ACP completion in the general population can be attributed to a general lack of awareness and education of ACP for the provider and patient, lack of effective communication between provider and patient, and fear of age-based discrimination preventing the patient from discussing end-of-life information (Sullivan & Dickerson, 2016). Other reasons included a misconstrued understanding of ACP by the patient, differences in values and beliefs that lead a patient not to want to engage in advance care planning, and simply the social and

cultural ideas of not wanting to discuss end-of-life and death in general (Sullivan & Dickerson, 2016).

The current literature on Native Americans and the completion of an ACP point to several reasons ACP completion rates are lower in Native American and Alaskan Natives communities. For example, some have speculated that barriers leading to lower completion rates of ACP in Alaskan Native communities have been related to geographical remoteness, language barriers, and lower health literacy levels (Johnson, 2019).

One of the significant barriers that impacted ACP completion was that some of the principles behind advanced care planning contradict the values and norms of many Native American and Alaskan Native communities (Dennis & Washington, 2018). In a study by Dennis and Washington (2018), it was found that many of the Western values of importance in ACP, such as individual autonomy and desire for control at the end of life, are in great contrast to many traditional indigenous values and views (Dennis & Washington, 2018). This difference is believed to lead to lower rates of ACP in Native American and Alaskan Native communities (Dennis & Washington, 2018).

Another barrier stated in the literature was a general lack of awareness or knowledge about ACP. The study by Dennis and Washington (2018) with 20 Ojibwe elders also showed that most elders did not know what ACP was or why it was important to complete the process. Their results showed that a general lack of knowledge about what ACP is and what it entails existed in the group of Ojibwe elders they interviewed (Dennis & Washington, 2018). Because of this, the elders did not understand the importance of ACP and what benefits it would bring them. The article by Isaacson (2017) also showed that 93% of the Lakota elders who participated in her educational project regarding Advance Directive (AD) and palliative/hospice care had never

heard of a living will/ AD. This is important to note since ACP helps guide elders in creating an Advanced Directive.

Spero Mason (2019) highlighted the need to recognize that "culture is fundamental to effective intervention design, implementation, and research (pg. 593)." Understanding the health of minority groups includes understanding their culture and how it impacts their ideas of health and every aspect of their lives (Mason, 2019). As Mason stated, we are cultural beings, and our culture affects our lives and decisions in many ways (Mason, 2019). In order to be able to fully adapt the Ponca Health Clinic's current approach to ACP to be culturally adequate for the Ponca patients, we first must have a thorough understanding of their cultural background and the social and historical atrocities, including "genocide, forced removal from lands, damaging federal, state and local policies and practices" that have shaped and impacted the experiences of these individuals (Stanley et al., 2017). There is a need to address and attempt to reduce the health disparities that the Native Americans in our country experience (Purtzer, 2019; Rumbaugh Whitesell et al., 2020; Stanley et al., 2017). Currently, no research exists regarding how to approach culturally adapting ACPs to meet the needs of the Ponca Tribe. Literature and examples exist of other teams adapting their approaches to ACP for other indigenous tribes and communities. But it is crucial to keep in mind that each tribe is unique in their culture, so the approach for one tribe might not entirely be adequate for another (Rumbaugh Whitesell et al., 2020). In general, there has been a strong push in the last few decades to increase the completion of ACPs in the general population (Carney et al., 2021; U.S. Department of Health and Human Services, 2018; Yadav et al., 2017).

Nevertheless, there is still a significant lack of research on Native American and Alaskan Native communities regarding ACP and end-of-life planning (Kwak et al., 2019). Since the

Native American population has an even lower estimated rate of ACP completion, efforts should be focused on culturally adapting ACP approaches to best fit the Ponca Tribe (Carney et al., 2021). It is imperative to look at past approaches and practices to identify possible interventions that could work with the Ponca elders with some adaptations.

CHAPTER 3 – METHODS

A systematic literature review was completed utilizing CINHALL, PsycINFO, Embase, PubMed, and Google Scholar. The literature review included both peer-reviewed and grey literature. Both qualitative and quantitative studies were also included. Only literature from the United States was included in the review, and the review had no time constraints on dates of publication. Key terms like "Native American AND End-of-Life," "Native American AND Advance Care Planning," "American Indians AND Advance Care Planning," "Indigenous Communities AND Advance Care Planning," and "Culturally appropriate Advance Care Planning" were used to search all of the mentioned databases. Broader key terms were utilized to capture as many articles as possible that could contain any useful content addressing the three specific aims of this project.

Figure 1. Databases and Key terms

Databases:

CINHALL, PsycINFO, Embase, PubMed, Google Scholar

Key Terms:

Native American AND End-of-life

Native American AND Advance Care Planning

American Indians AND Advance Care Planning

Indigenous Communities AND Advance Care Planning

Culturally Appropriate Advance Care Planning

After the searches, the articles' abstracts were read, and many were skimmed to decide whether they met the search specifications. At that time, it was also determined whether or not the articles contained useful information that would aid in completing the project's aims. Those who did not were discarded. The inclusion and exclusion criteria were chosen to ensure that the right sources were included in the literature review (see Figure 2). The inclusion criteria included (1) peer-reviewed and grey literature, (2) qualitative and quantitative studies, (3) no time constraints on publication dates, (4) source must involve Native American and/or Alaska Native Tribes located in the United States, (5) source discusses or gives examples of cultural adaptations of ACP, ADs, palliative care, or end-of-life care for a specific Native American or Alaska Native Tribe OR source provides information on how to better prepare providers to engage in ACP discussions and end-of-life planning with culturally diverse populations. The exclusion criteria include (1) any literature focused on an indigenous community outside of the United States, (2) source does not discuss or give examples of cultural adaptations of ACP, ADs, palliative care, or end-of-life care for a specific Native American or Alaska Native Tribe OR source does not provide information on how to better prepare providers to engage in ACP discussions or end-of-life planning with culturally diverse populations.

Figure 2. Inclusion and Exclusion Criteria	
Inclusion	Exclusion
<ul style="list-style-type: none"> ▪ Peer-reviewed articles and grey literature ▪ Qualitative and quantitative studies ▪ No time constraint on publication dates ▪ Source must involve Native American/ Alaska Native tribes located in the United States ▪ Source discusses or gives examples of cultural adaptations of ACP, ADs, palliative care, or end-of-life care for a specific Native American or Alaska Native Tribe <p style="text-align: center;">OR</p> <ul style="list-style-type: none"> ▪ Source provides information on how to better prepare providers to engage in ACP discussions and end-of-life planning with culturally diverse populations 	<ul style="list-style-type: none"> ▪ Any literature focused on an indigenous community outside of the United States ▪ Source does not discuss or give examples of cultural adaptation of ACP, ADs, palliative care, or end-of-life care for a specific Native American or Alaska Native Tribe <p style="text-align: center;">OR</p> <ul style="list-style-type: none"> ▪ Source does not provide information on how to better prepare providers to engage in ACP discussions and end-of-life planning with culturally diverse populations

Two semi-structured interviews were scheduled with various knowledgeable about working with the Ponca tribe alongside the literature review. Dr. Beth Ritter, an Associate Professor of Anthropology at the Department of Native American Studies at the University of Nebraska Omaha, was interviewed regarding the cultural and historical background of the Ponca Tribe. An interview was also scheduled with Jason Gillespie, APRN FNP-BC, a staff member at the Ponca Clinic Fred Leroy Health and Wellness Center in Omaha, NE. Mr. Gillespie has been working on the ACP project with NGWEP and has experience working with the Ponca Elder in helping complete the ACP process and has been a part of the task force working on the NGWEP partnership project with ACP. The interview with Mr. Gillespie was to gain insight into the clinic-level issues and learn more about his and other providers' experiences with working with

ACP and elders. Both individuals were presented with the findings from the literature review regarding what other tribes had done. They were then asked about the feasibility of applying those adaptations to the Ponca Clinic. Figure 3 contains the interview questions guide.

Figure 3. Interview Question Guide
<ol style="list-style-type: none">1. Overall historical context and understanding of end-of-life of the Ponca Tribe2. Cultural acceptable strategies to complete ACPs3. What are some provider level or clinic level barriers or facilitators that affect an elder's ability and/or willingness to complete ACP?4. Feasibility of adapting previous interventions found as part of the literature review to Ponca Health<ul style="list-style-type: none">• Perceived barriers• Possible benefits from the use of intervention(s)• How the intervention(s) would need to be adapted to best fit the Ponca elders and the current clinic workflow

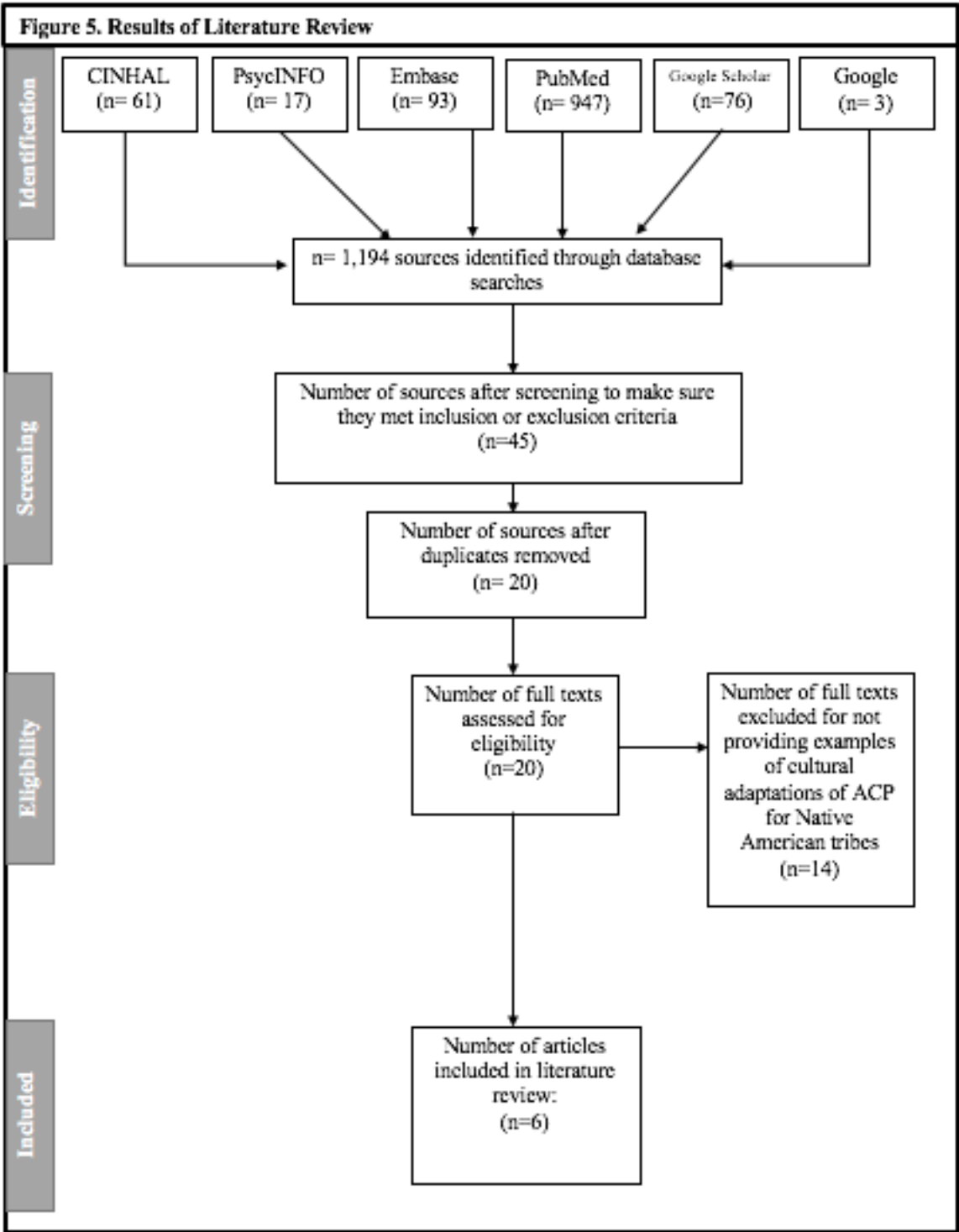
The interviews were conducted in person and via Zoom, catering to the availability and preference of the individuals interviewed. The interviews were recorded using the Voice Memos application on iPhone. The interviews were then analyzed and reviewed, and common themes were highlighted and reported. Their answers were taken into consideration to help determine what changes can be made to help make the Advance Care Process more appropriate for Ponca patients.

CHAPTER 4 RESULTS

Literature Review

The initial literature searches resulted in a total of 1,194 results. The articles were reviewed to see if they met the inclusion or exclusion criteria (see Figure 2). Only 45 articles from the initial search fit the inclusion requirements of this search. After the elimination of duplicates, the search resulted in 20 articles that either addressed the need to culturally adapt ACP for indigenous communities, contained information about cultural adaptations of ACP or

ADs for other tribes or served as general background information about health disparities seen in Native American communities (see Figure 1). Of those 20 articles, only six articles discussed the cultural adaptations of ACP and Advanced Directives to better suit a Native American or Alaska Native Tribe. Only 4 of those 6 were journal articles that contained actual attempts at the adaptations (Dennis & Washington, 2016; Isaacson, 2017; Lillie et al., 2020; Owen et al., 2022). The rest were either the already adapted material for a tribe, suggestions on how to better prepare providers to approach ACP in a more culturally sensitive way, or suggestions on how to best approach culturally adapting ACP with a Native American or Alaska Native tribe. The 14 other articles were about the need to culturally adapt ACP for native tribes, cultural differences in approaching death and planning of death, or the general background of ACP and Native American groups in the past. There was no literature regarding the specific interventions for the Ponca Tribe regarding any end of life or ACP.



Only six articles discussed the cultural adaptation of an ACP, end-of-life planning, AD projects with a Native American or Alaska Native community, and how to better prepare a provider to discuss ACP and end-of-life planning with culturally diverse populations. Four

common themes emerged within these six documents as to how to best approach culturally adapting ACP and AD within a Native American or Alaska Native tribe. The themes were to involve the elders, to increase education efforts and awareness of ACP and ADs, to adapt the language and imagery used in ACP and AD materials, and to focus on more training on providers, so they feel more comfortable addressing ACP with elders in a more culturally sensitive way.

Figure 5. Articles included in Literature Review

Author	Year	Title	Implementations (if any)	Themes
Dennis & Washington	2018	“Just Let Me Go”: End-of-Life Planning among Ojibwe Elders	N/A	<ul style="list-style-type: none"> Elders were unaware of what ACP was Elders shared that they were interested and willing to discuss ACP
Isaacson	2017	Wakanki Ewastepikte – An Advance Directive Education Project with American Indian Elders	<ul style="list-style-type: none"> Elders were trained to promote ACP and palliative care Created brochure with ACP and palliative care information Trained elders attended community events and educated other elders and the community on ACP 	<ul style="list-style-type: none"> Use of simple, easy to understand language Use of topics and themes that were important to the elders in brochure Use of culturally meaningful graphic in brochure Strong involvement of elders in implementation efforts
Lillie et al.	2020	Culturally Adapting an Advance Care Planning Communication Intervention with American Indian and Alaska Native People in Primary Care	<ul style="list-style-type: none"> Adaptation of ACP material Involvement of tribal members through the use of focus groups Inclusion of specific cultural section in ACP material 	<ul style="list-style-type: none"> Tribal members gave feedback on how to adapt ACP intervention to best members Use of simple, easy to understand language in material Recognition of the importance of culture in material
Owen et al.	2022	Weaving Pathways: Talking with our Elders	<ul style="list-style-type: none"> Use of community discussions to discuss EOL Adapting ACP materials to better fit the population 	<ul style="list-style-type: none"> Use of simple, easy to understand language Used workshops specifically catered for providers working with the tribe on how to best approach ACP with their patients Importance of educating the community about ACP Use of culturally appropriate topics in material
Alaska Native Health Consortium	2017	Advance Care Planning Resources	<ul style="list-style-type: none"> ACP educational material (brochure, ACP questionnaire packet, and graphic depicting end-of-life journey) 	<ul style="list-style-type: none"> Use of simple, easy to understand language Use of culturally appropriate graphics and imagery
Zager	2011	A Call to Improve Practice Concerning Cultural Sensitivity in Advance Directives: A Review of the Literature	N/A	<ul style="list-style-type: none"> Importance of training, educating, and increasing a healthcare provider’s awareness of ACP Importance of being culturally sensitive and understand various cultural beliefs when addressing ACP and ADs Suggestion to provide cultural competence training to providers

Involving the Elders

One of the key similarities in 4 of the six articles mentioned was that the researchers ensured that the tribal elders were involved in one way or another (Dennis & Washington, 2016; Isaacson, 2017; Lillie et al., 2020; Owen et al., 2022). The elders were consulted about what they perceived as the barriers to ACP and/or ADs and what things might aid in addressing and breaking down those barriers (Dennis & Washington, 2016; Isaacson, 2017; Lillie et al., 2020; Owen et al., 2022).

Isaacson (2017) did this by including three elders from the Lakota tribe in her team. The elders provided their feedback on how to adapt the educational brochure regarding ADs and palliative/hospice care (Isaacson, 2017). They were also trained on how to be palliative care/ AD educators (Isaacson, 2017). The educators were trained by Isaacson, the nurse researcher, on how to discuss ADs and palliative/hospice care and carry out those difficult conversations confidently and comfortably. The elders then were the ones who were on the ground and in the community carrying out the educational project and speaking with other elders about ADs and palliative/hospice care (Isaacson, 2017). This group would present at certain events like health fairs, powwows, and the elder meal program site. They also kept track of the date of the presentations and the number of participants present (Isaacson, 2017). In four weeks, the elders conducted 270 face-to-face sessions educating on ADs and palliative/hospice care (Isaacson, 2017).

Dennis and Washington (2016) utilized semi-structured face-to-face interviews with 20 Ojibwe elders living on a Great Lakes reservation. Their interviews focused on general health and well-being topics and discussed end-of-life topics (Dennis and Washington, 2016). The interviews gave insight into the elders' attitudes and practices relating to ACP. This study did not

focus specifically on implementing an intervention that would make the ACP process more culturally fitting for the Ojibwe elders, but it did result in very useful information regarding the elders' attitudes and practices regarding ACP, which is a crucial thing to have when looking on how to create adaptations of ACP processes that better fit with a tribe's cultural values, attitudes, and practices around end-of-life planning. It is key to consider a tribe's cultural values and priorities when adapting ACPs (Lillie et al., 2020).

The study by Owen et al. (2022) hosted community discussions led by a community elder who had experience in end-of-life care. These discussions were part of their pilot project to increase AD education and awareness in the Ojibwe community. The discussions with the elders and community centered on general education about ADs and end-of-life wishes (Owen et al., 2022). They demonstrated that approaches focused on relationship-centered events were most effective, and they received positive responses from their efforts. In combination with their other two approaches in this project, these discussions resulted in an 18% increase in the number of ADs at one of the tribal clinics (Owen et al., 2022).

Lillie et al. (2020) used a combination of 6 focus groups and cognitive interviews with their participants for their study. Their study included 35 individuals, 19 either patients or caregivers, and 16 health professionals (Lillie et al., 2020). The study was conducted in the Southcentral Foundation and First Nations Community Health Source health systems (Lillie et al., 2020). It is to be noted that only two-thirds of their participants were Native American or Alaska Native. They utilized the focus groups and cognitive interviews to receive feedback on how they could develop a culturally adapted tool to begin ACP and those kinds of conversations (Lillie et al., 2020). The feedback from both the focus groups and cognitive interviews resulted

in the input necessary to make the initial version of their tool better fit the participants'" perceived needs and more culturally suitable (Lillie et al., 2020).

Increase Education Efforts and Culturally Adapting Tools

Many of the studies found that a lack of education about ACP and ADs which resulted in a lack of awareness of the issue proved to be key in the low rates of ACP and AD completion witnessed in many of those communities (Dennis & Washington, 2016; Isaacson, 2017; Lillie et al., 2020). All stressed the importance of education on the understanding and cultural acceptance of ACP. This is partly why five of the six sources found addressed the educational component of ACP (Alaska Native Tribal Health Consortium, 2017; Dennis & Washington, 2016; Isaacson, 2017; Lillie et al., 2020; Owen et al., 2022). Both Isaacson (2017) and Owen et al. (2022) focused on meeting with the community and educating the elders about ACP directly. Both highlighted that engaging with the community and having discussions centered around ACP and ADs is important in increasing the elders' understanding of the importance of ACP and ADs (Isaacson, 2017; Owen et al., 2022). In addition to just talking to the elders in the community, many of these studies went a step further and developed educational tools to increase awareness. The Alaska Native Medical Center (2017), Isaacson (2017), Lillie et al. (2020), and Owen et al. (2022) all developed educational tools to increase education and awareness of ACP and ADs. Some created culturally appropriate brochures and handouts (Alaska Native Tribal Health Consortium, 2017; Isaacson, 2017; Lillie et al., 2020), and some are in the process of developing their educational toolkits (Owen et al., 2022).

These tools were, or are being, culturally adapted using several methods that the elders' themselves pointed out were ways to better suit the varying populations. Even though these studies focused on different groups of elders, the suggestions to culturally adapt the educational

tools were very similar. One of the main themes focused on simplifying the language by removing the jargon and hard to understand phrasing so it would be easier to read and understand (Isaacson, 2017; Lillie et al., 2020; Owen et al., 2022). The topics and themes included in the brochures and tools were adapted to focus on topics relevant to the tribes. In this instance, certain statements like 'if we do not make these choices, the government will make them for us' were also included per the request of the elders (Isaacson, 2017).

Owen et al. (2017) also included more information about autopsies and postmortem care to ensure it aligned with the growing interest in traditional end-of-life practices that require that the body remain intact for the Ojibwe tribe. Lillie et al. s' (2020) study stated the importance of ensuring the educational content and content in the ACP guides is "clear and understandable to the population and individual with whom it occurs" (p. 183). Their study showed that straightforward, descriptive, but not wordy language is important to increase a population's understanding of ACP practices (Lillie et al., 2020). The Lillie et al. study even included a "culture" section in their ACP guide to better grasp how much cultural values and beliefs played a role in the specific individual when completing the guide (2020).

This study also included another key addition, a question regarding if the patient wanted anyone else involved in the ACP conversation (Lillie et al., 2020). This is important to note, considering that some Native American cultures see end-of-life planning as a family or community thing rather than personal choices that an individual makes (Dennis & Washington, 2016; Zager, 2011). Another important topic mentioned in two articles that is important to note is that ACP conversations are ongoing and that changes can be made as time goes by (Lillie et al., 2020; Owen et al., 2022). Small changes in even the language the information presented in the educational materials proved important for certain tribes. For example, in Isaacson's study, the

elders stated that they felt more comfortable speaking about certain topics in the Lakota language, so in the brochure, certain things were written in Lakota in addition to English (2017). Another important theme commonly done was the inclusion of culturally relevant graphics and designs on the ACP educational materials and tools (Alaska Native Tribal Health Consortium, 2017; Isaacson, 2017; Owen et al., 2022). The Alaska Native Tribal Health Consortium created a palliative care map that used culturally relevant graphics to depict the ACP/ palliative care planning process (2017). This map contains minimal words but guides the individual through the entire process. Isaacson's (2017) study resulted in a brochure that contains artwork designed by a local artist. One of the pieces of art included in the brochure was a pair of worn moccasins to help symbolize the ending of their life journey (Seegert, 2016). Owen et al. (2022) had a similar approach and used the artwork of a local Ojibwe artist in their cultural tailoring of their ACP.

Training the Providers

There was some literature regarding the call to have health care providers be able to understand and be aware of diverse cultural differences, especially when it comes to ACP (Zager, 2011). In order to create trust between the provider and a patient, the provider must be culturally aware of the differences in values, beliefs, and preferences of the patient (Zager, 2011). According to Zager (2011), the literature states that this is important and is a prominent theme in this area of research. Even though this is true, only one article provided steps on how to help train health care providers to feel more comfortable working specifically with a Native American or Alaska Native tribe. The pilot study Owen et al. (2022) completed provided key points to address when completing a workshop with health care providers on how to better serve the Ojibwe community when talking about ACP, ADs, and end-of-life care. Some of the key points they suggested include:

- "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 End of Life (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 the 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." (Owen et al., 2022).

Most of the studies, as was shown, seem to use a combination of all these approaches.

According to the literature, these approaches to culturally adapting ACP and Advanced Directives for Native American and Alaska Native populations seem to be the only types of adaptations that have been carried out so far.

Interviews

The original goal for the interviews in the proposal was to be able to speak to several staff members from the Ponca Clinic, faculty members of the Native American Studies program at the

University of Nebraska Omaha, and the Ponca and Omaha Tribes' Cultural Liaisons, totaling in at least ten interviews with distinct persons of interest. Emails were sent out asking for interviews in early February 2022. Contact was established only with Dr. Beth Ritter from UNO and Jason Gillespie from the Fred Leroy Health and Wellness Center. Given the project's time constraint, only those two leads were followed.

Dr. Beth Ritter, Ph.D., has been working with the Ponca Tribe of Nebraska since the tribe became federally recognized again in 1989. She has published many articles about the culture and history of the Ponca tribe. Even though Dr. Ritter is not personally a member of the tribe, she provided some helpful feedback about the effectiveness of the cultural adaptations used by other tribes. Dr. Ritter mentioned during the interview that she could not speak on behalf of the tribe but instead provide a perspective based on her work with the tribe in the last several decades. She shared that she does not think that this concern regarding ACP might be something the tribe might see as "important or applying to them, given their world views, the expectation of bad outcomes, or the expectation that their family members will take care those decisions for them." Dr. Ritter also shared that the different views between the western approach of ACP being an individualistic decision-making process and family-focused one of the tribes might serve as a significant barrier.

Dr. Ritter then further discussed that the Ponca Tribe is unique compared to some of the other tribes mentioned in the studies since they do not have a reservation and are an "urban" tribe. This means that most of their members live in urban areas and are not all concentrated in a specific geographic area. Because of this, implementing a similar educational approach as Isaacson's did which focused mainly on locations and events within the reservation, might be challenging to carry out with the Ponca tribe. She did mention that elder programs would be

more likely to discuss topics like ACP with the elders, so that might be an approach that could be used to further expand education and awareness efforts for ACP. Dr. Ritter strongly emphasized that a grassroots effort would be the best way to approach increased ACP completion rates among the Ponca Tribe elders. She shared that it is important that the tribe identifies the low rates of ACP completion as an issue because they would not see it as a problem just because an outside organization says it is. Dr. Ritter shared that these types of projects, like culturally adapting ACP to better fit the Ponca tribe, will work best if they identify this as a need and they are the ones to help generate and give their perspective on what kinds of solutions are to be implemented.

After being presented with the different approaches to culturally adapting ACP and ADs for the various tribe, Dr. Ritter emphasized the need to focus on ensuring the tribal elders were included in the implementation of any cultural adaptations to the ACP process at Ponca Health. She mentioned that a Community Based Participatory Research (CBPR) model might be an effective approach to culturally adapting ACP for the Ponca Tribe since it would involve the community and look at what the community sees as their needs and effective solutions. Dr. Ritter shared that an intervention with similar components to the Isaacson (2017) study with the Lakota tribe might be a good approach to take. She made sure to reiterate that each tribe is unique and that it is imperative to make sure we do not assume that what will work with one tribe will be just as effective with another.

The interview with Mr. Jason Gillespie was also informative regarding the best approaches from more of a provider side of things. Mr. Gillespie provided great insight into the needs of the Fred Leroy Health and Wellness Center when it comes to barriers and issues with ACP practices. He shared that the main issues are a lack of understanding from the patients about

what ACP is and why it is important to complete it, and a general shared emotion of discomfort from the provider side when talking about ACP with a patient that might be affecting the completion rates of ACPs in the clinic.

After being shown the approaches being done in the studies, Mr. Gillespie seemed to agree that some of those approaches might have some feasibility in being carried out from a provider perspective and might prove to be effective in increasing ACP rates in the clinic. Mr. Gillespie agreed that increasing the educational efforts surrounding ACP for the elders with the use of focus group type presentations and educational materials like brochures would be a great start in increasing the Ponca elders' awareness of what ACP is and why it is an important conversation to have with their providers. During the interview, Mr. Gillespie shared that from his experience, that a lot of the time, the elders did not have a very good understanding of what ACP entailed and all the topics mentioned in the Five Wishes ACP document they utilized. He also shared that before the pandemic, Billy Boyd, an attorney with Nebraska Legal Aid, would have regular lunch presentations with the elders about ACP and ADs at the clinic. Billy Boyd is the attorney who helps Ponca Health patients create their ADs and legalize them. Mr. Gillespie shared that the seniors would have lunch and listen to the presentation, but this activity was halted due to the pandemic. He also shared that aside from those presentations and the Five Wishes handout, no other educational materials regarding ACP and ADs were given to the elders. After looking at the brochures and other tools used by the Alaska Native Health Consortium and the ones used by the Lakota tribe that resulted from the Isaacson study, Mr. Gillespie believed that the elders and the clinic would benefit from something like that as well. He says that the elders often do not know their options for ACP and end-of-life planning from a

medical perspective. So, educational material and presentation solely focusing on increasing the elders' awareness and knowledge of ACP and their options would be ideal.

To address the provider side of the issue and the commonly shared emotion of discomfort around bringing up ACP with their patients, Mr. Gillespie agreed that training and workshops catered towards the providers would be of great benefit. If the providers could have more regular trainings around discussing ACP with patients and being culturally sensitive about it, it might bring more confidence in being able to address the topic with their patients. Mr. Gillespie shared that ACP discussions are always a bit hard given the nature of the topic but that providing more constant training to the providers might prove beneficial. Overall, Mr. Gillespie agreed that the approaches that the other groups have taken might also be beneficial to the Ponca elders, with the proper cultural adaptations, of course.

CHAPTER 5 – DISCUSSION

The literature on culturally adapting ACP for any Native American or Alaska Native Tribe is scarce. The little that does exist provides different approaches to culturally adapting the advance care process and approach to advanced directives. This is why this study is important since it is paving a new pathway for NGWEP and the Ponca Health Clinics to contribute to the small pool of literature. Combining all the approaches taken by previous studies would ideally address all the barriers Mr. Gillespie identified at Ponca Clinic.

The Fred Leroy Health and Wellness Center had previous efforts already in place to educate the elders about ACP, as was shared by Mr. Gillespie. Prior to the Coronavirus Pandemic, the elders would come to the center and have an educational presentation by Billy Boyd. The elders would go the lunch and listen to Mr. Boyd present. Due to the pandemic, these

lunch presentations were paused. Restarting these educational sessions again would be a great start to addressing the need to educate the population regarding ACP. In a similar manner as to Isaacson, Mr. Boyd and the clinic providers, could identify and work with a few elders who attend the ACP presentations and train them on the ACP process and have them table for and present at other common meeting areas for elders such as the Tired Moccasins club, Ponca Tribe events, and health fairs here in Omaha, NE. Having the elders reach out to the community members and be the spokespeople for the ACP initiative, would ideally help influence other tribal members into wanting to learn more about the ACP process and to complete it. Presenting and targeting areas outside of the Ponca clinic is also very important due to the fact that the Ponca Tribe is not located in a set geographical area such as reservation. Not all Ponca Tribe members receive services at the Fred Leroy Health and Wellness Center, or any other facility, so it is important to have educational presentations and efforts focused outside of the Ponca health facility as well.

In addition to the educational presentations with Mr. Boyd, the elders would also benefit from the creation of informative brochures about ACP and the decisions it entails, and the options they have. Once again, Mr. Boyd and the Ponca health staff could recruit a handful of elders who are willing to provide feedback about how to best create the materials to educate the rest of the elders and other tribal members on ACP matters. Involving the elders in the educational efforts and further efforts to culturally adapt the ACP process at the Ponca Health clinics would be key to better understand how to best adapt the interventions to best fit the tribe. The elders hold the valuable key and would be able to provide important feedback as to what to include in the educational materials that would better suit their cultural values, beliefs, ideas, and practices. They would be the ones that could point out what topics or type of information to

include, ideas on the types of graphics and illustrations to use that would be meaningful to the elders, and how to best approach the rest of the tribe about this topic. This would ensure that the tribe and, most importantly, the tribal elders are included in the decision-making process. As Dr. Ritter shared, the issue identification and solutions should come from the tribal members, not the outsiders.

In addition to this, the clinic could utilize Mr. Boyd's services to focus on teaching and educating the providers on how to better address ACP with their patients. The more education the providers have on ACPs, the more confident they would feel in addressing this topic with their patients (Zager, 2011). In addition to general education about ACPs, the providers should also receive cultural competency training specific for working with Ponca Tribe members and other Native American and Alaska Native Tribes since they also can receive services at the Ponca Health Clinics. These kinds of regular trainings would increase their awareness about ACP and how to best approach it with the population they work with in a culturally sensitive and appropriate way. Following a workshop approach similar to Owen et al. (2022) would be a great start in order to merge the general ACP education with the cultural competency training. The literature did not provide exact toolkits for provider trainings other than the pilot workshop Owen et al. (2022) are still testing and developing. In the future this might serve as a resource Ponca Health can utilize to train their providers. As of now, various basic ACP training courses exist and are available for use. The CDC (2015) has an ACP training course that is specifically catered for public health and healthcare providers so they can feel more comfortable with knowing how to have such discussion with patients. One barrier foreseen with this implementation would be finding the time for providers to complete the training since many of them are already very busy. One method to make this kind of training easier to complete would

be to possibly break it down to various segments and schedule team meetings where the content can be covered in smaller fractions. This could be led by Mr. Boyd. The providers would not feel as burdened to complete a large course in one sitting. By splitting up the training or workshops into smaller, more digestible chunks, it might be easier for the providers to complete. This, in addition to the educational material, would help create a good toolset for the providers to feel more comfortable and confident in initiating discussions around ACP.

Ensuring that the approach the NGWEP and Ponca Health Team take includes some of the approaches taken by others, such as involving the Ponca Tribe members and elders in the decision making and implementation process and focuses on both the patient and provider education side of things, might set this project up for a successful result.

Making sure that the elders have a say and know they are part of the project could allow them to see the importance of ACP and feel empowered to teach their peers about it is key. Targeting the elders and helping them make a health behavior change, in this case completing the ACP process, would help promote those behavior changes to be adopted by the younger generations. The elders have a very influential status in their community and having them engage in ACP processes could spark a chain reaction. This would loosely follow Roger's (1962) Diffusion of Innovation Theory. The "innovators" and "early adopters" would be the elders who would help pave the way for the rest of the community to partake in the "innovation", or in these cases a certain health behavior. The elders would be the first group to begin partaking in ACP, which then will ideally lead the following generations to also complete the ACP process.

This study has several limitations, the main one being a lack of insight from any Ponca Tribe members, especially any elders. This study focused solely on the existing literature and the insights from individuals outside of the Ponca Tribe. The literature was also very scarce, which

limited the study to concentrate only on the six pieces of literature and other sources mentioned. So, it is not to say that other approaches would be less effective, but that the literature only reports on the four previously mentioned approaches to culturally adapting an ACP.

This project identifies how other tribes have adapted their ACPs and ADs and provides some starting points on how the Ponca Tribe could begin their cultural adaptation of the ACP process at their Ponca Health Clinics. The insight of the Ponca Tribe members is crucial in making any of these adaptations feasibly for their tribe. The goal of these efforts is to "culturally" adapt the ACP process, and in order to do so, we must ensure that these approaches are tailored to the culture of the Ponca Tribe. This can only be done with the involvement and the insight of the Ponca Tribe members. No outsider can complete this integral step of adapting the interventions to best suit this tribe. The involvement of the tribal elders is key to ensuring the success of the cultural adaptation of the ACP process that would ideally lead to higher rates of completion in the future. The following steps would be to present these results to the Ponca Tribe members and begin culturally adapting them to fit the tribe.

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