

End-of-Life Care in American Indian Populations of the Southwest

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Abstract

American Indians and American Native (AI/AN) populations have faced health disparities for a period of time. Although their incidence for some chronic diseases such as cancer, may be lower than the general population, they suffer from the poorest survival rates of any ethnic group. As the AI/AN populations age and live longer with chronic disease as seen with the rest of the general population, the discussion of palliative care is becoming more important. Currently, there is not a lot of literature about palliative care that is specific to the AI/AN population. The paucity of research serves as an impetus to learn and examine the need of available palliative care resources for the AI/AN populations. We present the analysis of twenty interviews with staff members of local hospice organizations and hospitals. The interview questions ask participants about their views and experiences in delivering palliative care. Through these discussions, we investigate the current needs, social and cultural barriers, and the infrastructure of how palliative care is accessed and delivered.

KEY WORDS: palliative care, end-of-life care, American Indian, Alaskan Native, hospice

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Introduction

Definition of Palliative Care

The World Health Organization defines “palliative care” as a form of care that improves the quality of life of patients and their families facing problems associated with life-threatening illness by preventing and alleviating physical, psychosocial and spiritual problems¹. Health care professionals often use the term “palliative care” interchangeably with “hospice care”, “end-of-life care”, and “terminal care”. Although the concepts of hospice care and palliative care are essentially the same, the term “hospice care” since the 1980s in the U.S. has a more specific definition under Medicare, that is palliative care that is offered only to patients who have a life expectancy of six months or less. Hospice care is a benefit that is available under Medicare Part A². The terms “end-of-life care” and “terminal care” are also referred to frequently, but may be misleading because palliative care is not only offered at the end of life. It can be offered early in an illness, to alleviate patients’ symptoms and improve quality of life. In fact, it is now becoming a more common form of care for patients who have chronic illnesses, such as heart disease and dementia³. In this proposal, “palliative care” refers to the WHO definition and “hospice care” refers to the definition given by U.S. Medicare.

Palliative Care in AI/ANs

According to the 2010 U.S. Census, 2,932,248 Americans have racially identified themselves as AI/AN alone⁴. Of this population, 7.3% is older adults (65 years of age or older), which has increased from 5.6% in 2000⁴. Life expectancy has also increased for AI/ANs from 63.5 years in 1972-1974 to 72.6 years in 2003-2005^{5,6}. The aging AI/AN population will likely encounter a greater cancer burden and other chronic illnesses in the future⁷. In anticipation of these population changes, the need for palliative care now and for the future is critical.

Furthermore, health disparities are still significant between AI/AN and their non-AI/AN counterparts. AI/ANs face higher rates of tuberculosis (500% higher), alcoholism (514% higher), diabetes (177% higher), unintentional injuries (140% higher), homicide (92% higher) and suicide (82% higher)⁶. Cancer ranks second among the leading causes of mortality⁸. Although the AI/AN population as a whole has an overall lower cancer mortality rate than the US general population, cancer mortality has increased by 5% in AI/ANs during 1996-2001 compared with 1990-1995, even though it has decreased by 6% in the US general population during the same time period⁹. Unfortunately, AI/ANs with cancer generally present to providers at a later stage in their clinical course than non-Hispanic whites, and they suffer the poorest survival rates of any U.S. ethnic group¹⁰. The steady rise of the older AI/AN population, as well as the higher incidence in terminal disease, begs the question of whether palliative services are being offered to those AI/ANs who need them.

In 2004, the Quality of Cancer Care Committee of the National Cancer Institute, NIH, assessed the palliative care needs of the Indian Health Service (IHS), an agency of the Department of Health and Human Services (DHHS), through a survey of AI/AN tribal health directors on available and needed palliative care services. More than half of the directors responded that there is a critical need for palliative services such as pain management, advance care planning, hospice care, and bereavement support¹⁰. In 2005, the “Spirit of Eagles” Program, which is sponsored by the Mayo Clinic in Rochester, MN, sent tribal health directors a questionnaire about availability of end-of-life and palliative care services. Sixty percent of the health directors reported inadequate community access to end-of-life care, and 70% of them reported pain management services as the most pressing need. Other major areas of concern and need included advance care planning, hospice contracts, care for dying, and bereavement support¹¹.

The majority of published articles about palliative care focuses on the care for patients with terminal cancer. Although cancer remains the leading primary diagnosis at admission to hospice care agencies in the U.S., there may be a shift towards a greater number of incoming patients with chronic illnesses, such as heart disease and dementia, in the future³. As cancer treatments continue to advance, fewer patients with cancer may enter into hospice care¹². With an aging population, it is expected that there will be an increase in the number of people living with chronic illnesses. Currently in the U.S. general population, about 80% of older adults (65 years and older) have one chronic condition, and 50% have at least two chronic conditions¹³.

Unfortunately, there is a significant lack of published research about palliative care specific to AI/ANs. Evidence is suggested by the limited number of results in a literature search on PubMed. As of February 20, 2012, in searching Medical Subject Headings (MeSH) terms of “North American Indian,” “palliative care,” and “terminal care,” only a total of 38 publications appear. Of these, most of the published research has been conducted with the First Nations populations and tribes in Canada. Although these populations have different cultural practices and beliefs from AI/AN tribes in the U.S., some parallels may be drawn between these two indigenous groups that both face health disparities and that both value traditional culture and the importance of family and community. The published studies on the Canadian First Nations populations present possible challenges that AI/AN populations may also encounter, such as cultural competency in care, and availability of resources for patients and their family members. Although this research has opened a door for more discussion, more research that is specific to AI/ANs in the U.S. is necessary to identify the existing barriers and challenges.

In a recent report, “Moving Beyond Paradigm Paralysis: American Indian End-of-Life Care,” researchers have evaluated four successful palliative care programs in Arizona, New Mexico, and Oklahoma. The programs include the Fort Defiance Home-Based Care Program on the Navajo Nation, the Cherokee Nation Home Health Program, the Zuni Pueblo Home Health Care Agency, and the University of New

Mexico Palliative Care Program¹⁴. The case studies highlight unique aspects of each program's approach, attitudes, and strengths that contributed to its success. These programs have demonstrated that meeting the needs of AI/ANs in palliative care is achievable. While these programs serve specific AI/AN populations, it remains unclear where individuals from tribes from other areas go for their palliative care. Where do patients and families who do not reside near any of these four programs go for palliative care and support? Do they go to IHS hospitals or local hospice care agencies? Are there programs or home health care agencies available on their reservations? Are these programs meeting the needs of AI/AN individuals and their families? No one study has yet answered these questions.

Research on palliative care for AI/AN populations in New Mexico has also shown that there are still many questions that remain unanswered, and that there is a lack of program organization and clarity in the policies, procedures, and actual practice regarding palliative care services. A recent University of New Mexico study has shown for the first time that there are no written "financial plans, policies and procedures, or standardized forms of documentation in medical charts" at IHS facilities throughout the Albuquerque IHS Area⁵. In the Phoenix Area IHS (PAIHS), one of the 12 regional service areas of the IHS, there is no documented evidence of these measures in palliative care. As of now, it is unknown if any such overarching program procedures and policies are in place for this region.

Palliative care is an important form of care that can provide patients with terminal illnesses and their family members clinical, physical, psychosocial, and spiritual support. Although more palliative care programs are being created, few patients elect to enter hospice care. Often, people seek palliative care very late in their care trajectory¹⁵. If palliative care is initiated earlier, patients and family members may benefit more from the continuous care and emotional support that includes pain management, advance care planning, caregiver support, and bereavement services. Earlier planning allows the patient to communicate his or her desires for a plan of care, as well as alleviate stress that the patient and family members may have with planning and making decisions. Physicians who raise the discussion about palliative care options may also have an easier time building a relationship with the patient, facilitating better communication and understanding patient needs so they can accommodate them as best as possible.

This project proposes to address these issues about palliative care for AI/AN populations: 1) Geographic availability of palliative care programs; 2) Whether existing palliative care services are meeting the needs of AI/AN patients and their families; 3) Whether any informal or formal overarching program policies and procedures in palliative care exist in Arizona; and, 4) The trajectory of palliative care planning for AI/AN patients. An assessment of the concerns and needs of AI/AN patients and their families will be completed. The results of this assessment will initiate more discussion among hospitals, hospices, the IHS, and tribes about where to go from here, and how they may work together in a partnership to provide

better palliative care. The goal of this collaborative discourse is to create a plan of how to improve the palliative services for AI/AN patients and their families. This project was undertaken as a curriculum requirement to complete medical school. It was approved by the Indian Health Service, Phoenix Area Office Institutional Review Board and the University of Arizona College of Medicine Institutional Review Board.

Materials and Methods

Recruitment of Interview Participants

There were a total of thirteen interviewees. The interviewees were recruited from local organizations in Phoenix, Arizona, which included a medical facility in Phoenix that treated only American Indian and Alaskan Native patients, and three hospice agencies. They were recruited by word of mouth, networking, and emailing contacts. There was no specific qualification that we were seeking in participants, other than they had to have had experience in participating in the delivery of palliative care to local American Indian populations.

We first interviewed nine participants at the medical center. Those participants provided possible points of contact at hospice agencies in the community. One of the hospice agencies employed a research coordinator, who also identified staff who worked with AI/AN patients, and provided their contact information. The sample from the three hospices consisted of four staff members.

Interview Sample Demographics

The range of years of experience working with the AI/AN populations was between 8 months and 32 years. One of the participants had worked for some years with AI/AN populations in the state of Washington before moving to Arizona. Of the 13 participants, six of them were of American Indian descent. Roles included physicians, mid-level providers, case managers, spiritual care providers, community health educators, social workers and administrators.

Interview Survey Method

The interview survey was designed as an open, inductive survey, to elicit a diverse group of responses to each question. It consisted a total of 14 questions, some of which included follow-up questions depending on the individual's answer. The questions addressed different themes that were chosen after reading current research on end-of-life (EOL) care in American Indians. These themes included existence of a current structure of delivery of palliative care and services, cultural appropriateness of services and training, comprehensiveness and availability of current EOL care, and areas of need for improvement. Every participant provided consent to be interviewed and I conducted every interview which lasted between 45 to 90 minutes. Participants' responses to the questions were transcribed onto a laptop during the interview. They were conducted at their respective institutions and coffee shops.

Interview Questions:

- 1) Based on your experiences working with the AI/AN population, do you think that there is an organized structure/system of delivering end-of-life (EOL) care services for patients who opt for them?
- 2) At your institution, are there currently any formal end-of-life services or programs that are used by AI/ANs? If yes, please explain. If no, please share the process of how patients are receiving EOL care and where they are being referred.
- 3) At your institution, are the EOL care services culturally appropriate? Are the services accommodating for cultural practices (ie- traditional medicine, rituals, healers)?
- 4) Do you receive any cultural awareness or competency training specific to AI/AN cultures from your institution? Do you think the training is sufficient? How do you continually improve? Describe the trainings that you receive and how often you receive them.
- 5) At your institution, what other types of support do your EOL services offer (ie- pain management resources, advance care planning, bereavement support)?
- 6) If your institution does not provide directly EOL services, where do the majority of AI/AN patients and their families receive their EOL care? Where do patients who do not reside in Phoenix go for palliative care and support? Are there programs or home health care agencies available on their reservations or in their home communities?
- 7) Do you think that the current services are meeting the needs of AI/AN patients? Please explain why.
- 8) What are the top three areas in EOL care that need more attention (ie- pain management, bereavement support)? Please explain why.
- 9) What are your suggestions for the future of EOL care services? What improvements, if any, would you like to see and believe would benefit AI/AN patients and their families?
- 10) What does palliative care mean to you? How is that different or related to from EOL care?

Risks and Benefits of Participation

Less than minimal risk occurred during participation, and no participants declined answering any question in the survey. Every participant was a volunteer and did not receive any compensation or direct benefit.

Results

The participants' responses were grouped by themes that emerged from their answers. Key texts from the transcripts were lifted and highlighted in the results.

Existence of Current Structure and Services

Question 1: Based on your experiences working with the AI/AN population, do you think that there is an organized structure/system of delivering end-of-life (EOL) care services for patients who opt for them? The majority of participants (6/13 participants, 46.2%) provided the answer, "It depends" (Please see Table 1). Each respondent addressed that an organized system existed depending on certain variables. Five variables mentioned were 1) location, 2) the particular tribe, 3) the particular IHS service unit or organizations involved, 4) a patient's resources, and 5) a patient's tribal support and connection. The following were a few highlight texts from the interview transcripts that further elaborated.

One participant from the medical center stated that the majority of primary care providers were knowledgeable or aware of the process of referring a patient to hospice. However, there were challenges in the rural areas, oftentimes on the reservation because there might not be a local hospice provider or service. Another participant stated that there was no formal organized structure that specifically addressed end-of-life care within the Indian Health Service. The manner in which facilities and clinics addressed these concerns was variable depending on their context. Another participant highlighted the importance of the patient and the family being connected to tribal support. Services rendered through the tribe and community were extremely valuable in palliative and EOL context and the opposite was true. "...If they're not connected to the tribe and they're randomly in the hospital, it's chaotic and more difficult to get them to hospice."

On the other hand, there were five participants (38.5%) who did not think there was an organized system of delivering EOL care. Their responses reflected the difficulties and barriers that prevented the development of a system. Barriers included communication, reluctance in discussion about EOL care due to cultural differences, the breadth of cultural diversity among tribes, lack of policies and guidelines, lack of education and resources among the medical community about EOL care.

One participant mentioned the need to assess each case individually. *"We refer on a case by case basis to hospice agencies which do a good job. But there's no system in place."* The financial resources of the patient had to be considered, as well as the location and preference of where and how they received palliative or EOL care. This participant also mentioned the role of advanced care planning and how it related to communication with the patient and family. When questioned further about the importance of advance directive planning, the individual stated that advance directive was "...not just a piece of paper where you say who you want making decisions and DNR or DNI...What are your beliefs? What are your thoughts about pain, depression, your family? What do you want to be told? What's important? It's not just a legal document. But the patient can fill out as much or as little as they want. And it's also an

educational tool for patients to look at what they can look at and I don't think a lot of people understand all the facets."

Other respondents expressed the complexity of providing EOL care to American Indian patients and families as a result of the tribal diversity of spiritual and cultural understanding and beliefs. "There's no such thing as American Indian people. There are Navajos, Pimas, Tohono-O'odoms, Yaquis, and everyone has a different belief in what happens, different cultural values....Each group of people has their own beliefs that don't necessarily correspond with other people."

Participants also noted that many of their patients did not like to discuss EOL as it was taboo to discuss the topic even when it came to appointing a guardian or power of attorney. One participant discussed the differences between home health care and hospice care for EOL, and that many clients were not aware of the differences between services that were potentially provided. This participant stated that in their experience, hospice care was more inclusive of the patient and the family. "...I don't feel like the clients have the knowledge of what hospice is. They just associate hospice with death. I try to encourage providers that hospice doesn't mean death. It's just another resource to them, and where they might improve and come off of hospice."

One of the hospice interviewees stated that much of the medical care that was delivered to AI patients was outsourced due to funding limitations. As a result, the ability to navigate the system of EOL care was challenging for both patients and providers.

There were only two respondents who believed that there was an organized system. One interviewee responded that the system was not solely identified for EOL care, but that "the system is structured so that the care is available. It might be somewhat piecemeal, but it's available." The other interviewee responded that the system of delivery is "in its infant stages."

Question 2: At your institution, are there currently any formal end-of-life services or programs that are used by AI/ANs?

The majority of interviewees (61.5%) said that there were no formal services used, although there were outside services that were easily accessible. "We rely on EOL programs in the community. ...We do palliative care in the clinic, although we may not formally call it that. We are still giving them treatment and trying to aggressively manage their symptoms (symptom management, pain management, depression) by keeping them out of the ER. If they don't have a hospice provider, we can provide that." Interviewees also commented on the lack of resources to establish any formal program, and sometimes, the care was offered piecemeal and unevenly divided among departments.

According to one interviewee, the accessibility to palliative care services was dependent upon from which medical department they sought care. If the healthcare facility did not have a palliative care program, the responsibility to deliver palliative care could fall on any medical provider, irrespective of their discipline.

One of the interviewees, a primary care provider, noted that the medical providers initiated referrals for hospice care, and case managers then worked with the patient and their families to complete the referral process. This interviewee also stated that the provider who initiated the referral might not be a primary care provider, and that it might be a hospitalist or hospital-based specialist. The choice to maintain a relationship with the primary care provider after enrolling in hospice depended on the patient and/or family.

The transition to palliative/hospice care involved multiple steps. "It takes a physician's order, a clinical review from an admission nurse to determine eligibility, and a lot of counseling to educate not only the patient but also the family members. Once they accept the benefit and meet criteria, they sign medical consents to treat and then they are enrolled in the hospice benefit."

While there was no formal program, case managers knew how to access care for patients and understand the steps, timeline, and loopholes of attaining appropriate EOL services. "It's an understood practice. ...We may get called immediately to meet the patient or I might call them at home to have that discussion with them. We're alerted by a consult. The hospitalist will make the consults to the case managers to initiate hospice referral. It's more like a practice, than a formalized program. ...When the EOL discussion is needed, that discussion happens in that clinical setting, and a decision is made about that. ...Some patients don't have primary care doctors, and we have an express care and emergency care clinic, where patients can tap into that system. If there's a complex problem, they'll get referred into the system. It's available for all, but it's not that everyone has a PCP."

One of the hospice interviewees shared the multidisciplinary approach once the patient was referred. "The whole team is required to meet the patient - nurse, social worker, hospice aide, spiritual- in five days. The PR coordinator is usually the one to sign that patient on, and makes the initial assessment and sees if the patient is eligible. She gets the process started, and gets to know the patient's family. And then the admissions nurse does all the paperwork- consents, what hospice does, and what if the patient seeks aggressive treatment. After paperwork, the team which is assigned to that patient does all the assessments and what type of plan of care we're going to do for that patient."

Four of the 13 interviewees responded that there were formal programs utilized by AI patients. This question was interpreted differently by each interviewee. The word "formal" meant something different to each person. There were variable settings in which a formal program was noted.

"...We have policies and procedures that address what we do clinically and the manner in which we communicate to patients and families in EOL situations. It's an interdisciplinary team approach. Palliative and EOL care are delivered in inpatient and outpatient settings, primarily with oncology and HIV, but occur also in primary care. But there's probably a team approach within the Hem/Onc and HIV setting.

There's the oncology team, diabetes team, HIV team. There's no palliative care team. There are health care providers that provide palliative care."

A hospice interviewee found AI populations on and off the reservation used the hospice services to the same extent that other ethnic groups do. "...We have nurses that are specific to the reservation. We have some cultural sensitivity training.... We have the support of social workers, grief counselors, and spiritual support for many religions and ethnic groups."

Cultural appropriateness of services and training

Question 3: At your institution, are the EOL care services culturally appropriate?

All interviewees agreed that EOL care services were culturally appropriate. However, many acknowledged the difficulty accommodating every tribe, as each tribe had their individual culture and individuals within each tribe practice traditions differently. "We worked really hard to make that (cultural competence) one of the guiding foci of what we've done. If we don't address the cultural aspects, then our patients won't be receptive to receiving care. It involves a high level of trust with palliative care and EOL care. If you don't have that, it's guaranteed that patient's quality of life and care will suffer."

Question 4: Are the services accommodating for cultural practices (ie- Traditional medicine, rituals, healers)?

Twelve of the thirteen interviewees (92.3%) believed the services accommodated cultural practices, and one interviewee responded with, "It depends." One interviewee said, "Patients most often go back to their reservations, where they feel most comfortable, and get these services. I think we do our best, with what we have. We don't have a lot of resources for Traditional healers. We try our best to get someone to come here, like a priest or a healer. It's not formalized, but we try to accommodate as best as we can." Another interviewee highlighted the importance of having the individual patient's beliefs and preferences direct EOL care. "Let the patient direct you in their care. There's always someone to go to because this (medical facility) is intertribal and there's a lot of sharing."

A hospice interviewee said, "If they're Native and Traditional, I need to get that tribe's Traditional practitioner. Sometimes, the practitioner is limited to what he or she does himself or herself. You have to help the patient understand too. Each tribe has its own practitioners. For the most part, the families know of someone who can come in and say a prayer for that person in the Traditional way. ...The main thing is to meet the family's need, and to make sure that patient dies with dignity. If it were a part of that patient's tradition and it helps with the family's closure, then we'll help do that."

Another hospice interviewee noted another type of cultural accommodation, which was the inclusion of multiple individuals in addition to the patient with EOL care. "... I think that's one of the biggest accommodations. That you can go from a small group that you are supporting emotionally to a vast part of a community. I think one of the biggest elements of EOL specific to Native Americans is the family

presence as death is approaching in those final hours. Typically in a non-Native home, we might see only immediate family. But in end of life hours, we might see 100 to 150 people gathering....”

The interviewee who responded with “It depends,” offered an explanation for some of the barriers in medical facilities in accommodating Traditional rituals using Traditional herbs and plants when these elements were required to be burned and smoke was produced. “...One of the rituals that’s used for healing or cleansing, for the removal of negative energy is the use of smudging.... Sometimes, (there is) concern for starting a fire, or setting off the sprinklers or fire alarms. ... When someone identifies a particular denomination and needs Traditional prayers, they request a ceremony. We’ve had people who said before they start treatment, they need to go home for a ceremony. We’ll do the (hospital) discharge and won’t initiate treatment until they come back. If they can’t go back home, they’ll go to the sweat lodge for healing. If we can get the medical clearance for the lodge, they can sit outside the lodge and hold a ceremony for them.” The delivery of spiritual/cultural care required careful coordination between the healthcare team and the patient and family.

Question 5: Do you receive any cultural awareness or competency training specific to AI/AN cultures from your institution? (They were then asked to describe the trainings that they received.)

Eleven of the thirteen (92.3%) interviewees said they did receive cultural competency training specific to the AI/AN cultures. Few interviewees noted that they had a week long training about cultural awareness during the new employee orientation, and that there were non-mandatory sessions of continuing education a few times each year. The cultural awareness training was not specific to end-of-life care. However, other employees commented on mandatory yearly online training with modules and certifications that incorporated a general education about AI/AN patients, but it was not specific to end-of-life care. Other modes of education included videos, staff development presentations, and events. One hospice interviewee noted limited training due to funding and resources. Another hospital interviewee noted that the training consisted of yearly or bi-yearly morning seminars. That participant said, “Our cultural sensitivity training is usually a morning seminar that covers many ethnic groups and NAs are a part of that. It makes up about 25% of the day. I think it’s a great introduction to cultural sensitivity but dealing with the multiple tribes in the Northwest, the cultural accommodations vary from tribe to tribe. So it’s hard to get very specific because each tribe is different. The variables are extensive....”

On the other hand, two interviewees responded that they did not receive cultural competency training. One commented that there was informal training, and if a staff member had questions about AI/AN cultures, he or she was able to seek out AI/AN employees who were familiar with the culture for help.

Question 6: Do you think the (cultural awareness or competency) training is sufficient?

Of the 11 interviewees who received training, five of them thought the training was sufficient and five of them thought the training was not sufficient. For those interviewees who did not believe that the training was not sufficient, most explained that cultural competence was an ongoing learning process. One participant said, "Cultural competence should be ongoing, because we can never learn everything about cultural concerns or perspectives. ... (Ethical care) involves culture, values, morals, beliefs, especially in palliative care. ... The training here can be improved and can be ongoing. We can have evaluations of someone's performance directly tied to cultural competence. It's subjective. How do you rate cultural competency?" Another interviewee probed further and questioned the definition of cultural competency and its purpose. "...What they first need to do is decide what cultural diversity is, regardless of race. It can be your religious beliefs, ethnicity, familial lifestyle. What is cultural diversity and what do you want to do with it? Is it to foster communication, to increase the knowledge of the local culture?..."

A participant explained further that it was almost impossible for training to encompass and teach about all AI/AN cultures due to the vast diversity. For that reason, oftentimes training came from experience by working one-on-one with patients. "It's kind of difficult because there are over 500 tribes because we're in Phoenix metropolitan area and it's a melting pot for all tribes and communities. It's hard to touch on training that speaks to all those various Indian nations. Ultimately, the things that we do know, we learn on the job." Another participant attributed limited training to limited funding and resources to support ongoing training.

The interviewee who answered neither yes nor no, said that she could not answer whether or not the training was sufficient, due to her AI upbringing. Her own culture was a part of her training, and therefore, the training she received from her institution was not reflective of her training by life experiences.

"I can't say whether the training's sufficient because I grew up in my culture, and I'm sensitive to needs of the people in my family and in the Navajos, but the same belief occurs in other cultures as well. It's innate, in-born, and you have to be aware of it and can't ignore. But if I were Anglo or of a different culture, even if I were Navajo and not raised culturally, I would need that training to be more sensitive to the needs of the clients that I'm caring for."

Question 7: How do you continually improve (cultural awareness or competency)?

Each interviewee had a unique response and perspective of attaining cultural competency. Some answered that cultural competency was not attainable. Some answered that they attended conferences and regular palliative care meetings, personal experiences with patients and providers, visits to local communities, their work environment and colleagues, reading, asking questions and sharing stories.

A participant reported that she learned mostly from an annual nursing conference. “...(An annual national conference is) where I keep up with all the EOL issues and spiritual care. Not only with the modern or Western side of the story, but I always look into the AI side. We usually go to the interest group, AI/AN committee, and we usually discuss EOL issues and how they’re being served in each state.... That’s how I get my training and how I continually improve. Discussions and sharing information, and what are sensitive issues for certain cultures in EOL and for certain people.”

Another interviewee commented on the inability to attain knowledge about every tribe, but focused on the importance of keeping an open mind. This participant improved by gaining experience through working with patients and colleagues. “Most of what I’ve done is learn from patients and providers. You learn from experience and talk to people and find out what their needs are. It’s less important for me to know about the Hopi cultural practices, than being open to any cultural practice no matter where I am. ...Talking to staff and patients, I realize that I will never know (about every culture). I don’t know about so many tribes and cultural practices. I will never understand every culture and what practices are and I just have to remember to be open to everything.”

Sharing stories among co-workers, patients and families was an important form of learning and way to improve. According to one participant, “For the Native people, we’re all pictorial based. The sharing of the stories is a good learning tool for people to say, ‘This is how a traditional Hopi family takes care of their patient.’ In group discussions and meetings, the learning comes in itself, and if you’re open to it, then you get that opportunity to learn and add that to your knowledge base. Sometimes, we’ll get a speaker to come, and we’ll hear awesome and amazing stories. ...Sometimes, it’ll be Traditional or elder. They’ll tell stories. It’s an ongoing shared collective experience of being Native American, in this being a big community.”

In addition to interacting with others in the community, awareness and self-reflection were also important in improving. For one participant, “...Reflection makes me continually improve, laughing at myself, and asking questions. If I don’t understand, asking for guidance or teaching from someone....”

Comprehensiveness and Availability of Current EOL Care

Question 8: At your institution, what types of support do your EOL services offer (ie- pain management resources, advance care planning, bereavement support)?

Most of the responses included symptom and pain management, medical equipment, advanced directives, spiritual care services, bereavement for patients and the family, home health, ethics consult, volunteers who visited homes and accommodations for customs and traditions.

One participant discussed the availability of advance care planning with social workers and spiritual support, using the Five Wishes document. The interviewee also elaborated on bereavement support groups or individual counseling. However, for pain management, there were limited resources at the clinic in terms of availability, access, and EOL-specific care. "...We have a pain management clinic that's a half day a week, and procedural based. EOL is a very little component in that clinic, and there is no EOL-specific anesthesiology clinic."

Another participant noted the decentralization of EOL care services, and that each service was provided at a different clinic or site. "We have (pain management, advance care planning, bereavement support), them all, but they're in different places." Each provider had their own role, and addressed the individual issue whether it was bereavement or advance care planning. Sometimes, there might only be one designated staff member who took care of one aspect of EOL care, creating challenges in availability. When there was no program available, it was more difficult to access that one staff member. This participant remarked, "Access to care at our behavioral health is extremely limited. One of the things we want to do, not just for bereavement support, but for also cancer support, is to have a behavioral health program." Access to programs might also depend on whether the patient was hospitalized as an inpatient or seen as an outpatient. "We offer all those services (pain management, advance care planning, bereavement support). They're available inpatient. For outpatient, you really have to educate clients on the resources that we have...."

Two participants explained the difficulty of developing a formalized program for certain services, due to cultural barriers and lack of resources. "Bereavement prior to death is so patient dependent. It's hard to have a formalized program. Once they do the Five Wishes, they can see what their priorities are. Some don't even want to discuss it or the referral to hospice. The family doesn't even want to tell the patient sometimes that they have a terminal disease...." Another participant commented, "...Due to financial constraints and multiple Traditional beliefs of many patients of different cultures and tribes, you can't just offer a particular tribe a medicine man and not a client from a different tribe. There are over 200 tribes, and you can't satisfy each of them. ...It's completely up to the families to decide and know what the client wants. It would be nice to have Traditional healers available, but there will be a large gap."

A participant also stated that having a formalized program in an urban setting might not be beneficial to all AI patients. Many patients wanted to go back to their homes on the reservation and receive their EOL care there. "A lot of the clients want to go home because a lot of them are attached to their land. These clients are transitional. If they're here in the city, they'll be lost. It wouldn't be beneficial to a client if there were a formal end-of-life program here (in the city) that included all services. Especially when they're Traditional, they want the services and rituals to be at home. If a patient passes, they can only talk about death within a framed period of time. It's hard for them to go through the bereavement process if they

don't want to talk about it. It might be beneficial to urban Native Americans who didn't have Traditional beliefs...." A hospice interviewee echoed the same thought about AI patients' ties to their homes and families, and that influence on delivery of care. "We have inpatient units for symptom management, and the Native Americans have utilized that for actual symptoms or respite stay so the caregiver can have a break. Not often but they have. Leaving to go somewhere else is not culturally common. They would rather stay with their family than leave to go to another city."

A hospice interviewee discussed the agency's services and comprehensive and inclusive approach to providing services. The management of symptoms was essential to the EOL care. There were teams and providers that addressed a component of care. This participant was particularly impressed by the promptness and effectiveness of the pain management program. "EOL symptom management is our key part of the management for the family- pain, nausea, wound care, mobility, safety, respiratory support. Along with that, we have a clinical resource nurse, social worker, a respiratory therapy team, and a wound care team. There is a clinical resource person for any need that comes up. Our pain management program still impresses me... When our nurses go out to a family, if there is a pain that's not acceptable to that patient, that is addressed that day and the medications from that pharmacy are delivered that day. There is an immediate response to unacceptable pain levels per patient report...."

Question 9: If your institution does not directly provide EOL services, where do the majority of AI/AN patients and their families receive their EOL care?

Interviewees responded that where AI/AN patients and families seek care was a very individualized process. It depended on where the patient lived and came from, and whether that patient had particular resources. More often, they would commute to Phoenix to receive EOL care. If they wanted to go back to the reservation, they would likely go to the hospice that was most geographically convenient from their home. "Each reservation is unique. It's a web of care. With this patient who has particular resources, the web can be different versus a patient without services. What EOL care services are available in that local community, it's impossible for me to know that. ...When the patients are from the reservation, they are commuting back and forth when getting treatment and palliation. The majority of patients that we see in clinic tend to stay in the Phoenix (specifically for hospice care)." "If they decide not to do EOL care here (in Phoenix), they go home. They prefer to go home, to their community. They go to their closest hospice care near there."

A patient's belief system might also direct where they went for their EOL care. "Depending on their beliefs, they may not want to be at home to pass away. ...They may want to be in facility or in a hospital. It's very designed with that patient and where they are at with their cultural comfort. Some patients are very strong in their involvement with the tribe and belief system. The patient directs it. Even if they're

here, they refuse to go to hospice because they want to stay in their hospital. ...Some are reluctant to someone coming to their home.”

Question 10: Where do patients who do not reside in Phoenix go for palliative care and support?

The availability of hospice agencies and EOL services on the reservations was limited. “...For end of life, it’s going to be through their health care facility. It may not be formalized, but it’s back in the community on reservation. Some of these home communities have those services and some do not. The home health care agencies may be contracted....”

However, a hospice interviewee discussed the collaboration of urban hospice agencies and patients who lived on reservations, and the home visits. This interviewee elaborated on the importance and influence of having insurance and resources, and its impact on the EOL care provided. The patient’s health status also guided how often they were seen at their homes. “Some of their programs are contracted by their insurances. If the patient does not live in Phoenix, the palliative care support group (from a hospice agency) goes out to them. The insurance requirements are specific and tailor what is provided. It has to be compatible. How often the group goes out to the reservation depends on the patient’s status. If somebody signed on to the palliative program but is limited from hospice, but if their needs are changing and increasing, that frequency of nurse visits will increase. It’s always addressed per need. But not having insurance does not disqualify them for palliative support.”

Patients’ attitudes were also slowly and gradually shifting towards acceptance of the hospice concept and openness to building relationships with health workers outside of their community. A hospice interviewee commented on witnessing this shift, however also the cultural barriers and beliefs that persisted. “I think more and more of them are electing for hospice. ...That is also because we’ve built a relationship with that community. We (hospice staff members) are not aliens anymore. From my experience, accepting hospice is very hard for them. ...They go to emergency rooms for care because there aren’t many clinics or doctors. They’re in and out hospitals repeatedly. If someone’s talking to them about hospice, they don’t accept it till later down the line. They’re usually not on hospice service for a very long time. They’re being talked to, but it’s not culturally acceptable to do hospice until there is clearly nothing else to be done....”

Question 11: Are there programs or home health care agencies available on their reservations or in their home communities?

Of the thirteen, five interviewees (38.5%) said that depending on which reservation, there were programs and home health care agencies. "(All patients) want to stay where they're used to. They want to stay within the IHS hospital. It varies with what services are available, depending on the patient and which community that they're living in. There are patients who are coming from all different communities. If they're coming from another area and they're going back to their home area, the EOL care available in their community is coordinated through their primary care doctor. There might be hospice agencies available, but very rarely...."

Another interviewee commented on how much the location of a patient's home affected their care. "It depends on where they live. ...It depends on their location. ...Most of the reservations will have a public health nursing program with their community health nurses, so you can get someone to eyeball them and bring them into the closest clinic. ...(The services may) not be on the reservation, but surrounding the reservation. There are a few agencies who provide life-long term care, like home aides. But for skilled nursing services, they don't go on reservations directly."

Four of thirteen interviewees (30.8%) responded that there were no home health agencies or programs on reservations. One interviewee commented, "(There are) no home health on reservations, except community health nurses and staff. (There is) no private home care on the reservation." Another interviewee responded, "It's very difficult. This is where the needs are. ...Out on the reservations, people have hardly anything, and rely on community support. There are community resources on reservations that are grass-roots or either contract care if they're eligible for specialized care. Many reservations don't have access to hospice. ...A lot of people come into Phoenix, and then they go back home. They come down periodically for check-ups. For palliative care, they're referred to nursing homes, and a lot of the burden is borne by the family, and they don't have good quality of life because of it."

Another interviewee agreed that the reservation did not have the resources to provide home health, palliative and hospice care. As a result, the participant had seen ripple effects on the patient and the family, especially during the grieving process. "...Sadly, a lot of the patients are put on medications because of the limited resources that each facility has. There's no time to discuss their grief process over an hour. They're only allowed 15 minutes and given an antidepressant instead of helping them through their grief, recognizing the different factors that are grieving them, giving them different resources, or trying different elements of therapy. Those types of therapy aren't available mostly due to financial constraints...."

Two interviewees responded that there were home health agencies and programs on the reservations. One interviewee identified reservations that had agencies available, however said that there were no hospice agencies. Another interviewee explained that hospice agencies were slowly being accepted on reservations, and for the past 5 years, there was a growing cultural acceptance for hospice workers to come into their homes. There was also a stronger push to increase the number of AI/AN nurse population so they could directly provide the EOL care.

Two respondents could not give a “yes” or “no” answer and were not sure, due to the limit of their experiences.

Areas of Improvement in EOL Care

Question 12: Do you think that the current services are meeting the needs of AI/AN patients?

Four of thirteen interviewees responded that the current services were not meeting the needs of AI/AN patients. One respondent explained that the current services were not meeting patient needs because the services were underutilized likely due to lack of awareness on behalf of patients and providers and lack of cultural competence of providers.

Another interviewee explained the challenges of insurance eligibility for urban patients who live off the reservation. “...When the majority of patients, the user population, are the urban Natives living off the reservation, the majority do not have insurance and aren’t eligible for contract health. If they aren’t on the reservation for more than 120 days, they are no longer CHS (contract health services) eligible. If you work for a tribal reservation or reside on reservation, you’re in CHS category. For other tribes, they have criteria that you must be a tribal member specific to that community. Tribal affiliations and geography hinder patients from receiving the services.”

Four of the thirteen believed the current services were meeting the needs of AI patients. One interviewee commented on how individual patients also built together which services worked for them, relying on both what was available in Western medicine and what was available in Traditional medicine. Another interviewee highlighted the newness of hospice care to AI patients, and that services might be available but not well understood and accepted yet by patients. “...(Hospice care) It’s new to them. It’s been around since the 70s, but it’s still new. It’s scary. A lot of it has to do with cultural understanding....”

A hospice interviewee echoed the same concern that there was still a lack of awareness and education about what palliative and hospice care meant. “I think that we are meeting their needs. The concern is

that more education is needed on a community level, to encourage people to take on that (hospice) service so that we can meet those needs in a more efficient way. I think that's a new idea in the medical arena that they're just starting to become comfortable with. Their comfort and receptiveness, the number of people that signed on have increased over the last 3 years, which have been related to education and experience with hospice personnel."

Two of the thirteen believed the current services were meeting the needs of AI patients, but that the medical community could do better. One interviewee noted that although the services were provided, they were delivered in a way that was difficult for patients to navigate. "...There are so many patients who are coming in from other areas that we are concerned about. They're getting patchwork care. EOL and palliative care involve communication with families, and discussion about access to care due to economic, geographical, and cultural issues."

Another interviewee commented on the potential benefit of having an in-house hospice unit at a medical center. For AI patients, it might be more comfortable to be in a familiar environment where providers might feel more comfortable and knowledgeable about their cultures and needs. "...It could be better if for instance, if we had the ability to keep patients here more often. (AI patients) like to be around Native people and in an environment that they know and are comfortable with, and here would be nice to have a hospice unit available for patients. People on the outside don't necessarily feel comfortable and understand. ...When they're identified as an AI patient, the outside is a little uncomfortable because they're not sure how to meet that need."

Furthermore, another interviewee suggested making a more comprehensive multidisciplinary team for improvement. An in-house team would be more effective in catching patients who fell through the cracks and did not get the necessary referrals. "...But we should really be more comprehensive, a one-stop shop where people can get their services met and a multidisciplinary team. There's not a lot of patients who get a referral in situations where it's end of life, so we can do a lot better."

Three of thirteen responded that the current fulfillment of needs depended on the population and the type of services. According to one interviewee, current services were meeting the needs of urban AIs, but not of rural AIs. This participant also noted the transient nature of many palliative and hospice care agencies on reservations. "...I doubt that there's a palliative care program that will go onto the reservation. It's so dynamic and ever changing. Palliative services may pop up and go away." Another interviewee echoed the same thought. For smaller communities, it was a challenge because there were rarely services available on reservations, and often the services were contracted out. The participant also recommended having care on reservations because it is "...always better to have someone there in the Native communities to provide that care."

Question 13: What are the top three areas in EOL care that need more attention (ie- pain management, bereavement support)?

Not every interviewee was able to provide three areas of EOL care that needed more attention. When we surveyed, we let them know that it was acceptable if they were not able to think of three. Therefore, there were different numbers of responses per individual. (Please see Table 4.)

Pain Management

The area that had the most number of responses from interviewees was pain management (Please see Table 4.) Five interviewees chose pain management as an area for improvement. One interviewee discussed the difficulty of pain management in cancer patients in particular, and that many patients were often underdosed and had inadequate pain control. Another interviewee agreed and offered an explanation about not providing enough medication. “So many of our patients who have a history of substance abuse are initially classified as drug seekers, until they have a full workup. They describe pain that’s more than what it really is. There is a problem with overuse and overprescription. If you’re a good patient, you’ll get pain medication. If you’re a bad patient and irritate someone, in all likelihood, you’ll get less pain medication. On the other hand, if you get the happy provider, then those providers get severely chastised for overprescribing.” A hospice interviewee also voiced the same concern about inadequate pain control. “Educating medical physicians that even if the patient has a drug history, the pain is still there. A lot of physicians say that they’re drug seeking, but if they’re dying, they need to get the pain meds that they need. A lot of them read the H&Ps, and they refuse to increase their pain meds. We need to respect the patient’s end of life.”

An interviewee elaborated that for people who did not receive, they often turned to alternative methods of pain relief such as alcohol. The absence of any other options could jeopardize the patient’s health further. “A pain specialist can provide an objective assessment of the patient’s needs. Alternatives can be explored so that the patient can live with chronic pain, and the patient can decide whether those (alternatives) are appropriate for herself or himself.”

Patient Education of EOL Care

The next main area with need for improvement that was found in responses was patient education. Four interviewees included this in their response. A hospice interviewee commented on the importance of education and the sharing of information. Sharing stories of experiences with palliative medicine and its benefits was essential to education and open discussion. “Education is so huge. ...One of the biggest challenges out on the field in remote reservations was the fear that of Natives to speak openly about cancer. If they spoke about the cancer, it would invite it. ...That’s the biggest challenge for Native populations, that if they had someone who died from cancer, they don’t speak about it again. ...”

Financial Support

Four interviewees included “financial support” as an area of concern that needed more attention. The interviewees elaborated on the importance of funding to provide specialized palliative care needs, and sometimes, the patient’s insurance status could dictate the type of care he or she received.

“...They’ll need specialized oncology care, but are they eligible and fall under contract care? Is this health care rationing? Contract care is used in mostly acute situations, and there is a certain limit of funding that’s dispersed to the tribes.” The limited resources could also interfere with being able to afford basic necessities. Another interviewee noted, “People don’t have money to pay for food. Sometimes, they need to get insurance authorization, and get other ways to pay for it.”

Psychosocial Support

Three interviewees included “psychosocial support” as an area of concern that needed more attention. Psychosocial support included more social support for patients and their families, and counseling for families. “Support if there’s no one (there for the patient.) (It is important) Getting reconnected with families for people living on the streets.” Another interviewee noted the importance of caring for the family as well, as the patient made medical decisions as a family unit. “Psychological support for the patient and family. A person with family is not alone. Decisions are not made per se as an individual, but how am I going to affect the family? How am I going to do this and how is the family going to do this? When you get the bad news, it’s not just the individual that has to deal with it. It’s the family too. ...”

Bereavement Support

Two interviewees specifically addressed bereavement support as an area of concern. Although this was a type of psychosocial support, these interviewees acknowledged the need to support the patient and family during the grieving process, or used the term, “bereavement support.”

Cultural Awareness

Two interviewees mentioned cultural awareness on the part of AI patients, and on the part of a care provider. One interviewee elaborated on the importance of cultural awareness as well as an awareness about the resources available. “Cultural awareness, awareness on the side of the patients, and provider awareness. ...Awareness of services available to patients, cultural awareness, and awareness of the hospice care providers. Awareness that hospice is an option for primary care providers. ...Planning needs to be better, but that’s a cultural issue. How do you plan for someone’s death when they don’t want to talk about it?”

Initial Discussion with Providers

Two interviewees included provider education as part of their responses. They emphasized the need for providers to be educated on palliative and hospice care, in order to provide better education to patients. The timing of the discussion should be more prompt, and should occur as early as possible to ensure comprehensive care. “I think preparation for EOL care could go better if doctors talked to families sooner about prognosis, not just Natives but all around.”

Spiritual Care

Two interviewees included the need for better spiritual care and understanding. This was another barrier for patients in accepting care. One interviewee commented on the importance of having a Traditional healer available to assist with the grieving process. “The client should be offered a Traditional healer practitioner to assist them through grieving process, to ask for comfort and knowledge or where the person has passed, just having blessings through the family. ...A practitioner can interpret dreams and can process through that (family member’s dream) and what they’re seeing.”

A hospice interviewee elaborated on the need to educate hospices about tribes’ spiritual beliefs. A hospice organization’s limited knowledge about spiritual beliefs could potentially hinder patients from joining a hospice service. “(The lack of education about spiritual beliefs) is a huge barrier when it comes to enrolling people, and when the nurse goes out and doesn’t understand their culture and spiritual needs. They just won’t come on service. ...If you sat down and explained to them and understood what their tribes believe in, you just need to listen and listen to what they need. We often go in there and tell them what they need. But really, we need to listen and let them open (up) to you.”

Availability and Access to Care

This was a broad category, in that two interviewees addressed different aspects about availability of care. For one interviewee, access to care meant availability specifically on reservations, whereas another interviewee saw the generalized need for more comprehensive care for both urban and rural AI populations in hospitals and on the reservation. One interviewee believed accessibility to inpatient services for both urban and rural patients could decrease ER visits. Another interviewee spoke about the access to care specifically on reservations and in remote areas. On the other hand, in an urban setting, case managers can work to get someone connected to palliative or hospice care.”

Networking Among Tribes

One interviewee mentioned a need to increase networking among tribes in order to coordinate better care for patients. “...More networking with other tribes in the area to make sure patients can go home to their reservations and get their services there because often our older patients don’t want to stay in Phoenix and want to go back to where they’re from.”

Transition of Care from Hospital to Home

One interviewee mentioned a need to improve transition of care from hospital to home. Another commented, "I think the transition back home back to the community is important because you want to make sure that the patient is getting the appropriate support and resources they need when they're back in the community. Sometimes, that doesn't happen. That puts an additional challenge or burden on the patient...."

Travel

One interviewee believed travel was an area to improve care. Commuting between their homes on the reservation and a medical facility in the city could be a constraint to receiving care. "A lot of patients come from a distance. Sometimes, they're seen in a clinic, and yet, if they're scheduled for chemotherapy, they need for a place to stay. It's a long drive for them, and it's not safe for them. It's tiring, and they're sick the entire time. That puts a lot of stress on them."

Advance Directive Planning

One interviewee mentioned the need for better advance directive planning, specifically the medical power of attorney. "Not a lot of them have a MPOA (medical power of attorney). ...Not a lot of them have had these conversations. A lot of times, the families have to guess...."

Question 14: What are your suggestions for the future of EOL care services? What improvements, if any, would you like to see and believe would benefit AI/AN patients and their families?

The following is a compilation of suggestions from interviewees:

"Having palliative care on the reservation."

"I think there's a lot of community teaching that needs to happen on end of life. We need to communicate community health issues, EOL care and what's available to the people, how else they can get help other than being in the hospital. ...More education in the community and teaching...."

"...(I would like a) more comprehensive program focusing on palliative care and making sure that they're getting appropriate pain management, and more culturally competent care, more networks between tribes and us. Hopefully, the hospice programs can also provide culturally sensitive care, and network with hospices. ...Having providers and other staff know what other services can be offered so they can talk to patients about it."

"Making more awareness. Educate them (patients and providers). You have to ask Traditional healers. Having resources, and having something available or a questionnaire to patients when they elect hospice (a questionnaire that asks do you know what hospice means and are you familiar with it?)..."

“Having a very strong case management program, making sure everything’s in place before the patient leaves, before they go back to their community. Support for families because if there’s an end of life and the patient goes back to their family, it can be emotionally draining and challenging. The family doesn’t always get the support that they need and don’t fully understand what’s going on, and what resources are available to that patient.”

“If we could have a palliative care team and resources to develop a palliative care team or service, that would be extremely effective rather than the fractionated approach. It would be more effective because you tend to gain expertise and skills relative to your focus. ...The communication would be better. The patients would have access to care in a more efficient manner. ...I’d like to see...a concerted palliative care program where we have a team that can and does work with patients across disease states. ...(There’s also) the need for hospice on the reservations.”

“(I would like to see) education and helping to define a standard way for this care to be offered because that’s the only way for things to get done. There has to be money behind. It’s forgotten and people don’t think about it. But it’s still a real need. Those that have health insurance are very fortunate.”

“To provide as much care as we can for AIs, regardless of resources. To provide the same amount of care for all; it can’t be everything for everyone.”

“What would be really great is if several units encompass Traditional healers in their practice, more on healing than on end-of-life. ...(It would be nice to see) grief counseling for families and clients and not to instantly medicate them, but to go through the grieving process with a Traditional healer or practitioner, someone to go through healing with.”

“...Writing my experiences down and sharing them with other people. Writing things down- my experiences with all these Native patients- the people working with them and what I’ve learned from them. and having it in written form and having people learn from that.”

“Patient education, pain management, and meeting their spiritual needs.”

“I think Medicare has very well defined qualifications for hospice care. ...Palliative care does not have that, and has a much shorter time frame. My hope is that we can extend the length of a palliative program. We think of the 2-3 months before they might qualify for hospice. It would be nice if those palliative identifiers would be as clearly defined.”

Table 1: Interview Questions # 1-4 and Responses Given as Percentages

Question	Yes (%)	No (%)	It Depends (%)
Do you think that there is an organized	15.4% (2/13)	38.5% (5/13)	46.2% (6/13)

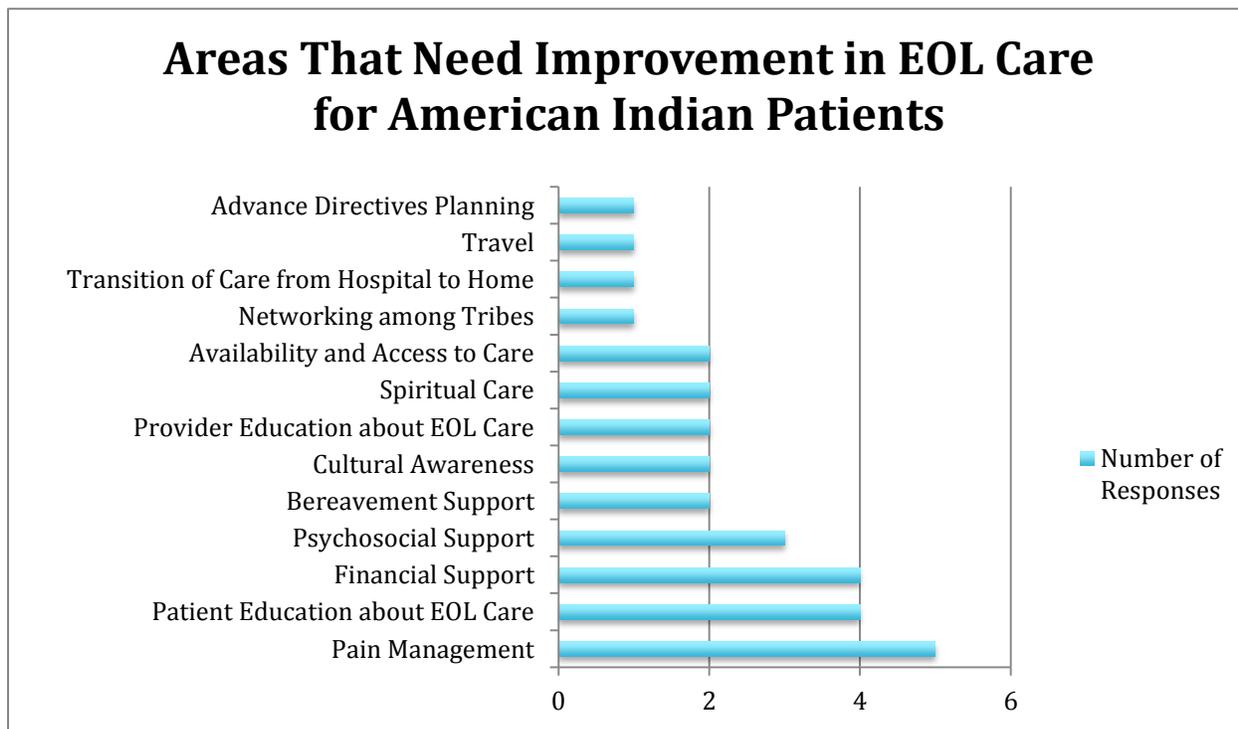
structure/system of delivering end-of-life (EOL) care services for patients who opt for them?			
At your institution, are there currently any formal end-of-life services or programs that are used by AI/ANs?	30.8% (4/13)	61.5% (8/13)	7.7% (1/13)
At your institution, are the EOL care services culturally appropriate?	100% (13/13)	0	0
Are the services accommodating for cultural practices (ie- traditional medicine, rituals, healers)?	92.3% (12/13)	0	7.7% (1/13)
Do you receive any cultural awareness or competency training specific to AI/AN cultures from your institution?	84.6% (11/13)	15.4% (2/13)	
Do you think the (cultural awareness or competency) training is sufficient?	45.5% (5/11)	45.5% (5/11)	9.0% (1/11)

Table 2: Interview Question #6 and Responses Given as Percentages

Question	Yes (%)	No (%)	It Depends (%)	I don't know./No clear answer. (%)
Are there programs or home health care agencies available on their reservations or in their home communities?	15.4% (2/13)	30.8% (4/13)	38.5% (5/13)	15.4% (2/13)

Table 3: Interview Question #7 and Responses Given as Percentages

Question	Yes (%)	Yes, but we can do better (%)	No (%)	It Depends (%)
Do you think that the current services are meeting the needs of AI/AN patients?	4/13 (30.8%)	2/13 (15.4%)	4/13 (30.8%)	3/13 (23.1%)

Table 4

Discussion

Existence of Current Structure and Services

Based on the interview transcripts above, there was a difference of opinion among the interviewees about whether there was an organized system of delivering palliative care services to the AI population. This reflected a possible need to improve communication among different organizations, but also a need to better define the current structure of EOL services. The majority of the participants (6/13, or 46.2%) answered that an organized system existed but under certain circumstances. The five variables mentioned were location of medical facility, the tribe, the IHS service unit, a patient's resources, and a patient's tribal support and connection.

According to some responses, there was an organized system at the medical facility in Phoenix. The medical facility offered EOL services but not a formal organized structure. Every patient's case was handled individually by a multidisciplinary team.. A medical provider, case manager, or spiritual care provider began the discussion with advance care planning, using The Five Wishes document. It consisted of an in-depth discussion with a patient and his or her family about the patient's medical power of attorney, preferred or declined medical treatments, comfort care, the manner or delivery of care, and disclosure of information to friends and family.

At other facilities and on the reservation, however, interviewees agreed that there was variability between sites. Most did not comment on specific differences or deficiencies of any program. However, there was speculation that reservations lacked EOL services and hospices, and therefore, might not be able to participate in any organized system yet.

Furthermore, participants noted variability among tribes, and among patients' individual connection with tribal resources. Each tribe had its own belief system and traditions, and individuals varied widely on how they adhered to a tribe's traditions and practices. Each tribe had its resources that it allotted to members, but each individual depending on whether they were "connected" with the tribe's resources might benefit differently. A hospice interviewee noted the organization of care depended on the patient's support from the tribe. If the patient were connected with the tribal community resources, there would be more guidance and help for that patient to find the best services that fit them. If they elected for hospice, they could be referred more easily. The tribal services also assisted patients to apply to ALTCS (Arizona Long Term Care System- a Medicaid funded program for individuals who are 65 years or older, blind, or disabled and need ongoing services at a nursing facility level of care), and if they didn't qualify for ALTCS, they could apply for funds from the tribe. If the patient were in the hospital but were not connected to tribal resources, then it would be more challenging to set the patient up with hospice.

For participants who did not believe there was any organized system of EOL care, their responses applied broadly- both within and outside of their institution. One participant said that the care was fractionated to the extent, where there was no cohesive system. Each patient was cared for on a case by case basis. The primary care provider identified the patient in need and referred the patient to a case manager, but no one went through a formalized EOL program. There were no policies or guidelines to initiate care.

Some interviewees believed attaining an organized system was unachievable due to barriers of belief systems and cultural diversity of each tribe. Many AI patients had a difficult time talking about dying and death, and therefore EOL care, due to their beliefs. In some cultures, discussion of death was believed to bring death upon the patient. Therefore to some interviewees, without a discussion, it was a challenge to engage patients and their families in EOL care and establish a culturally appropriate system. Many patients also preferred to return to their community on the reservation, which required a system that incorporated rural patients. Another interviewee said it would be very difficult to create a system due to the "wide and varying beliefs" of each culture. Lastly, one interviewee explained that the medical community and the patient both required more education about what hospice was, before any formalized program could begin. Hospice and palliative medicine were still new concepts for patients and providers. The word "hospice" still had a strong connotation of death. Non Native providers might also be intimidated to initiate the conversation because they lacked knowledge about cultural beliefs and differences, and as a patient with certain beliefs, the patient might not want to participate in that conversation.

Most participants (61.5%, 8/13) said there were no formal EOL services that were currently used at their respective institutions. A key word in the question stem was “formal.” For most interviewees at the medical facility, the consensus was that while there was no formal program, there was an understood process of care and referral. The primary care provider could provide informal palliative care at the clinic that includes services such as symptom management, pain management, and mental health. If the patient were interested in hospice in an outpatient or inpatient setting, the PCP or a hospitalist would submit a consult with case management through the electronic health record. A case manager and chaplain would then discuss palliative care options with the patient and family before a decision was made. If hospice or palliative care were elected, case management would find the appropriate services, the company and payer for that patient and set them up with an agency. The patient, however, might have an easier time accessing these services depending from which department they received care. There was variability. Providers from certain departments might be more well-versed and familiar with the referral process and what EOL care entailed. The PCP might be the only one that provided palliative measures but to a more limited extent.

Another interesting aspect about the informal practice of palliative medicine was the role of a patient’s insurance status and resources within IHS. Palliative care could be covered under Contract Health Services (CHS), Medicare, or AHCCCS. CHS was a tribe-specific insurance that covered medical care that could not be provided through IHS or the Urban Indian Health Program. It could be used at hospitals or with providers who were in a contract with IHS. The CHS funds however were limited each year for tribes, and were distributed on a need basis. This had evolved over the last 2 to 3 years, where previously only priority one (life or limb) services had been covered by IHS. If a patient were to elect palliative care, they either had Medicare, AHCCCS or CHS eligibility. If the patient had none of the above, he or she would often go the Emergency department for all their EOL care.

Hospice interviewees had varied perspectives on whether there was a formal program or service at their agencies. For one interviewee, the process of how a patient was referred to their agency was also informal, but understood. The public relations (PR) coordinator was the first contact. The PR coordinator made an initial assessment to see if the patient was eligible. The admissions nurse coordinated the consent forms and paperwork. Afterwards within the next five days, there was a team meeting with the patient, nurse, social worker, hospice aide, and spiritual care coordinator. The team and patient with the family completed assessments and decided upon the plan of care. There were several teams that covered Maricopa County. The patient’s residence determined which team went out to meet that patient. These teams worked at skilled nursing facilities (SNFs), group homes, assisted living facilities, private inpatient hospice units.

Another hospice interviewee noted that there was no specific formal program used by American Indians, but there were programs in place. “Our Native American population on and off the reservation uses ... services to the same extent that any other ethnic group does.” Once the patient finished the process of referral, this specific hospice agency offered a palliative care program which covered 6 months prior to hospice care, the period when patients were trying to meet the Medicare requirement. These patients then could transition into their hospice program. They also offered direct entry into the hospice program

Cultural Appropriateness of Services and Training

All participants agreed that their EOL care services were culturally appropriate. Many interviewees commented on how diverse the American Indian populations were. There were over five hundred tribes, each with a unique culture and with unique traditions and beliefs. It was difficult to accommodate every patient’s individual traditions, such as finding a medicine man or woman from a specific tribe. Often, patients had options, and providers accommodated as best as they can. Twelve of the thirteen interviewees believed their services accommodated for cultural practices. Patients could request that their Traditional and healers or practitioners visit with them at their healthcare facility. However, one participant highlighted the challenges of incorporating some cultural practices. For instance, the ritual of smudging, which involved the burning of elements (ie. sage, cedar and tobacco), created concern as a fire hazard, particularly in high acuity patient care areas where the use of oxygen is common. Other traditions incorporated use of other plants and herbs but the interactions with other medications were not well understood. There could be a risk of adverse reactions. The health care team and organization accommodated these rituals as best as possible with attention to the safety for the patient and other patients in the hospital.

Providers who interviewed have a lot of experience working with different tribes, and they were sensitive to the individuality of each one. One interviewee commented, “We look to past knowledge and situations and what that family’s expectations were. It’s all individually based.” Another interviewee said, “Let the patient direct you in their care. There’s always someone to go to because this is intertribal and there’s a lot of sharing. It’s not really an issue, even though that there are all these different tribes are here.” The medical facility and the local hospice care agencies either had staff members who were AI/AN, or who had years of experience working with the AI/AN populations. The cultural sensitivity and appropriateness of the care helped to establish the trust and rapport between patients and providers. One interviewee said, “If we don’t address the cultural aspects for American Indians, then our patients won’t be receptive to receiving care. ...If you don’t have that (high level of trust), it’s guaranteed that patient’s quality of life and care will suffer.”

A recurring theme in discussion with participants about cultural accommodation was the importance of family and community in most, if not all, AI cultures. When a patient made a decision, oftentimes the

decision was made as a group with input of multiple family members or even a community on the reservation. Sometimes, the patient would not make the decision. Instead, it might be one spokesperson from the family, like an older brother or spouse. The journey or path from life to death was a collective experience for patients and their families. One interviewee noted that groups in a room included up to 100 to 150 people when the patient was in the final hours of life.

Providing culturally appropriate care required continuous education. Eleven of thirteen interviewees said that they received cultural awareness training about AI/AN cultures from their institutions. At the medical facility, training was usually given as part of the orientation for new employees. Some interviewees said that there was no ongoing training, but others said that there were mandatory yearly online trainings for certifications. These trainings were not specific to EOL care or to only American Indian patients. They were general cultural sensitivity trainings. At a hospice agency, training included a yearly seminar that taught about cultural sensitivity, where about a quarter of the material was about American Indian cultures, as well as local cultural events. However, for another hospice agency, there was no formal cultural awareness/sensitivity training.

When asked whether the training was sufficient, about half of the responses believed that it was and the other half believe it was not. For those who did not believe it was enough, they recommended that training could be more frequent and that performance evaluations should incorporate cultural competency as a skill to be evaluated. Many interviewees emphasized that cultural competency was an ongoing learning process, and that it was difficult to learn the cultures of all tribes. Sometimes, training might focus on a single tribe and its traditions, but what was applicable to one tribe was not applicable to all tribes or moreover to individuals. Additionally, they emphasized that it was important to have an open mind, mindfulness, and willingness to learn when talking with patients. Learning was derived from talking to staff, patients, and communities, sharing stories, asking questions, reading, and attending conferences. One AI interviewee said that her background also shaped her cultural awareness. Her competency already started from her upbringing. This was likely true for most of the AI providers who had grown up in their cultures. The sensitivity and awareness to AI/AN cultures and differences had been instilled in them, whereas non-AI/AN staff might need more training and experience. A question asked during the interview by a participant was “What is cultural competency and what do we want to do with it?” The purpose of cultural awareness was hopefully, to provide care in the most respectful and sensitive way.

Comprehensiveness and Availability of Current EOL Care

At the medical center, the types of EOL support services that were offered included symptom and pain management, advance care planning, bereavement support, spiritual care, ethics consults, social services, behavioral health and accommodations for cultural practices like talking circle meetings, sweat

lodge, and Traditional healers. Symptom management was offered inpatient if the patient became hospitalized, and in an outpatient setting of the clinic. Pain management was usually offered but not specifically tailored for palliation or EOL care. Pain management could be done by both anesthesiology and non-anesthesiology medical providers. The decentralization of care could create confusion and difficulty navigating care. As a result, it often created issues for creating substance abuse and narcotic abuse disorders, as patients sought other ways to diminish pain.

At the medical facility, advance directive planning was often completed using the Five Wishes document, as mentioned above. Bereavement support, grief support and behavioral health were offered but limited due to limited personnel resources. The bereavement support was not offered as a formalized service. Spiritual care was often offered through chaplaincy. If the patient wanted blessings or healing ceremonies, there were Traditional practitioners who could assist them. For many patients, they already had Traditional healers, who came and provided spiritual and cultural interventions such as blessing and ceremonies at the request of the patient and/or their family..

Social services helped coordinate the care for the patient and family. For some clients, it was important to have the burial performed within a certain number of days of death. Social services tried to accommodate the patient's family's request as best as possible, and coordinate arrangements. Another area of care provision for social services was the transition of care from the hospital to the patient's home community.

When interviewing hospice care agencies staff, their services were very similar to those offered at the medical facility, but more specialized towards EOL care. Services included pre-bereavement and bereavement support, volunteers who provided services at the home of the patients, spiritual care, advance directive planning, home health, pain management, and palliative medical treatments such as chemotherapy and radiation. At one agency, EOL symptom management was provided by a team of specialists which included a clinical resource nurse, social worker, respiratory therapy team, and wound care team. They also had inpatient hospice units that offered respite stays for patients to support the well-being of their caregivers.

When asked where the majority of patients received their EOL care if not given at the interviewees' home institutions, most interviewees outlined the complexity of the web of care for each patient. The referral process was very individualized. Where the patient sought care depended on multiple factors; they included a patient's reservation location, resources and insurance eligibility, and preference to go home or stay in a hospital. For patients who were in or near Phoenix, most interviewees said that these patients went to local hospice agencies. These referral hospices might change from time to time. There were over 100 hospices in Phoenix, and most hospices work with group homes. Preference to die at

home or stay in a hospital varied depending on cultural beliefs. The insurance status, CHS eligibility, and whether the tribe would cover payment of palliative care costs all factored into the decision of where a patient was eligible to receive care and how extensive the access to care was...

For the interviewees who worked for a hospice care agency, most of their patients were within the Maricopa County. There were a few health care agencies located on reservations that were run by the tribe. The providers close to or on reservations needed to be contracted with IHS in order for some hospice care agencies to service them. For one interviewee who worked under a hospice care agency with the AI population for 15 years, the individual expressed their impression of a shift in thought among patients, and a growing acceptance for hospice workers to come to homes over the past 5 years. The younger generations were more open to non Native works providing EOL care, although there was still a preference for Native nurses. If patients did not elect or are not eligible for any hospice, the alternatives included skilled nursing facilities, which were split into a long term care, dementia care, and hospice care unit, assisted long-term care facilities, and group homes.

Many interviewees were not aware of the locations of hospice agencies on or near reservation communities. However, they knew that patients often picked the closest hospice to their home if they wanted to return to their reservation. The patient's PCP coordinated the EOL care in the community. One interviewee mentioned that there was a lack of resources on most reservations to establish hospice units or home health care. For palliative care, most patients on reservations went to group homes or SNFs, or went home where unfortunately, a lot of burden of care was upon family members. Home health nurses or community health representatives (CHRs), if they were available, provided what they could for patients at their homes. Home health care agencies were often not found on reservations.

Areas of Improvement in EOL Care

Interview participants were split about whether the current EOL services were meeting the needs of AI patients. Four of the thirteen said yes, that we were meeting them. Two said yes, but that we could improve. Four of them said no, and the last two said that it depended on which populations you were talking about. The overall thought, however, was that the medical community was meeting AI patients' needs to some extent, but there were areas that required improvement. The facilities did the best that they could with what they had. However, there was a need for more resources to establish better care.

The four main areas identified by participants that needed improvement included pain management, patient education about EOL care, financial support, and psychosocial support. Most interviewees recommended having a specialized pain management clinic or a palliative care physician. There was a need to have specialized pain care for patients with chronic pain who required long-term management.

This was especially important because when patients did not have adequate pain medication, they sought more dangerous and addictive alternatives. Another recommendation was to have a hospice unit at the medical center in order to allow patients who needed longer stays and comfort care. Medical centers that served only AI/AN patients provided a familiar environment. If there were a hospice unit, the hospital could have more unified, cohesive delivery of care, instead of offering resources through different programs and departments by piecemeal.

Another main area for improvement was patient education about EOL care. Many providers mentioned the newness of palliative care in the past 20 years, but the definitions and awareness about palliative medicine were still in its infantile stages. There was a lack of knowledge of what EOL and hospice care was. There were also strong cultural beliefs that might hinder patients from having discussions about it. More education and outreach about hospice was the first step to diminishing that fear from patients. Sometimes, services were available, but might be underutilized for those reasons. On the reservations, community health representatives and Native nurses might be the first step to achieving this. They had established presence on reservations, and they also had the cultural awareness to establish rapport and trust with communities. Their relationships might make it easier to open that conversation about EOL care.

Financial support was a concern that required more attention. Financial support applied to multiple levels, from institutional resources to basic monetary support for food. A need for financial aid was true from the level of the individual patients to large medical centers. More money was needed to fund inpatient hospice and hospice agencies on reservations. The lack of resources on reservations created challenges to establish any care center or personnel to provide home health. As a result, patients did not benefit from services if they returned home. Building an organized network of palliative and hospice medical care required resources to build centers that were accessible to both urban and rural populations, qualified personnel to work there, and communication among these centers and hospitals. Funding could also help patients individually who struggled with the costs of care and living. Patients and their families could benefit from financial aid on travel between their homes and urban centers and agencies.

Lastly, psychosocial support for the patient and family was an area of need. The “majority of Indian families are co-dependent.” Families were usually involved in patient decisions and care. There was a need for more support throughout the end of life grieving process. Counseling and behavioral health services were limited. Medical centers might benefit from a more comprehensive behavioral health program. The lack of resources affected grief counseling and bereavement support. One interviewee noted the high number of patients who struggled with the grieving process, especially when their therapy was shortened, and could subsequently have depression and/or substance abuse. Having psychosocial

and behavioral health issues could cyclically affect the patient, family, surrounding community, and their livelihoods.

Other areas of concern that had been mentioned by interview participants included bereavement support, cultural awareness, provider education about EOL care, spiritual care, availability and access to care, networking among tribes, transition of care from hospital to home, travel, and advance directives planning. These issues varied from site to site and from participant to participant.

Strengths and Limitations of this Project

A strength of this project was the fact that interview participants were from different institutions. This allowed a comparison of how different institutions practiced and delivered EOL care to AI patients. Another strength was the open-ended questions in the survey allowed everyone to interpret the question in their own way and respond using their own personal experiences in this field. It allowed wide variation in the responses and at the same time, gave a diverse picture of what was happening.

The weakness of this project was its lack of power in the small sample of participants (n=13). There might have been even more varied perspectives, had there been more volunteers. Recruitment was difficult, as many staff members at local hospice care agencies either did not have time to interview or they did not have much experience working with AI/AN patients. Another weakness was the interview data was extrapolated from the transcripts, which might only show a fraction of the interviews. The select texts were chosen based on their key points, eliminating repetition.

Conclusion

After reviewing the data from this project, the following were recommendations about the direction of EOL care in palliative and hospice medicine. From the interviews with participants, there was an organized system that was still developing, in terms of delivering EOL care to AIs in Phoenix. Multiple factors influenced this structure, and there was no easy and quick solution to building a system that worked effectively and efficiently for all populations. It would take time. There were many variables that needed to be addressed on different levels. At the base, you had organizations like big medical centers that had gradually developed understood processes for attaining care. However, due to decentralization of care and diversity of cultural and tribal representation, medical facilities were limited in their knowledge of how other medical facilities operated. There would be a benefit to an overarching network that encouraged communication about programs and policies. There needed to be fluidity and communication within the system. Having formal guidelines and policies and procedures about palliative and hospice care for each

institution could help guide decision making for providers, and help open discussion between patients, their families and the healthcare team.

Currently, there were informal processes in place from how a patient without a primary care provider could enter into the referral process to how a patient was assessed for hospice care. Providers and case managers knew what to do but it was still a very fractionated system. Teams from certain medical departments could initiate the referral, but what if that patient was on neither of those teams? It was easy for patients who need EOL care to fall through cracks. What would be beneficial was for these patients to have a palliative care team and clinic. Then, medical providers who might not have any background in palliative medicine would not have to take dual roles as a palliative care physician. Instead, they could send patients to a physician who was specialized in EOL care, and could provide all the EOL services at one place.

There was a need to also establish more care centers closer to reservations. Many patients relocated closer to Phoenix because many of the facilities were in and around the city. If patients decided to seek care on their reservations, there were very few resources for them, and rarely, there were care centers available. Additional funding to establish skilled nursing facilities, assisted long-term care facilities, group homes, and home health agencies on reservations was needed and these entities would then form support a network between urban and rural sites, and for urban and rural populations.

It was agreed that culturally appropriate care was delivered to patients to the best of the ability of providers, and with the resources that they had. Developing cultural awareness was a life long learning process, and ultimately, competency might never fully be achieved. But keeping an open mind and being sensitive to the beliefs and practices of a patient was the most important. No formal training or class could teach a provider this. It developed over experience with patients and their families. For the most part, cultural practice and customs were accommodated, as long as the safety of the patient and the hospital was maintained. A recommendation was to promote cultural awareness through more education for providers. Although most would come from experience, it was always beneficial to have workshops and trainings that incorporated AI cultures. If resources permitted and tribes allowed, meeting people of local tribes on reservations and learning directly from those communities were another way to learn. The goal would not be to learn the culture of every single tribe, but it would be for enrichment and enhancement of cultural education. Lastly, feedback through quality improvement surveys and evaluations from patients would also provide some insight as to whether they thought the care was culturally appropriate.

Resources and funding were often the limiting factor if an agency did not have a service or support. Interview participants highlighted areas of concern in EOL care, and the solution to most of these issues

required more funding. For financial support, it was a matter of attaining more funds at all levels and applying for more money. An open forum between tribal leaders, intertribal advisory groups, representatives from the Indian Health Service and hospice agencies about the allotted funds for members' palliative services might also be beneficial. Once resources were available, making sure that all stakeholders were aware of all resources available to them was critical.

Pain management, patient education about EOL care, financial support, and psychosocial support were the top four areas that needed improvement. The recommendation was to establish a pain clinic that could provide palliative care.. Inadequate pain control could lead to multiple emergency room visits, and substance abuse. A patient's quality of life could severely deteriorate due to pain. As for patient education about EOL care, our recommendation was to promote outreach through CHRs and nurses within American Indian communities. People who had established rapport, could help teach members of the community about what palliative and hospice care was and invite others to join the discussion, so that dying and death conversations were done in a culturally appropriate and sensitive manner. Lastly, there was a need to improve behavioral health programs and make sure that they had a presence at urban medical centers and near reservations. Support for patients and their families was important to their quality of life now and in the future. Addressing bereavement and possibly depression for loved ones after someone dies was best provided and received through a multidisciplinary team approach..

As stated above, these were the recommendations to possibly drive the field of EOL care forward. It was a very challenging and complex field, with many barriers, both financial and cultural. There was a big need for better communication among each institution, to facilitate an open discussion about establishing a network of care for patients and their families. In addition, more research was needed in the field of palliative medicine specifically in the AI/AN populations. There was limited literature on this topic, and in order to better understand how to serve these patients, we needed larger and more in-depth surveys and studies.

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