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## “All My Tears Were Gone”: Suffering and Cancer Pain in Southwest American Indians

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### Abstract

**Context**—Although minority patients with cancer pain are more likely to be undermedicated for cancer pain than non-Hispanic Whites, little is known about the experience of cancer pain in American Indians (AIs).

**Objectives**—To describe the experience of cancer and cancer pain in a sample of southwestern AIs.

**Methods**—Ethnographic interviews were conducted with 13 patients and 11 health care providers, caregivers, and community members; two questionnaires were used to collect demographic and pain data.

**Results**—Barriers to pain control among AIs included difficulties describing pain, a belief that cancer pain is inevitable and untreatable, and an aversion to taking opioid pain medication. Prescriber inexperience also was cited as a barrier to pain management. AIs described a strong desire to protect their privacy regarding their illness, and many felt that expressing pain was a sign of weakness. The inability to participate in spiritual and cultural activities caused AIs distress, and some discontinued treatment or missed chemotherapy appointments to engage in these activities.

**Conclusion**—Results revealed new knowledge about the cancer pain experience in AIs. The observation of the close relationship between treatment compliance and the patient’s ability to participate in ceremonial and spiritual activities provides new insight into the problem of incomplete cancer treatment in this population. The finding that AI patients have a multidimensional conceptualization of pain will assist clinicians with obtaining more detailed and informative pain assessments.

### Keywords

Cancer; pain; pain management; American Indians; Native Americans; suffering

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### Disclosures

The authors declare no conflicts of interest.

## Introduction

The incidence of cancer in American Indians (AIs) is lower than in non-Hispanic Whites and other minority populations, but AIs are more likely to be diagnosed at later stages of disease and to have poorer outcomes (1). Most people diagnosed with cancer will experience pain in the course of their disease, whether from surgery, procedures, treatment, or the actual tumor (2–5), and as many as 90% of people with advanced cancer report pain. Minority populations are more likely to be undermedicated for all types of pain, including cancer pain (1–6). Patient fear of addiction, poor management of undesirable side effects from opioids, and a lack of practitioner knowledge of addiction and pain management contribute to undertreatment of cancer pain (7–9).

In recent years, attempts have been made to better understand and alleviate cancer pain (9–19). Although recent pain research has included AIs (20), the experience of AIs living with cancer pain is still poorly understood. In the few published studies on pain in AIs, barriers to successful pain management include prior negative experience with cancer and cancer pain treatment, belief in traditional medicine to relieve pain, lack of integration of traditional healers into the medical management plan, fear of addiction, side effects of medications such as sleepiness, and limited beliefs in the efficacy of drugs to relieve pain (11,17–19). Unrelieved cancer pain can result in the loss of hope and social isolation (18). The purpose of this article is to describe the experience of cancer pain in a southwestern population of AIs and explore the insights and perspectives of health care providers related to the management of cancer pain.

## Methods

The perspective of critical realist ethnography was used in this qualitative study to build an understanding of both the cultural setting in which the informants received their care and their experience with cancer pain. Because culture has been shown to influence how individuals express and experience pain, and AIs have historically been an oppressed culture, it was important to approach the phenomenon with an awareness of how the underlying social constructs of oppression influence daily life and health care in this population (21).

## Sample

The sample included AI patients with cancer and key informants, specifically health care providers, family caregivers, and community members. All informants were English speaking, able to read, and aged 21 years or older. The AI patients with cancer were limited to individuals who had been diagnosed with or treated for cancer within the past year. The provider and caregiver informants were selected based on their ability to contribute specific insight regarding the treatment of cancer pain in AIs. The data from the health care providers, family members, and community members were used to provide context to assist in the interpretation of the data from the informants with cancer.

## Recruitment Procedures

Purposive sampling and snowball techniques were used to recruit the sample, taking advantage of the expertise and insight of key informants to gain entry to the community (22–25). Recruitment took place in an urban oncology clinic not affiliated with the Indian Health Service (IHS) and in one tribal community. Interviews took place at a location determined by the informant, with most typically taking place at the oncology clinic at the time of chemotherapy appointments. All informants were residents of New Mexico, and all AI

informants were members of New Mexico tribes. AIs from more than one tribe participated in this research.

### Data Collection Procedures

Qualitative data were collected through interviews, field notes, memos, informal conversations, and observations. The interviews were open-ended, semistructured, and either digitally recorded or recorded through handwritten notes, the latter because many AI informants refused audiorecording. Two questionnaires were used to collect demographic/medical and pain data. The questionnaires were employed to triangulate data around the phenomenon under study, informing interpretation and enhancing the trustworthiness of findings (25). The Brief Pain Inventory-Short Form (BPI-SF) (26) measured pain location, medications used, intensity, and the degree to which pain interfered with daily life.

Data saturation, an issue that arises with a smaller sample size, was achieved through member checking. During member-checking interviews, data analysis was confirmed, and informants were asked whether the findings brought to mind any other related topics that had not been uncovered during the primary data collection and analysis process. Informants were clear in their confirmation that the findings were representative of the experience, and no new concepts or ideas were brought up during these meetings. During member-checking interviews, informants did observe the absence of the most traditional AI voice in the findings, and discussions regarding those experiences were included in the analysis.

### Data Analysis

Transcripts of the interviews were analyzed using descriptive qualitative methodology (27,28). Data were first reviewed as entire transcripts and then were analyzed through a process of immersion, synthesizing, and recontextualizing (28). Following immersion in the data, data were coded and categorized into themes and patterns. Visual mapping techniques were used to illustrate the data. The process of drawing multiple maps of these concepts, or conceptual clusters, helped to develop a better understanding of cancer pain in the context of cancer and the AI culture. This iterative process led to deeper abstraction of the data, as the visual representation identified the intricate relationship between themes and related concepts (29).

Field notes and memos were integrated into the interpretation of data (28). Informants validated preliminary results to establish authenticity and trustworthiness of the findings, and new findings from the validation process were incorporated into the analysis (30). Additional review of the data and coding were provided by an external expert, who examined data from interviews and emerging categories and themes to assess the credibility of the analytic process and to verify findings. Because “interviewing and observing is an evolving process” (30, p. 110), the research team maintained dependability through constant memos and notes documenting the process of data collection. The BPI-SF scores were analyzed using descriptive statistics. Based on findings from earlier work (31), data from the BPI-SF were compared with the qualitative interview data, with attention to confirmation or discrepancy between the reported pain and the impact pain had on the lives of the informants.

### Methodological Rigor

Qualitative research can be assessed and the results can be trusted to reflect the reality as understood by the underlying philosophy of the research through discussion of the credibility, transferability, dependability, and confirmability of the research process. Credibility was established through informant observation, triangulation of the data collected, and heterogeneity of informant selection (30,32). Transferability occurred through

the inclusion of thick description of the data to allow the reader the opportunity to assess generalizability of the findings to other, similar AI groups. Dependability was addressed by ongoing review of the data and findings through consultation with experts and member checking, where appropriate. Confirmability was achieved through the careful maintenance of an audit trail (32). Although cultural reasons precluded audiorecording of the interviews with AI informants, notes were taken during the interviews and transcriptions of the notes, with included field notes and observations, were made immediately following the interviews. Field notes included interactions, actions, and the researcher's (first author's) subjective state during interviews. Thoughtful consideration of the researcher–informant relationship was included in field notes in an effort to isolate any effect from this relationship (32).

### Protection of Human Participants

Recruitment took place through a third party to protect the identities of potential informants and to avoid coercion. Prior to contact with any potential informant, a health care provider or lay health care worker first contacted the person to ask permission for the researcher to contact him or her. During this initial contact, the clinicians gave potential informants an informational brochure, introduced the proposed study, and obtained verbal consent to be contacted by the researcher. The study was approved by the Yale University Institutional Review Board. In addition, the study was reviewed and approved by a tribal council, and a research agreement and resolution were drafted and signed by the principal investigator and the tribal governor. A signed informed consent form, which was written at the fifth-grade reading level (33) as determined by the Simple Measure of Gobbledygook (SMOG) readability formula (34), was obtained prior to completion of the questionnaires and interview.

All informants received a \$10.00 gift card and an AI-themed art poster. According to the literature, provision of incentives as part of research with minority populations improves informant retention (35). In AI communities, the exchange of gifts is a traditional practice, which implies that bonds of respect, trust, and interconnectedness have been made between the giver and recipient (35).

### Results

The sample comprised 24 informants: 13 AIs with cancer (five men; eight women) and 11 health care providers, caregivers, and community members (eight men; three women). Key findings from this study are detailed in Table 1.

#### AIs With Cancer

The mean age of the AI patients with cancer was 58 years (range 36–76 years). All identified themselves primarily as AI, although one described herself as biracial, with AI as her primary racial identity. All spoke both their traditional language and English, and one informant was trilingual, also speaking Spanish. Six (46%) were married, one was widowed, two were separated or divorced, and four had never married. The majority of patients (46%) were unemployed as a result of their illness. Six of the 13 informants reported their occupation as self-employed artisan, but many were unable to work because of fatigue or other side effects from treatment or disease. One-third (31%) attended some college, and 15% went to a trade school after high school.

All patients had undergone treatment for their disease, including surgery, chemotherapy, and radiation. More than half of the informants had advanced or stage III/IV disease. To protect

the privacy of the AI patients, specific details about diagnoses and treatment are omitted from this report.

### Health Care Providers and Community Informants

Eleven non-patient informants from the community completed interviews: six registered nurses, two physicians, one family member, one key informant with knowledge about the cultures and communities, and one traditional medicine practitioner. The health care providers and community informants comprised six who identified as being AI and five who identified as being Caucasian. Only one identified as being Hispanic/Latino. Among health care providers, the sample had an average of 15 years of practice experience, and five of the health care provider informants reported that they had a patient population made up of at least 60% AI patients. All of the health care providers practiced in New Mexico, and all informants lived in New Mexico.

### Cancer Pain

Informants often agreed that they had pain but were unable to express it in words. Some described it as a “teasing pain” or as pressure or tightening. Some described it in terms of intensity, using words such as “bad” or “terrible,” but not using true descriptors beyond these adjectives. Others struggled with a description and were only able to repeat back exemplars or prompts from the researcher, for example, “Can you tell me about your pain; for example, is it a stabbing pain?” “Yes, stabbing.” Health care provider informants validated these challenges and conveyed frustration with pain assessment in AI patients, including difficulty in localizing pain. In support of their comments, the researcher observed during interviews that AI informants were more likely to gesture to a section of their body in a sweeping motion, indicating a vague location rather than a specific point or anatomic location.

In place of a simple descriptive response, informants chose to illustrate their pain experience through lengthy storytelling. In these stories, some described the pain pattern and others used descriptions of how pain interfered with activities to illustrate the degree to which their pain was distressing to them. For example, one informant had certain pains that only bothered her during the day and other pains that disturbed her only at night. When asked to describe her pain, she said, “The back was worse, I think. Like somebody was pushing something to hurt it. The back was worse during the day. Then the stomach [pain] would keep me from sleeping on my stomach at night, and that was bad.”

When asked to describe his pain, another informant gave a very vivid description of his disease as being like a magician, unpredictable and viciously cruel:

I see my body change by itself. I see myself deteriorate right before your own eyes. It's like pulling a rabbit out of a hat, like a magician—the hand is faster than the eye. The cancer is like that, it fools your mind. I watch my back just deteriorate. I went from limping to crutches. I went from crutches to a walker. I went from a walker to a wheelchair. I went from a wheelchair to bed. It's like a magician doing stuff, especially when your mind is sound and you watch yourself fade away and your mental state of mind, it will really tear you up. I think I've made myself sick with some of this.

AI informants with cancer were asked to rate their pain using the BPI-SF (26). All pain intensity ratings were based on the 0-to-10 scale, with zero being no pain and 10 being the worst pain imaginable. The worst pain intensity in the last 24 hours was rated at an average of 5.3, the least pain average was 2, and the average pain was 4.75. The average pain intensity at the time of the interview was 3.1, and three of the six informants who had denied

the presence of pain in the first question of the BPI-SF rated their pain intensity as something other than zero for this question, a direct contrast to their first response.

When AI informants were asked to describe their pain using the BPI-SF, some were able to describe and quantify it clearly and easily ( $n=4$ ), whereas others were unable to assign a numeric value to it or to localize or describe it ( $n=9$ ). The AI informants who were able to clearly converse about their pain tended to be younger (average age, 47.5 years), be divorced or never married ( $n=3$ ), be female ( $n=3$ ), and speak English in the home ( $n=4$ ). The informants who had more difficulty describing and quantifying their pain were older (average age, 62.3 years), were married ( $n=6$ ), were self-employed as traditional artists ( $n=4$ ), and spoke their traditional language or a combination of English and traditional language in the home ( $n=8$ ). The group that was more traditional as measured by language, marital status, and employment had a more difficult time with conventional pain assessment.

### Emotional Pain

Emotional pain included sadness, depression, existential pain, and frustration or anger with cancer, its treatment, and the overall cancer journey. Informants described deep sadness at experiencing the end of life. Several informants revealed that they had lived through a family member's cancer death and experienced fear and sadness knowing what lay in store for them. As one informant described, "When I was first diagnosed, I had lost [a family member] to cancer and a month later after she passed, I was diagnosed. All my tears were gone. I just could not accept the fact. I was not scared, but my emotions were in shock."

The stress of dealing with illness within the context of family contributed to the emotional suffering. Informants described feeling frustrated, aggravated, and emotionally fatigued as a result of coping with disease or managing their cancer. Emotional distress was greatest for those who felt that their physical pain limited their ability to think about anything other than pain, interfering with the intellectual and emotional processes of the brain. As one informant stated:

It's like being put down because of my thinking because the pain is there. I can't concentrate because of the pain. I can't walk because of the pain. It keeps me away from activities, chores, things I have to do.

Suffering emotionally was the reality of living with cancer and cancer pain. Another informant asked, "Why me? Why do I have to go through this?" This informant relied heavily on his family for support, but when he was struggling with the existential meaning of his pain, he described feeling the need to isolate his family instead of exposing them to his struggles. "I try not to think about it. That's when I go outside and do my yard work or go in my shop.... Why do I have to go through this? At first, it was really hard. When you hear cancer, it's like death."

For informants who were receiving opioids for cancer pain, there was some discussion of feeling persecuted for their medication use. Informants felt responsibility to their families and communities, which included refraining from opioid use. Informants who required opioids described feelings of persecution and distrust from family members who felt they were inappropriately medicating their pain. These feelings were a source of emotional pain for the informants.

### Spiritual Pain

Spiritual pain emerged as a strong source of distress for informants for several reasons. For some, having neglected ceremonial activities earlier in life brought into question causality

related to cancer, as well as spiritual angst concerning their understanding of their spirituality in relation to their disease. As one informant stated:

Spiritual pain—it's a really hard setback, especially for me. When I wasn't living here [in the tribal community], because I didn't go to participate in my spiritual ways, like that's why I have spiritual pain ... the spiritual part—praying and being Native American and I pray to my Creator and ask him for help—I don't get what I want and I start blaming: Why did you create me just to watch me suffer? Do you really love us as your children? As your creation? You start questioning your spirituality.

This sample found it difficult to separate emotional and spiritual pain from physical pain. As one informant stated, “The inside physical pain binds up really deep with the spiritual self because of the pain being so deep. Sometimes you can't tell the difference where you're actually hurting.”

Another, perhaps more clinically relevant, cause of pain was related to the side effects of cancer and its treatments. In this community-oriented culture, the ability of individuals to participate in traditional activities is critical to their relationship with their tribe. Many informants described their inability to participate as being damaging to their spiritual health. Another participant stated, “Spirituality inspires the body to excel beyond its normal capacities,” suggesting that involving oneself in spiritual practice helped create a setting for healing to take place. The link between spirituality and healing was explicit for these informants.

Spiritual practices in this culture go beyond attending religious services and include communal work such as planting crops, dancing, singing, or drumming. Cooking and feeding community members are also ceremonial acts. As one informant stated:

That food is ritual food; it's more spiritual than comfort food. It has to do with spirituality, like the bread in Catholicism. When someone is practicing for ceremonial dances, they have that same food for meals, because it's the *right food for their people to eat* [emphasis added].

As a result of the inability to participate in traditional activities, many informants described ceasing treatment or missing chemotherapy appointments so they could contribute to traditional and ceremonial activities. Although this study did not collect data regarding number of missed appointments as a result of ceremonial obligations, anecdotal data from health care providers suggested that AI patients withdrew from care frequently without explanation.

## Pain Management

Pain management consisted of both pharmacologic and nonpharmacologic strategies. Only six informants were on regularly prescribed medications for their pain, and one of these described having to ration her medication to provide adequate pain management between visits to her pain specialist because her prescription was not meeting her pain needs. Acetaminophen was the most common over-the-counter drug used for pain prior to diagnosis. Those with pain who were now taking opioids ( $n=7$ ) took formulations that contained an opioid and a nonsteroidal anti-inflammatory drug or acetaminophen in combination. When informants experienced severe or unbearable pain, they tended to go to the regional IHS hospital for pain management, because the IHS pharmacy could dispense medication free of charge and because they were most familiar with the IHS system. Once discharged, they often discontinued the use of opioids and resumed over-the-counter analgesics for pain management.

Informants described a strong desire to protect their privacy within their communities. As is true in rural populations across the country, gossip is common, and being the subject of gossip is undesirable. Informants made efforts to prevent information about themselves from being spread around the community, especially information about their cancer and treatment. Expressing pain was seen as a sign of weakness, and informants were keenly aware that complaining about their pain would only extend their vulnerability, such that their image in the community would be further degraded beyond that of simply being ill. To manage pain, many informants relied on nonpharmacologic pain management strategies, including elevation, massage, distraction, visualization, prayer, heating pad or hot pack use, position change, use of nutritional supplements such as vitamin B<sub>6</sub> for neuropathy, movement, and use of topical rubefacient heat rubs, such as Icy Hot® (Chattem, Inc., Chattanooga, TN).

Both AI informants and health care providers described the aversion of AIs to taking any type of pills. Health care providers stated that it was unusual for AI patients to use opioids to manage cancer pain, and AI informants validated their aversion to taking a daily oral medication, particularly opioids, regardless of potential pain relief. One health care provider stated, "If I had to generalize, I would say that the Native population ... they are a little more superstitious and a little more hesitant to take pain medication." As one family member described, "He never took anything. He always would just say, 'It'll go away.' And he wouldn't take anything, even for a toothache. Then they had to pull all his teeth." One health care provider stated:

Elders are hesitant to take narcotics. They aren't up front about it, but they won't take them. The older folks would rather suffer with the pain than feel they were out of touch with the earth/world. They don't like the hazy feeling.

Health care providers and AI informants stated that the strong aversion among AI patients was associated with the hazy or foggy feeling one experiences when first introduced to opioids. This side effect was considered so unpleasant that patients frequently would choose to suffer from extreme pain rather than endure it until they developed a tolerance to the medication. AI patient understanding of the short-term nature of many of the side effects associated with opioid use was poor.

### Barriers to Pain Management

AI informants overwhelmingly expressed the belief that pain from cancer is inevitable and untreatable. This fatalism and the challenges of the AI population to be able to accurately describe their pain are barriers to effective pain management. In addition, limited education about pain management was a barrier for AI informants with cancer, family members, and health care providers. According to the health care provider informants, misinformation about opioid use, concerns about addiction, and misunderstandings about pain medications prevented AI patients with cancer from asking for and following through with prescribed pain management.

Health care providers identified the family as an important resource for their AI patients, but observed circumstances in which the family actively prevented patients from using appropriate analgesics. Fear of prescribing, fear of retribution for overprescribing by the state board of medicine, fear of overprescribing and causing death, and poor knowledge about the use and variety of analgesics were all cited as barriers to adequate pain management. In addition, prescriber inexperience was specifically cited as a barrier to pain management. The IHS frequently employs newly licensed clinicians through a federal loan repayment program, and health care providers believed these clinicians lacked the experience and clinical judgment to prescribe adequate analgesia to AI patients living with cancer.



## Discussion

Results from this research reveal new knowledge about the cancer and cancer pain experience in American Indians. Among the participants, the types of cancer represented with this sample closely reflected the top five cancers occurring in New Mexico AIs, according to the National Cancer Institute's Surveillance Epidemiology and End Results data (36), with breast, colorectal, and gynecological tumors most common. The observation of the close relationship between treatment compliance and the patient's ability to participate in ceremonial and spiritual activities provides new insight into the vexing problem of interrupted and incomplete cancer treatment in this population. Barriers to pain management included aversion to the side effects of pain medication, beliefs that opioids should be reserved for end-of-life care, and a perception among many that they were not ill enough to require regular opioids for their pain. The belief that morphine and its derivatives are medications of last resort, and that cancer pain is inevitable and untreatable is widely shared in both AI and non-AI populations (37,38). In addition, the finding that AI patients have a multidimensional conceptualization of pain will assist clinicians with obtaining more detailed and informative pain assessments, which will in turn contribute to better pain management for these patients. Identification of the relationship among physical, emotional, and spiritual pain has uniquely been identified in AI and Alaska Native populations (20). Suffering is associated with advanced cancer and end of life (39), and existential suffering is well recognized as a significant component of the cancer experience (40).

Struggles around self-identify and values are challenged when individuals with a life-threatening disease question the meaning of their lives, the nature of their connection to the spiritual world, and their sense of self in relation to the values by which they have lived their lives. In a culture in which the core values of community, spirituality, place, and language form the foundation of the society, the individual experience of cancer and illness brings to the surface the existential tensions of self versus community and traditional healing versus allopathic medical care, and the consequences of living a less traditional life. Understanding that the AI patients are connected to a community-oriented culture is critical in understanding the decision-making process, attribution, and self-efficacy of these patients (41).

Opioids carry with them a discourse around addiction, particularly in the mainstream media, where stories of opioid abuse are frequent. In the geographic region of study, there exists a persistent and disturbing trend of opioid addiction among certain cultural and economic groups (42). According to the Centers for Disease Control and Prevention, New Mexico has the highest number of opioid-related drug overdose mortalities in the nation, and AIs are among the highest population nationwide with opioid-related mortalities (43). Despite the prevalence of opioid addiction in this region, none of the informants in this research cited fears of addiction as a barrier to their own opioid use. In contrast, informants were much more likely to cite side effects of opioids or an aversion to taking medications in general as barriers to their own pain management. This is an important difference from the general population, in which fears of addiction are frequently cited as barriers to opioid use for cancer pain (37).

## Limitation

Most likely the result of a historical mistrust of research, patients who were highly traditional did not volunteer to be interviewed for this research. Based on discussions with both AI informants and health care providers, this subgroup is more apt to refuse treatment for cancer and also more apt to refuse to engage in research, making them inaccessible for interview. Regrettably, this is an important piece of the cultural experience for people in these communities.

Another limitation was that the interview data from most AI informants were recorded using written field notes and direct transcription of key quotes, rather than being audio-recorded. To improve the quality of the data, the interviews were periodically suspended to verify the accuracy of the notes, in an effort to clarify and improve the transcription in the moment. This confirmation served as early member checking, although additional member checking took place following data analysis as well.

Limited access to the target population was another limitation. Ethical researchers working in disenfranchised populations must take care to leave no footprint in the community in which the research is conducted. To avoid the perpetuation of negative associations with research, the researcher took special care to conduct interviews in a way that did not invite excessive conflict or ill will. This meant that when there were moments of high emotions in interviews, the researcher had to purposely decrease the intensity of the questioning. This was especially an issue when interviewing male elders because of cultural boundaries regarding age, sex, and community status between the interviewer and the interviewee. To limit the effect this had on the quality of the data collected, findings were reviewed with other community informants to ensure authenticity of the results.

Data regarding the frequency in which patients withdraw or miss scheduled care for unexplained or cultural reasons was beyond the scope of this project. This information would have contributed to the understanding of the barriers to receiving care and the relationship between cultural and community responsibilities and self-management of the AI patient's cancer. Future research should investigate the link between missed and discontinuations of scheduled care and the traditional and ceremonial calendar for further insight into the role of ceremony and traditional activities with AI patients with cancer.

Sample size in this study is a limitation. Generalizability is not considered the gold standard with qualitative research, as the qualitative experience of a small sample is not representative of a larger population. In addition, AI tribes are diverse and unique and have vast tribal and geographic variations, so assertions that findings from this research would apply to other AI groups would be inappropriate.

### **Implications for Practice**

Clear barriers to pain assessment arose through this research. Based on these findings, the researchers suggest that clinicians working with AI patients allot enough time to allow for a discussion of pain and the multiple dimensions that are troubling their AI patients with cancer. By allowing time for storytelling, clinicians can develop deeper insights into the true nature of symptom distress with their AI patients. In a patient who denies pain with an otherwise painful condition, further questioning on other quality-of-life measures may provide a more accurate understanding of that person's pain experience. In addition, culturally congruent patient education that emphasizes the importance of around-the-clock pain management and clarifies misconceptions regarding opioid use and tolerance is needed for AI patients and their families.

Although many AI patients are reluctant to discuss their ceremonial responsibilities with non-tribal members, when developing a treatment plan for these patients, it would be helpful to discuss whether there are particular events or dates for which patients want to feel their best. Designing a treatment plan with these dates in mind may contribute to better treatment adherence and fewer unanticipated treatment interruptions.

## Conclusion

Cancer pain management in southwestern AIs has been shown to be difficult in the best circumstances. Future research should investigate collaborative development with community partners of culturally congruent pain-assessment instruments, as well as the feasibility and efficacy of culturally targeted pain management education for patients and their providers in this patient population. In a population where the combined stressors of daily life add incrementally to the burdens of a person with cancer, good pain management has the potential to greatly improve cancer outcomes, as well as enhance AI patient quality of life throughout the cancer trajectory.

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**Table 1**

## Key Findings

Topic	Details
Pain Description	<ul style="list-style-type: none"> <li>• Verbal pain descriptions were hard to elicit</li> <li>• Pain was described through storytelling</li> <li>• Numeric designation through use of the pain scale was more difficult with elders and individuals who lived a more traditional American Indian life</li> </ul>
Emotional Pain	<ul style="list-style-type: none"> <li>• Stress of coping with cancer in addition to family demands</li> <li>• Existential pain</li> <li>• Pain of stigma related to use of opioids for pain management</li> </ul>
Spiritual Pain	<ul style="list-style-type: none"> <li>• Issues of causality from lack of participation in spiritual activities</li> <li>• Difficult to identify/conflated with physical pain Caused by isolation from community and spiritual activities, and inability to eat traditional food during ceremonies</li> <li>• Led to interruptions in treatment schedule</li> </ul>
Pain Management Barriers	<ul style="list-style-type: none"> <li>• Reluctance to use prescribed analgesics</li> <li>• Desire for privacy prevented participants from seeking help in community</li> <li>• Lack of knowledge about pain management</li> <li>• Fatalism limits pain management</li> <li>• Family was both prohibitive and contributory to good pain management</li> </ul>