

CHRONIC PAIN MANAGEMENT IN A RESERVATION BORDER TOWN

by

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DEDICATION

To all people of every culture who endure unrelenting chronic pain and to the healthcare providers who treat them.

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ABSTRACT

Pain is a growing national public health problem that contributes to spiraling health care costs and significant societal burden in the United States. It is the most common reason for seeking health care services, and is the leading cause of disability (CDC, 2008). Inadequately treated pain has profound social, psychological, economic, and physiological consequences for patients, their families, and society (American Pain Society, 2009).

A community-based participatory research (CBPR) approach was used for this project to develop a knowledge base about issues associated with chronic pain and its treatment among Native American people in Winslow, AZ. Mixed methods (qualitative and quantitative) were used to gain insight into the local factors that contribute to the self-management and treatment of chronic pain. Two sources of data were used for this assessment. Data were collected from people living within the community and from health care providers working with the community. Patients with chronic pain were interviewed to explore patient factors that influence pain management. Healthcare providers participated in a survey to explore physician factors that influence pain management at WIHCC and to compare the survey results to the results on the same survey of Texas providers as reported by Weinstein, et al (2000). Qualitative content analysis was used for the interview data with patients and quantitative analytical strategies were used with the provider data.

The results of the provider survey indicated that there are negative psychological traits toward patients with chronic pain such as authoritarianism, intolerance of ambiguity, reliance on technology, and locus of control which are factors that are known to negatively influence pain care (Weinstein et al, 2000). Lack of knowledge regarding pain and pain management along with

perceptions and fears related to drug regulatory agencies were additional factors that were found, constituting additional barriers. Patient participants were generally dissatisfied with the pain care practices at Winslow Indian Health. Patient reported treatment goals that included relief of pain, improved quality of life, the ability to return to work, the ability to perform household chores, and the ability to participate in more physical leisure activities.

This results of this practice inquiry indicate there is a disconnect between patient and provider views and expectations around pain treatment and the need for further studies to determine the best ways to address chronic pain at the local level. The development of a pain management program is recommended to address the unmet needs of patients with chronic pain. Education in pain management is recommended for healthcare providers, including information regarding the benefits of non-pharmacologic therapies for pain management. The practice inquiry also supports the need for new policies at the local, tribal, and national levels to address pain as a growing public health issue.

CHAPTER 1: BACKGROUND AND SIGNIFICANCE

Introduction

Pain is a growing national public health problem that contributes to spiraling health care costs and significant societal burden in the United States. It is the most common reason for seeking health care services, and is the leading cause of disability (Centers for Disease Control (CDC), 2008). Ethnic background has been shown to have an effect on pain treatment and outcomes (Green, 2003). Green, Caracelli and Graham (1989) found that racial disparities were present in all health care settings and involved all types of pain. In recognition of the growing issue of pain management in this country, the National Pain Care Policy Act of 2009 was designed to address barriers to the effective assessment and management of pain. This Act was subsequently signed into law in March 2010.

Proper treatment and adequate pain management are crucial to the prevention of permanent disability, but people who suffer from pain often face significant barriers that prevent this from occurring (O'Rorke, Chen, Genao, Panda, & Cykert, 2007). Focus on the treatment of pain has necessarily increased in this country because the large segment of the population known as the "baby boomers" are reaching their senior years and are living longer than previous generations; advanced age is associated with a higher incidence of chronic disease and painful conditions (Pergolizzi, Boger, Budd, Dahan, Erdine, & Hans, 2008)

While the medical community recognizes the overall need for improved management of pain, they also feel pressure from state, federal, and local governments regarding the potential for aberrant use of the opioid medications they prescribe (O'Rorke, et al, 2007). This has led to inadequate treatment of pain world-wide (Von Korff & Simon, 1998; World Health

Organization, 2008). The Medical Society of Milwaukee, Wisconsin, for instance, has proposed legislation for pharmacies to “flag” providers who prescribe large volumes of narcotic analgesics (Barton, 2008). These pressures have caused health care providers to engage in a casual form of patient profiling in a self-defensive effort to avoid being tied to patients engaged in drug diversion (Brennan, 2007). Medical and popular literatures indicate a recent increased awareness of the influence of ethnicity on the ability to access adequate pain treatment (Green, 2003; International Narcotics Control Board, 2004; Joranson & Ryan, 2007; Kramer, 2002; O’Rourke, et al, 2007). The reasons for disparities in pain treatment are complex and involve issues with patient/provider communication as well as with the health system.

Background

Consequences of Untreated Pain

Inadequately treated pain has profound social, psychological, economic, and physiological consequences for patients, their families, and society (American Pain Society, 2009). Pain causes a cascade of negative physiological events including increased heart rate, increased blood pressure, and circulating inflammatory hormones that put patients at increased risk for myocardial infarctions, stroke, post-surgical bleeding, and a host of other adverse events (Zagara, 2008). Uncontrolled pain aggravates co-morbid conditions like diabetes by causing the release of catecholamines, a hormone that leads to a rise in blood glucose levels (Krein, Heisler, Piette, Makki, & Kerr, 2005). Inadequate treatment of acute pain can lead to maladaptive behaviors and pathologic neural alterations that evolve into chronic pain syndromes. All types of pain can result in decreased mobility; sleep disturbance, impaired immune system functioning, depression, and medication dependence (Zagara, 2008). Pain undermines the quality of life and

impairs social functioning, including the ability to maintain employment. Chronic pain causes huge social and economic burden and is clearly linked to low socioeconomic status (American Pain Society, 2009; Brennan, Carr, & Cousins, 2007).

Barriers to Pain Treatment

Cultural barriers and attitudes about opioid medications among patients and health care providers contribute to the problem of untreated pain (Brennan, Carr, & Cousins, 2007; Kramer, Harker, & Wong, 2002; Lovering, 2006). However, the problem of prescription drug abuse in the United States further hampers the treatment of chronic pain because it leads providers to restrict prescriptions for opioids for fear these drugs will fall into the wrong hands. Recent research indicates that 20% of the US population has used prescription drugs for nonmedical purposes (Substance Abuse and Mental Health Services Administration (SAMHSA, 2010). In fact, the abuse of pain medications is more popular than the abuse of all illicit substances (SAMHSA, 2007). Hydrocodone and oxycodone are two of the most commonly prescribed drugs for pain. Hydrocodone is also the preferred drug of abuse for initiates age 12 and older, followed by oxycodone (Brennan, et al, 2007; SAMHSA, 2010). Fifty-six percent of abusers reported obtaining the most recent prescription drug they used from a friend or relative; of these, 81% reported that the friend or relative obtained the drug from a single health care provider (SAMHSA, 2010). The country's "war on drugs" has resulted in more scrutiny by regulators of opioid prescribing and dispensing and this, in turn, has had a profound effect on the prescribing practices of health care providers (Brennan, et al, 2007). While the medical community recognizes the overall need for improved management of pain, they also feel pressure from state,

federal, and local governments regarding the potential for aberrant use of the opioid medications they prescribe (O'Rourke, et al, 2007).

Native Americans and Pain

While Native Americans' (NA) experiences with pain mirror the general United States population, there is a higher incidence of chronic disease, motor vehicle accidents, and accidents associated with rural agriculture and traditional lifestyles that can lead to chronic pain (Indian Health Service (IHS), 2009). The higher prevalence of conditions such as rheumatoid arthritis and complications associated with skyrocketing diabetes rates compared to other Americans also increases the potential for inadequately treated pain among Native Americans (Ferucci, Templin, & Lanier, 2005; IHS, 2009). Statistical data from the IHS (2009) indicate that diabetes rates among indigenous peoples are more than three times higher than the general population, and this disease is known to cause painful neuropathies (National Diabetes Information Clearinghouse, 2010). Genetic markers for a painful condition called ankylosing spondylitis have been found twice as often in Native Americans as in Caucasians (Brown, 2007).

Native Americans often face additional treatment barriers that may be amplified by persistent health disparities and cultural barriers that result in inadequate treatment. Many of the Indian reservations in this country are in very rural and isolated locations (IHS, 2009). Rural communities face unique challenges that influence the impact of pain including barriers to accessing basic health care services (Agency for Health Care Research and Quality, 2008). Further, tribal health centers are typically staffed with non-Native health care providers who have been educated within an allopathic model (IHS, 2009). Generally speaking, these providers have limited or no knowledge of how local culture impacts patient/provider interactions. The

consequent failure of Western medicine to address the spiritual and cultural aspects of Native American health beliefs and communication styles can lead to suboptimal treatment outcomes, mistrust, and patient dissatisfaction (Mead, Cartwright-Smith, Jones, Ramos, Woods, & Siegel, 2008).

Published research on cultural influences among Native Americans regarding the reporting of pain to the medical community is limited. In a study by Kramer, Harker, and Wong (2002), urban Native Americans delayed seeking health care advice for painful conditions and openly commented on the cultural practice of minimizing pain. These findings were supported in a report by Weiss (2005). When they did present for care, symptoms were revealed in a subtle, guarded manner. Verbal descriptions of mild pain symptoms may therefore represent symptoms of serious conditions within this population. These findings have been supported by verbal reports from numerous healthcare providers who work with Native people at Winslow Indian Health Care Center (WIHCC), including the researcher. According to one cultural expert (who is also Native American), pain may be viewed as a consequence of being in disharmony with the environment or as a result of the negative and harmful effects of the environment (Morgan, 2008). Health beliefs in NA culture are grounded in the concepts of harmony and respect for all things (Morgan, 2008). In this culture, traditional healers are charged with removing *naayee'ji* (the negative and harmful effects of the environment) through healing and purification ceremonies that have endured for thousands of years (Morgan, 2008).

Given the fact that most IHS health care providers are non-Native, patient/provider cultural differences are likely to be a powerful barrier to adequate pain management in this setting. Research is needed to determine the scope of problems associated with pain among

Native Americans, the perceived causes and solutions for disparities in pain treatment among Native Americans, and the desired treatment approaches by this population.

Research with Native American Populations

While native people acknowledge the need to study health issues within a population-specific context, the actual development of and participation in research is often difficult (Strickland, 2006). Gaining access to indigenous communities requires intensive relationship building efforts on the part of researchers (Strickland, 2006). In order to understand the context of the current research environment within Native American lands, it is necessary to revisit the past.

For more than 200 years, American Indian tribes have been researched by anthropologists, medical scientists, and other outsiders mostly for the purpose of gaining insight into their culture (American Indian Law Center, 1999). Much of this research and the subsequent reports have been debasing, exploitive, and disrespectful of cultural mores. “Helicopter research” was frequently conducted to fulfill the motives of outsiders rather than for the benefit of the tribes (Bommersbach, 2008; Oberly & Macedo, 2004).

An example of “research gone bad” in Indian country was a series of research studies initiated by academics at Arizona State University that began in 1989 and continued until 2003. Now known as the “Medical Genetics Project,” the initial research project was presented to an Arizona tribe as a study of diabetes that would help them discover why the incidence of this disease was skyrocketing among the tribe. The blood samples given by tribal members for this purpose were never used to study diabetes but ended up in research laboratories around the world where they were used in various ways without the knowledge or consent of the donors. Blood

samples were drawn from most of the adult members of the tribe and used to study mental illness, inbreeding, and Indian migration patterns. A long legal battle continues in attempts to force the return of all remaining blood samples but many of the donors have died. According to tribal beliefs, the study participants who have died are prevented from entering the Spirit World because their blood is lost. The tribe's very origin was also attacked as a result of unauthorized research on the blood samples; the samples were used to conduct genetic research to test a theory that American Indians are not native to this continent but migrated across the Bering Strait (Bommersbach, 2008; Hart, 2003). Colonization has produced many such examples that illustrate the reasons tribes have developed a mistrust of the research process and refuse or are reluctant to participate in studies (Arizona Biomedical Research Commission, 2006; Oberly & Macedo, 2004).

In spite of the past, Native American tribes acknowledge the pressing need for research to explore the many health issues that disproportionately afflict indigenous people and to design programs to reduce staggering health disparities (Warne, 2006). Community Based Participatory Research (CBPR) methods can help overcome the fear and resistance to research efforts. CBPR methods are attractive to Native American tribes not only because they are more respectful and relevant, but also because the tribes can retain control over the study process from conception to publication while engaging in equal partnerships with academic researchers. Several biomedical research institutions have established ongoing CBPR projects with Arizona tribes (Arizona Biomedical Research Commission, 2010). Some Native communities within North America have, in fact, begun mandating CBPR for tribal research (Flicker, Travers, Guta, McDonald, & Meagher, 2007). Storytelling is the traditional method of passing information among Native

American people (Garwick & Auger, 2003). CBPR can incorporate storytelling into data collection methods to obtain valid and locally relevant research results. The use of traditional methods to communicate information that is relevant to a study is less threatening than traditional research methods.

Purpose of the Project

The purpose of this practice inquiry was to develop a knowledge base about issues associated with chronic pain and its treatment among Native American people. The results of this inquiry will be used to develop a pain management program within an institution that provides health services to this Native American community. A community-based participatory research (CBPR) approach was used for this transcultural project to improve relevancy and validity. This project specifically addressed the first step in this CBPR program and used formative assessment techniques to identify the problem, setting, population, and resources associated with the management of pain among a Native American population.

Specific Aims

The purpose of this project, a community-based assessment, was to describe and evaluate pain assessment, treatment, and management from the perspective of Native American patients and their health-care providers. Quantitative and qualitative methods were used to compare and explore:

1. Patient factors that influence the management of chronic pain, including:
 - a. Pain assessment and influences of patient/provider communication;
 - b. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;

- c. Patient self-treatment practices and remedies for chronic and acute pain;
 - d. Outcomes of pain management according to patient-centered goals; and
 - e. Perceptions of the risk for use and potential for abuse of prescription opioid medications.
2. Provider factors that influence pain management, including:
- a. Reluctance to prescribe opioids for chronic pain;
 - b. Fear of patient addiction;
 - c. Fear of drug regulatory agencies;
 - d. Knowledge about pain and pain treatment;
 - e. Psychological attributes related to pain and pain treatment; and
 - f. Bias about gender and age.
3. Similarities and differences between Winslow providers and providers in the Texas Pain Study by Weinstein, Laux, Thornby, Lorimor, Hill, Thorpe, & Merrill (2000) related to factors that influence pain management.

In this project, patient/provider perspectives on pain assessment, treatment, practice, and outcomes were compared and contrasted to identify, describe, and document the professional/patient tensions and the clinical implications of those tensions. These findings can be used to design a pain management program to address chronic pain in this community. This research also generated hypotheses and additional research questions for future community-based research once the pain management program is in operation.

Significance of this Project

Quality, according to the Institute of Medicine (IOM), is reflected by the provision of services that are patient-centered, effective, and that use resources wisely (Agency for Health Research and Quality [AHRQ], 2010; IOM, 2001). Other parameters are safety, timeliness, and equity. A CBPR approach to data collection was used to engage the community in describing locally relevant perspectives on pain management. Engagement of community members in data collection increases the validity of the results and has provided important information that can be used to guide the development of a quality initiative to address chronic pain management in a Native American population. This practice inquiry provides information for development of a program that is patient-centered, effective, and efficient.

Creating a Quality Pain Treatment Program

High quality health care should exhibit six key characteristics. The essential elements of quality care are safety, timeliness, effectiveness, efficiency, patient-centeredness, and equity (IOM, 2007). These are further defined by the IOM as:

1. *Timely* – Wait times and delays are minimized for those who receive and provide care.
2. *Effective* – Services are provided based on scientific knowledge to all who could benefit and are not provided to those who would not benefit.
3. *Efficient* – Care avoids wasting equipment, supplies, ideas, and energy.
4. *Patient-Centered* – Care is delivered with “compassion, empathy, and responsiveness to the need, values, and expressed preferences of the individual patient” and ensures

that patients “have the education and support they need to make decisions and participate in their own care.”

5. *Equitable* – Care does not vary in quality because of personal characteristics, including gender, ethnicity, geographic location, or socioeconomic status.

These six quality elements provide a framework for the development and implementation of a pain management program and speak to the significance of this preliminary assessment.

Safety. Indigenous healing practices include the use of herbs, ceremonies, manipulative therapies, and other traditional healing practices (Warne, 2008). An understanding of local practices may prompt healthcare providers to be alert to issues such as herb-drug interactions that may impact treatment decisions. Patients with certain spinal conditions may be advised to forego manipulative therapies that could worsen their conditions or result in serious complications. Studies have shown that there are cultural differences in the expression of pain that may lead health care providers to under-estimate the severity of symptoms (Kramer, 2002; Warne, 2008). The practice of enduring and minimizing pain in the presence of healthcare providers can lead to undiagnosed medical problems that compromise care. Acute abdominal pain, for example, may be a symptom of ruptured appendix which can be life-threatening if not diagnosed and treated in a timely manner (National Digestive Disease Clearinghouse, 2010). It is imperative that healthcare providers are aware of cultural influences on pain self-treatment and communication patterns in order to deliver safe care (Office of Minority Health, 2009). This practice inquiry increased the understanding of local pain self-treatment practices. This, in turn can assist patients and providers in designing treatment plans that safely and effectively integrate traditional and allopathic interventions.

Timeliness. IHS facilities often experience difficulty in the recruitment of ample numbers of health care professionals (IHS, 2009). This can lead to fewer available appointments, long waiting room times, and fragmented care that compromise quality. The isolation of IHS facilities and clinic flow issues often lead to dissatisfaction and entrenched, paternalistic healthcare delivery models conflict with the ideals of recently educated healthcare providers (Rosenthal, 2008). Entrenchment in the paternalistic models of healthcare delivery traditionally employed by the IHS can limit the adoption of health policies and newer models of care that have been shown to positively impact patient care (Institute for Patient- and Family Centered Care, 2010)

Social and cultural factors that influence timeliness also contribute to care quality. The perception of time varies across cultures and patients may simply not understand the significance of or value appointment times (Schultz, & Kroeger, 1996). They may also have difficulty keeping appointments due to transportation issues and family obligations that extend to members outside their household (Morgan, 2008). Native American people who live on the reservation may travel 50 miles or more one way over muddy dirt roads in order to receive health care services. Bad weather or a washed-out road can undermine the efforts of even the most vigilant patients to maintain regular health appointments (Beuhler, 2006). In this practice inquiry, patients had the opportunity to talk about social and cultural factors that influence the timeliness of their pain care.

Effectiveness. The isolated location of tribal facilities can prohibit or limit the ability of health care providers to network and attend professional educational conferences (IHS, 2009). Many healthcare providers are unable to come to terms with the demands of frontier medicine and leave tribal healthcare practice once their service commitment period has ended. For

instance, only 44% of the providers who participated in this practice inquiry had worked at the IHS facility more than five years. Consequently, there is a high turnover of medical providers and a constant influx of young medical providers who are often inexperienced and inadequately educated in pain management (IHS, 2009). Studies have shown that the majority of healthcare providers from all disciplines have not been adequately prepared to deliver effective and appropriate pain care and that most primary care providers do not feel comfortable managing chronic pain patients (O'Rourke, et al, 2007). This practice inquiry provides information that will help enlighten local leaders regarding the need for provider education and regarding the expectations of patients when seeking pain care. As a result of pain education, providers may learn how to more effectively communicate with Native American patients about pain and will be better equipped to provide care that is more culturally acceptable and effective (Helman, 2006).

Efficiency. Fragmented care leads to missed information, duplicated and often unnecessary diagnostic studies, and repeated clinic or emergency room visits to obtain pain relief (Taylor, 2008). This ineffective use of resources is wasteful and also results in suboptimal pain treatment (Lewis, Combs, & Trafton, 2010). According to 2007 WIHCC data, only about 7% of the patients who seek care had been assigned a primary care provider at the IHS facility that serves the target community. When providers do not know patients from previous encounters, they must spend time and energy researching, eliciting a history, re-examining, and often re-ordering treatments and studies that are not readily available at each visit. Eliciting an accurate history is complicated by cultural and language barriers; this can be time consuming, repetitious for the patient, and frustrating for both the patient and the provider (Rosenthal, 2008). Extended

waiting room time and short face-to-face time are common, strong barriers to forming the therapeutic patient-provider relationships that are required for effective pain care (Institute for Patient- and Family Centered Care, 2010). Providers who lack adequate training in pain management tend to order more magnetic resonance imaging and other expensive, unnecessary studies (Taylor, 2008). In back pain, for instance, diagnostic studies are often poor indicators of significant pathology since many people who have abnormal spinal studies are pain free (Weiner, Kim, Bonino, & Yang, 2006).

Chronic pain patients are frequently difficult to manage and are a drain on health resources; they tend to have more consultations, studies, ER visits, and hospitalizations than other patients with similar co-morbidities (American Pain Society, 2009). A pain management program will provide patients with continuity of care and this will help eliminate duplications and omissions in services (Weiner, et al, 2006). Providers who are well educated in pain care should staff the pain program as this will result in more effective use of all available pain treatments (O'Rourke, et al, 2007). Pain care and the associated diagnostic work ups should be standardized as this will also eliminate waste and improve quality (American Pain Society, 2007). Mutual trust and rapport is a natural consequence of the continuous interactions over time between the patients and the members of a pain management team (Porsche, 2010). Once a pain management program has been developed, patients who are treated by a multi-disciplinary team of providers will no longer be frustrated by fragmented care; the “new patient” phenomenon that currently occurs day after day in nearly all patient encounters will not occur as frequently with chronic pain patients (Weiner, et al, 2006). This will dramatically reduce both patient and provider frustration with pain care.

Patient-Centeredness. In 2001, the Institute of Medicine (IOM) issued the landmark report entitled *Crossing the Quality Chasm: A New Health System for the 21st Century*. The six essential components of quality care were first outlined in this report, including a detailed explanation of patient-centeredness. According to this IOM publication, the hallmarks of patient-centered care are patient/provider partnerships that promote informed, shared decision making, development of patient knowledge, self-management skills, and preventive behaviors. The healthcare providers' knowledge of patients' home life, employment, cultural background, family relationships and other factors are used to inform health promotion and treatment decisions. Studies have shown that patient-centeredness produces better clinical outcomes and patient satisfaction with care (Institute for Patient- and Family Centered Care, 2010). Although this concept is central to the nursing paradigm, patient-centeredness has only recently been introduced into medical school curriculum (Rosenthal, 2008). Healthcare providers who were educated prior to the incorporation of this paradigm into medical education will need to closely examine their behaviors while accepting the fact that patients can play an active role in their own healthcare. Patients can understand interventions and protocols if given the opportunity and if properly explained (Institute for Patient- and Family Centered Care, 2010). Patient-centered care meets the needs of patients as opposed to simply dispensing advice. Advice is of limited use if patients do not have the means to follow it (Helman, 2006).

Language and culture have been shown to create powerful barriers to the development of therapeutic relationships between patients and healthcare providers (Chiang, 1993; Helman, 2006). Also, perceived power imbalances can interfere with patients' willingness to take an active role or may result in mistrust of the medical system (Lewis, Combs, & Trafton, 2010). A

general knowledge of a patient's culture is important but is not sufficient to provide patient-centered care; providers must also become familiar with patients on an individual level through engagement with the patient and family members over time to discover unique preferences and concerns (Silow-Carroll, Alteras, & Stepnick, 2006).

Native American (NA) patients have culturally influenced perceptions regarding the cause, purpose, and the communication of pain (Morgan, 2008). In this researcher's experience, NA patients sometimes speak of lightening and snakes as the possible source of their affliction. Some express mistrust in the allopathic healthcare system and may be more comfortable with traditional healing modalities. During the time the researcher was employed at WIHCC, it was not at all uncommon for public health nurses who regularly visit the homes of patients to report that patients have pantries full of unused pharmaceuticals. This reflects rejection of allopathic treatment and illustrates that healthcare providers must be willing to meet patients on their terms if they expect to impact health status (Helman, 2006). Pharmaceutical treatments are not always the best treatment choice; often more acceptable traditional and complementary alternative therapies can be harmlessly incorporated into the treatment plan (World Health Organization, 2006). It is important to accept that patients may need to consider a non-allopathic treatment modality if they believe their discomfort has been caused by supernatural forces or if they are not willing to accept allopathic interventions (Beuhler, 2006). In this researcher's experience patients are often very willing to discuss their traditional healing practices if respectfully asked to do so. Patients were encouraged to discuss these issues in this practice inquiry, and the researcher has attempted to extract a description of local practices and culturally influenced perceptions about pain, its purpose, and the way patients communicate about pain. A better understanding of

factors such as the language used to describe pain and the perceived barriers to obtaining pain treatment can guide future efforts to design a pain management program to address these issues.

Equity. Equitable healthcare does not vary in quality because of personal characteristics, including gender, ethnicity, geographic location, or socioeconomic status (IOM, 2001). Promoting equity in rural areas can include providing access to pain management services that have historically been unavailable due to location, isolation, and social issues (Beuhler, 2006). Equitable healthcare also includes providing effective pain treatment to patients who struggle with substance abuse (Fishman, 2007). It includes recognizing the high prevalence of disease processes and lifestyle choices that contribute to the development of painful conditions in rural populations (Helman, 2006). Equitable healthcare benefits the individual and society yet the evidence shows there is much variability in healthcare quality based on race, gender, age, socioeconomic status, and community (IOM, 2007). Inequities in healthcare result in health disparities, increase morbidity and mortality, increase healthcare costs, and diminish quality of life (AHRQ, 2010). Effective pain management begins with pain assessment but the literature indicates that ethnic minorities, women, and elderly people are less likely to have their pain assessed (Green, 2003). Very little is known about how individual factors such as culture, family, support systems, and preferences influence pain care (Palos & Ashing-Giwa, 2007). Efforts to improve pain care will need to include patients as full healthcare partners in order to elucidate these factors. Patients were interviewed in this study and were encouraged to express their views on factors such as culture, family, social issues, and preferences that affect pain care. This information can be used as the foundation of future pain management research and program design (Helman, 2006). Knowledge about local cultural influences increases the odds that

patients will be understood on their terms when they seek pain care (Bar-Yam, 2006). This knowledge informs the design of a pain management program and can help reduce barriers to effective care. The development of standardized pain assessment and care practices within a pain management program will increase the quality of care and will promote equity in the pain care that is delivered in this community (Weiner, et al, 2006).

Summary

Pain is a major health issue in this country and under-treatment results in significant individual, community, and societal burden. Multiple factors contribute to the problem of inadequate pain management including cultural issues and health system factors. The growing problem of prescription drug abuse is an added dimension that further complicates the provision of quality pain care. Native Americans and other minority populations are especially vulnerable to the problem of under-treatment and the subsequent negative outcomes associated with chronic pain.

A community-based participatory action approach was used for this assessment of local factors that influence pain management. Quantitative and qualitative methods were used to address the three specific aims:

1. Patient factors that influence the management of chronic pain
2. Provider factors that influence pain management.
3. Similarities and differences between Winslow providers and providers in the Texas Pain Study by Weinstein, et al (2000) related to factors that influence pain management.

The IOM lists six characteristics of quality that should be reflected in healthcare delivery: safety, timeliness, effectiveness, efficiency, patient-centeredness, and equity. The purpose of this

study was to describe the local perspectives of Native American people on the subject of chronic pain, self-management strategies, and experiences in seeking treatment within indigenous and allopathic healthcare systems. Patient and provider perspectives were compared and contrasted to identify and describe the tensions that complicate pain treatment within a tribal health setting wherein transcultural communication is critical to outcomes. The information derived from this inquiry can be used to design a pain management program that is culturally sensitive and that reflects the IOM quality indicators.

CHAPTER 2: FRAMEWORK AND LITERATURE REVIEW

Introduction

In Chapter 2, a literature review and discussion of the conceptual framework will be presented. The literature reviewed includes cultural influences and multiple barriers to pain management such as health system factors, social, and economic factors. Theoretical frameworks presented include general systems theory and whole systems of medicine. An overview of community-based participatory research and the relevance to complex systems and whole systems of medicine will be discussed.

Each year in the United States, consumers pay billions of dollars out-of-pocket for a range of complementary and alternative therapies (Nahin, Barnes, Stussman, & Bloom, 2009). Trends show that more and more Americans are becoming increasingly dissatisfied with the dominant allopathic model of health care delivery while complementary and alternative therapies are enjoying a renewed popularity (Nahin, et al, 2009). As the benefits of these modalities are being rediscovered, the dominant allopathic medical community has begun to question their effectiveness and demand scientific evidence to support their use. Payers also want evidence that alternative therapies are effective as consumers push to have them covered by health insurance plans (National Center for Health Statistics, 2006).

The National Center for Complementary and Alternative Medicine (NCCAM) (2005) defines WSM as “whole medical systems (involving) complete systems of theory and practice that have evolved independently from or parallel to allopathic (conventional) medicine (p. 30).” Chronic unremitting pain is a primary reason that people turn to alternative treatments, including whole medical systems, such as Traditional Chinese Medicine (TCM) and homeopathy (National

Centers for Complementary and Alternative Medicine, 2010). Ritenbaugh, Hammerschlag, Calabrese, Mist, Aickin, Sutherland, et al (2009) state that people suffering from chronic pain often seek out alternative treatments, including whole systems of CAM, to decrease dependence on medications, to improve the quality of their lives, and to decrease the disabilities associated with chronic pain and its treatment by the allopathic health care system.

Native American traditional medicine is a whole system of medicine that encompasses a range of treatments used by indigenous healers to provide holistic treatment for a multitude of acute and chronic health problems. Whole systems of medicine (WSM) have evolved over centuries and continue to be the primary source of healthcare for a majority of the world's population (NCCAM, 2007). The bio-psycho-socio-spiritual aspects of health hold equal importance in WSM. This stands in stark contrast to allopathic medicine which is concerned primarily with biologic factors alone. Methods of pain treatment that are used by NA traditional healers may be effective therapies that can stand alone or can be integrated with allopathic and other CAM modalities to treat pain, particularly in Native American populations.

Literature Review

Pain is a universal phenomenon that causes tremendous human suffering and interferes with individual quality of life and social productivity (American Pain Society, 2009). Thirty percent of the US population experiences some type of chronic pain. Fifty to sixty percent of those who are affected are often dramatically disabled; some for a few days, others for several months or permanently. It is estimated that pain-related financial losses exceed \$100 billion annually (Minnesota Center for Pain Research, 2006). In the United States, more than 100,000,000 people are afflicted with chronic non-malignant pain and pain-related issues prompt

as much as 80% of visits to a healthcare provider (American Pain Society, 2009). The cost of chronic pain to US taxpayers is estimated to be between \$15,000 billion to \$24,000 billion annually; more than \$150 billion is spent annually on health care and disability associated with pain (O'Rourke, et al, 2007).

A systematic review of studies concerning the prevalence and impact of chronic pain around the world revealed that an average of 20% of the world's population have inadequately treated pain in spite of the availability of effective treatments (Castro-Lopes, Borgeat, Collet, & Rhodin, 2005). Pain is undertreated for many reasons including cultural factors; misperceptions about pain medications, health provider barriers, health system barriers, and social stigmatization (Brennan, 2007). Drug regulating agencies also create barriers to the prescribing of effective pain medications (Castro-Lopes, et al, 2005).

Culture and Pain

The influences of culture on symptoms, patient/provider relationships, and adherence to treatment have been well-documented (Cuffe, Waller, Cuccaro, Pumariega, & Garrison, 1995; Helman, 2006; Pumariega, Johnson, Sheridan, & Cuffe, 1996; Saha, 1999). Culture in healthcare is an important factor that encompasses the values, beliefs, and behaviors of a person or group and the influence of these characteristics on health care practices (Suh, 2008). Cultural competence is, therefore, a critical factor in the IHS setting since a majority of health care providers are non-Native (Indian Health Service, 2009). Purnell and Paulanka (1998) defined cultural competence as “developing an awareness of one's own existence, sensations, thoughts, and environment without letting it have an undue influence on those from other backgrounds; demonstrating knowledge and understanding of the client's culture; accepting and respecting

cultural differences; and adapting care to be congruent with the client's culture" (p. 57). Giger, Davidhizar, Harden, Phillips, & Strickland (2007) stated that "only when self-awareness combines with insight about others then true sensitivity can be demonstrated by individuals, healthcare systems, and communities" (p. 98).

Cultural competency has been declared by the Office of Minority Health (2005) to be one of the main ingredients for reducing disparities in health care. It is a transcendence of the differences that both patients and providers bring to the encounter that enhances communication and enables the design of treatment plans that improve health outcomes (Helman, 2006). According to Suh (2008), the antecedents to cultural competence can be grouped into four domains: cognitive, affective, behavioral and environmental. In the cognitive domain, cultural awareness stems from an appreciation for cultural diversity and is the recognition that cultural competence is necessary. An examination of one's own cultural background and prejudice is a step toward cultural awareness. Cultural knowledge involves learning about the other culture's world view, language, history, politics, social, and economic factors (Suh, 2008). Cultural immersion is the most efficient way to achieve this knowledge but few health care providers have the opportunity to become immersed in Native American culture (Indian Health Service, 2009). The affective domain is comprised of cultural sensitivity which involves having an accepting attitude and a respect for cultural differences. The manifestation of proficient cultural skill is in the behavioral domain and this includes intercultural communication skills and health assessments that help determine the appropriate interventions within the context of the client. The environmental domain represents the setting in which a patient and healthcare provider from different cultures interact (Suh, 2008).

Multiple patient factors, many of which are culturally influenced, contribute to the barriers to adequate pain management (Helman, 2006). The ways in which they may create barriers are through their reluctance to report pain to physicians, reluctance to take pain medication, and lack of education regarding available pain therapies (Palos & Ashing-Giwa, 2007; Purnell & Paulanka, 1998). Gender is a strong predictor of pain recognition; women are more likely than men to reveal pain symptoms both verbally and non-verbally (Bertakis, Azari, & Callahan, 2004). They are also more likely than men to request various types of treatments and studies related to pain. Recognition of pain and documentation in the encounter notes was shown to be strongly influenced by the severity of pain reported by the patient as well as the practice patterns of the provider (Bertakis, et al, 2004).

The allopathic model has become the dominant mode of healthcare delivery in developed countries only over the past 50 or so years (NCCAM, 2007). This trend has culminated in a reactive, disease-focused, non-sustainable system of healthcare that threatens to collapse under the weight of this burden (Weiner, et al, 2006). As a result of scientific advancements and pharmaceutical development, people in developed countries are living longer with more chronic diseases (Weiner, et al, 2006). However, these same technological advancements have been accompanied by unsustainable rises in financial costs. Within the United States, the cost of caring for an older population who are surviving previously untreatable diseases is burgeoning (AHRQ, 2001). Further, the focus on allopathic models of health/illness has resulted in a disregard for whole systems of medicine that certain populations have used for centuries. This is particularly troublesome when indigenous populations, such as Native Americans, are required

to negotiate a Western culture that relies solely on the dominant allopathic system of care to address health-related issues (Office of Minority Health, 2009).

Native American Pain Response and Treatment

Published research on chronic non-cancer pain among Native Americans is limited. This presents a major gap in the literature and limits the efforts of health care providers to access information to guide their practice when treating pain in this population. A study by Kramer (2002) found that Native Americans tend to understate their pain levels and that this often leads to misperceptions and under treatment. These findings are supported by Warne (2008), a NA physician, researcher, and lecturer.

Both Warne (2008) and Morgan (2008) agree that NA health beliefs are grounded in the concepts of harmony and respect for all things. Both of these Native American cultural experts have expressed that pain may be viewed by NA people as a consequence of being in disharmony with the environment. It may also be viewed as a direct result of the negative and harmful effects of the environment rather than simply a physical ailment (Morgan, 2008). Traditional healers treat pain, as well as multiple other acute and chronic conditions, through healing and purification ceremonies that have endured for thousands of years (Warne, 2008).

Native Americans have at least partially integrated the allopathic model of healthcare used by the IHS and this is manifested by the increasing numbers of visits to IHS facilities (IHS, 2009). The IHS was formed and introduced to their environment as a result of land treaties that obligate the federal government to provide healthcare services to all Native American and Alaskan Indian people (Northwest Federation of Community Organizations 2009). Yet, many traditional Native American continue to reject allopathic interventions, particularly

pharmaceuticals (Palos & Ashing-Giwa, 2007). Native American research methods have traditionally involved consulting with the elders to determine the best actions in the face of uncertainty which modern tribal leaders equate to a “literature review” (Arizona Biomedical Research Commission, 2006).

Today Native Americans frequently combine traditional healing with allopathic medicine to treat common health issues such as chronic pain (Morgan, 2008). However, allopathic providers are frequently unsure of their role in helping these patients and cultural barriers to effective communication about pain often leave both parties frustrated (Palos & Ashing-Giwa, 2007). Health beliefs are culturally constructed but allopathic practitioners in the IHS seldom have the opportunity to gain an adequate level of understanding regarding local traditions. This severely limits their awareness of the influence of culture on patients’ acceptance of their treatment plans (Palos & Ashing-Giwa, 2007). Improved insight into decision-making strategies will enhance the ability to create jointly constructed patient-centered treatment plans that lead to better outcomes (Helman, 2006). An integrative, multidisciplinary approach may be the best method to address chronic pain management (Weiner, et al, 2006). Whatever the approach, cultural factors must be considered and increased provider awareness and incorporation of measures that address these factors are an essential component of the successful treatment of chronic pain (Helman, 2006).

Symbolic healing. Ceremonies play an important role in the overall wellbeing of traditional Native American people, but the healing potential of this practice is generally unappreciated by allopathic health providers (Warne, 2008). Symbolic healing is an integral and powerful component of traditional Native American health beliefs that has significant

implications for a multidisciplinary approach to health and illness. Religious healing, Shamanism, and Western psychology are versions of symbolic healing that invoke similar psychological processes (Dow, 1986). Traditional beliefs and practices are an important aspect of health and wellbeing even among those who have converted to Christianity since the influence of tribal mores on the worldview of tribal members persists through family and cultural ties. Christianity also uses rituals, myths, icons, and symbols that unite and define members of various sects (Barrett, 2000). Conversion to Christianity is, therefore, only a minor philosophical departure from Native American tradition. In fact, some Christian religions on the reservations have integrated Native songs and dances into their services (Morgan, 2008). Among younger generations of Native Americans, especially those who do not live on the reservation, a traditional worldview may be less pervasive as manifested by their widespread assimilation of the behaviors of the dominant culture and non-adherence to traditional taboos (Morgan, 2008).

The symbolic aspect of healing is ever present, even when effective physical and pharmacologic therapies are employed. Dow (1986) has provided several common theoretical constructs that explain the underlying mechanism of symbolic healing among various cultures. Among these are: suggestion, catharsis, social restructuring, and psychochemical action. A health provider's beliefs, whether traditional or Western, constitute his personal myth. Symbolic healing systems are culturally established: allopathic practitioners usually generate their personal myth around scientific knowledge while indigenous cultures may often place theirs in a supernatural realm (Dow, 1986). Symbolic healing has the potential to be a powerful, patient-centered tool that can be integrated into allopathic treatments for the alleviation of pain and promotion of health (Kirmayer, 2004). Unfortunately, the egocentricity inherent in the allopathic

model often leads to the failure of Western medicine to acknowledge the spiritual and cultural aspects of health and illness. In this study patients had the opportunity to describe traditional practices used to manage pain. Healthcare providers are generally ignorant regarding a patient's self-treatment plan (World Health Organization, 2006). Because health and spirituality are inseparable in Native American culture, it is imperative for allopathic providers to realize that spiritual care must be delivered with equal emphasis in order to create the opportunity for healing. Learning to communicate about Native practices, including ceremonies and spirituality, is a major step for most allopathic healthcare providers. However, a working knowledge of the importance and utility of ceremonies in restoring health and wellbeing can greatly enhance the ability to design effective pain treatment plans as well as other aspects of patient care (Palos & Ashing-Giwa, (2007).

For this inquiry, systems theories were the lens for exploring the perspectives of Native American people concerning chronic pain (Bertalanffy, 1968). Whole systems of medicine (WSM), such as Native American traditional medicine, are complex systems whose components are thought to be synergistic in producing positive health outcomes (NCCAM, 2010). The "active ingredients" in WSM are often difficult to identify and impossible to isolate. The bio-psycho-socio-spiritual components of WSM interventions, combined with the therapeutic effects of the patient/provider (or healer) interaction, are thought to produce effects that complement and perpetuate one another to produce often non-linear results over time (Bar-Yam, 2006). Understanding these elements is one aspect that was explored in this assessment.

Barriers to Pain Treatment

There are many barriers to the treatment of chronic pain, including healthcare provider barriers, patient barriers, health system barriers, and barriers related to drug regulating agencies.

Healthcare provider barriers. A study by O'Rourke, et al (2007) conducted in 12 academic medical centers revealed that most primary care physicians are not comfortable providing treatment to patients with chronic non-malignant pain and many lack adequate training in chronic pain management. Only 1% of the physicians in this study found pain management to be satisfying and 68% preferred a multidisciplinary approach.

Pain management is a complex task that involves consideration for all aspects of a patient's life (Palos & Ashing-Giwa, 2007). Visual pain scales and functional capacity are the parameters typically used by healthcare providers in outpatient care to evaluate extent of pain as well as the effectiveness of pain management. However, these scales have not been validated in Native American populations (Bertakis, Azari, & Callahan, 2004). A thorough pain evaluation involves much more than simply eliciting where a patient falls on a visual pain scale (American Society of Anesthesiologists, 2010). Assessment of a person's overall level of comfort may be a more appropriate approach. Comfort evaluation extends beyond functional capacity and includes the multi-faceted personal and environmental factors that contribute to the pain experience and influence treatment outcomes. Pain is a multi-faceted problem that must be approached from a broad perspective that encompasses the many factors that influence the perception of the pain experience. Comfort assessment is a term borrowed from palliative that is transferable to outpatient care. This terminology incorporates the network of systems that comprise a patient's whole being and which also interact to define the quality of a person's life. The concept of

comfort refers to the experience of relief, ease, or transcendence of physical, psycho-spiritual, environmental, and social needs. The components of comfort assessment are the physical, the psychosocial issues experience by the patient, the psychosocial issues involving the family, and the spiritual characteristics of the patient (Beth-Israel, 2008).

The high turnover rate among healthcare providers in the IHS system also limits the capacity for development of the high level of cultural competence that is necessary in order to evaluate these factors (IHS, 2009). Furthermore, allopathic medical training is focused on the biologic processes that contribute to disease, thus, very few healthcare providers have been trained to perform a comprehensive evaluation of all the synergistic factors that are present in chronic pain syndromes (O'Rourke et al, 2007).

Additional provider barriers to pain treatment include inadequate training and knowledge concerning pain management, improper assessment of pain, fear of patient addiction, fear of drug regulating agencies, concern regarding analgesic side effects, and concern regarding the development of tolerance to analgesics (Brennan, et al, 2007; Wienstein, et al, 2000). The ability to recognize pain is a basic but common barrier to adequate treatment. Bertakis, et al (2007) opined that physician attitudes also have an effect on the likelihood that pain will be evaluated in men versus women. They may view women as being more sensitive to pain and men as being physically stronger and more tolerant to pain. The competing demands of primary care plus time constraints also influence the likelihood that providers will identify and treat pain in the clinical setting (Lewis, Combs, & Trafton, 2010). Interestingly, a practice style that focused on prevention was less likely in the Bertakis (2007) study to result in a pain diagnosis than a technical practice style that focused on history taking, physical exam, and treatment. Provider

fears of patient addiction are generally unwarranted. Research has established that the risks for addiction to opioids are greatly exaggerated and they are very low when used during appropriate pain management (Taylor, 2008). Likewise, any adverse effects associated with pharmaceutical treatments can generally be managed through providing adequate patient education (Lewis, et al, 2010).

A published review by Brennan, Carr and Cousins (2007) cites “opiophobia” and “opioignorance” as major barriers to the appropriate treatment of pain. Surveys of both patients and providers consistently show unfounded anxiety about adverse side effects and concern about addiction, tolerance, and over-medication (Brennan, et al, 2007; O’Rorke, et al, 2007). Health care providers from all disciplines report inadequate training regarding pain treatment (O’Rorke, et al, 2007; Weinstein, et al, 2000). Education of providers regarding pain management increases their comfort with providing care to patients in pain and enhances their willingness to take charge of managing pain (O’Rorke, et al, 2007). Education of patients by providers regarding their pain therapy reduces the potential for treatment failure due to the frustration and noncompliance patients experience when they do not understand their treatment plans (Campbell as cited in Weiner, et al, 2007; Lewis, et al, 2010).

Patient factors. Among patients, negative attitudes about opioid use are associated with older age, lower socioeconomic status, and lower levels of education (Brennan, et al, 2007). Economic factors also influence pain care. Inadequate reimbursement for pain management remains a problem and the most appropriate treatment may not be reimbursed or it may be too costly for the patient (Joranson & Ryan, 2007). Access to care may be impacted by geographic location when patients must drive long distances to receive medical attention and treatments

(Beuhler, 2006). Furthermore, pharmacies in minority neighborhoods are less likely to stock opioid analgesics compared to pharmacies in predominantly white communities (Brennan, et al, 2007).

Rural living has been shown to be a barrier to accessing healthcare and, therefore, pain treatment (Beuhler, 2006). People in rural Arizona face harsh climate and geographic barriers such as temperature extremes, dust storms, flash flooding, and isolated unmaintained roads. The lack of public transportation further inhibits access to care and many people cannot afford automobiles or fuel. Lack of anonymity and the concept of insider/outsider are relevant to Winslow because it implies a limited ability for rural people to have private aspects of their life. The outsider/insider concept is important in respect to acceptance of all types of healthcare providers in rural communities (Long & Weinert, 2006).

One-fourth of the US population live in rural areas where there is a tendency to have a larger proportion of children and elderly than urban populations (Agency for Health Research and Quality, 2010). Rural residents tend to be poorer and less healthy than their urban counterparts yet have fewer primary care providers, hospitals, and many other resources available to treat their health conditions (AHRQ, 2010). Nearly one in three rural residents are in poor health and almost half have a chronic disease. Traumatic injuries are more common than in urban areas and outcomes are worse due to the lack of transportation and lack of emergency medical response personnel (AHRQ, 2010). Access to advanced interventional pain treatment may be further limited by the lack of available hospitals where these procedures are often performed. Rural hospitals struggle financially and many of them have closed their doors

altogether. The lack of insurance and prevalence of underinsurance contributes to the financial burden placed on rural health facilities (Younis, 2003).

According to Long and Weinert (2006) rural dwellers define health as the ability to be productive in their usual tasks. Their research indicates that people who live in rural areas tend to place little emphasis on comfort, cosmetic, and life-prolonging aspects of health. They also found that health is viewed as the ability to function in one's work role; pain is often tolerated for extended periods as long as it does not interfere with functional capacity. Rural dwellers generally resist help or services from "outsiders" or government agencies and help is often sought through informal systems. Family, relatives, and close friends are the usual resources when help is needed. The overall frequency of the use of healthcare professionals and formal human service agencies is much less in rural populations than in their urban counterparts. This self-reliance often leads to delayed entry into healthcare for serious medical issues (Weiner & Long, 2006). Rural living obviously has significant effects on a person's actions and the time it takes to seek treatment once symptoms have been identified. The Symptom-Action-Timeline model presented by Beuler, et al, (2006) contributes to the understanding of this process.

Health and illness behavior is determined by how people identify and respond to their symptoms (Lenz, 1984). The patient seeking treatment is the first step in the process of pain treatment. The Symptom-Action-Time-Line model proposed by Buehler, Malone, and Majerus-Wegerhoff (2006) can aid in the understanding of patients' treatment-seeking behavior. Buehler, et al, found that Native American women in Montana used the symptom-action-time-line (SATL) process to respond to health symptoms. The four stages are symptom identification, self-care, lay resources, and professional resources. Within each stage the person takes actions in

response to a symptom and then decides whether or not to go on to the next stage. Buehler, et al, (2006) compared the SATL of Native American women to that of Caucasian women. The following paragraphs constitute a summary of these findings.

The symptom identifications stage is the recognition of the presence of an alteration in health status. Physical signs and sensations, degree of interference in the ability to function, and intensity and duration were the symptomatic cues to perceived changes in health status. Symptoms were assessed by the women and given meaning and then it was decided whether or not action was needed. Knowledge and past experience with illness, severity and duration of the symptoms, and the extent to which this interfered with function were factors that influenced the perceived need for action. Variations in symptom identification were due to meaning given to the symptoms. Native American women believed that some symptoms were due to supernatural forces and sought the help of a medicine man. Both Native American and Caucasian women had lower thresholds for action toward symptoms in their children which resulted in shorter SATL processes for children.

The self-care stage involved self-initiated activities in response to symptoms such as getting more rest or consciously watching for further symptoms. The time-line for this stage was mostly dictated by the intensity of the symptoms and ranged from seconds to days. Sometimes self-care tools such as over-the-counter medications or heating pads were used. The majority of Native American women in this study used traditional self-care tools such as sage, sweet-grass, and medicine bundles; in contrast, Caucasian women used family health textbooks. Prayer and spirituality have also been mentioned throughout the literature as self-care strategies. Initiating

self-care, evaluating its effectiveness, and deciding to seek help if self-care was ineffective are the components of the self-care stage.

The lay resources stage is the third stage in the SATL, however, varying degrees of self-care continue through this stage. The women in the Buehler study asked for health advice from their informal network of family, friends, and neighbors in the third stage. The components of this stage are validation of symptoms, advice-seeking, receiving care, or seeking emotional support. Women particularly wanted advice from lay resources on whether or not they needed to see a doctor. Their mother was the most frequently used resource among both Native American and Caucasian women.

Seeking help from professional resources is the final stage of the SATL. Professional resources were utilized only after self-care and lay resources had been implemented and failed. The time-line from symptom identification to seeking professional advice ranged from two to five days for Native American women in the Buehler study. The range for Caucasian women was four to seven days for rural dwellers and one to two weeks for frontier dwellers. After visiting a professional, Native American women in this study often visited a medicine man if they felt the allopathic provider had not helped. Distance and transportation issues were the most frequently identified barriers to seeking professional care. Secondary barriers were the lack of female practitioners, the time required (especially waiting room time), and the fear of bad news regarding their health (Buehler, et al, 2006).

The literature suggests that men tend to delay seeking professional help as long as possible and may have very different, longer time-lines; however, most of the studies focus on women (Beuler, et al, 2006). Although the Buehler SATL seems to be representative of the

response to acute problems, O'Lynne (2006) proposed that chronic diseases may follow a different timeline. Previous experience may influence whether or not people forego self-care and lay resources. They may seek professional resources earlier as they become more familiar and knowledgeable about how to interpret symptoms of chronic disease when they recur. Furthermore, the time-line may be more of a circular process as people use self-care, lay resources, and professional treatments at the same time or a various times throughout the course of a chronic illness. Buehler's model does not account for psychological symptoms that frequently accompany chronic illness nor does it address the contextual variables that influence actions. The symptom-action process (SAP) proposed by O'Lynn (2006) has the action process embedded in an external context. In this model context influences which action or combination of actions is taken. The SAP and SATL models may aid healthcare professionals in meeting the health needs of rural dwellers but variables, such as gender, that influence time-lines need further research.

Health system barriers. The current inadequacies in pain care are not solely the result of physician-patient interaction. Pain management is given a low priority in the US health system, and there are multiple system barriers that inhibit effective pain management (Bertakis, et al, 2004; Office of Minority Health, 2009). Quality is a multidimensional property of health systems that requires the combined efforts of both providers and health care organizations. When there is support at the health system level health care providers are more likely to implement clinical practice guidelines and evidence-based practices that have been shown to improve pain outcomes (O'Rorke, et al, 2007). Clinical reminders in electronic health records are strong predictors of whether providers will implement clinical practice guidelines (CPGs) related to pain (AHRQ,

2010; Fung, et al, 2004). The Veterans Administration (VA) is a leader in the development of electronic health systems in the United States and has implemented a variety of clinical reminders to improve patient care. However, one large, national study of VA clinical sites revealed that reminders related to pain assessment are rarely incorporated (Craine & Kerns, 2003). The treatment of pain was strongly correlated with patient satisfaction with overall care in the Bertakis, et al., study (2007).

Since clinical reminders have resulted in higher rates of provider compliance with CPGs in general, the inclusion of pain-related reminders could improve pain outcomes (Fung, et al., 2004). The IHS and VA are both subject to the Government Performance Results Act (GPRA). An inhibiting factor is that although healthcare organizations that are subject to GPRA are required to adapt the implementation of CPGs to meet local conditions, pain is not among the priorities of GPRA and is not, therefore, a data-collection or quality reporting priority of these agencies (Government Performance Results Act of 1993). It is impossible to predict the adherence of IHS providers to CPGs for pain assessment and treatment as well as associated patient outcomes unless a local study of these quality indicators is conducted. One way to assist healthcare providers in providing quality pain care is to create guideline-specific task forces to develop a well-planned implementation processes and provide guideline summaries to providers. Including providers in this process fosters buy-in, which ultimately leads to improved likelihood for the incorporation of the CPGs into practice (Quiros, Lin, & Larson, 2008).

The lack of availability of certain pain treatments is a problem that exists in some health systems (American Pain Foundation, 2010). The Winslow tribal healthcare system is fortunate to have multiple resources in place that have been shown in studies to provide good results in the

treatment of pain (Patel, 2006; Sherman, Cherkin, Erro, Miglioretti, & Deyo, 2005). A multidisciplinary staff is already on hand and they are capable of offering a wide array of interventions that have the potential to improve pain care at this facility. The available types of professionals that can contribute to pain care are allopathic physicians, nurse practitioners and nurses, behavioral health professionals, pharmacists, physical therapists, a traditional healer, an acupuncturist, and a massage therapist. There are also classes for yoga and tai chi both of which have been shown in studies to have positive results in the management of chronic pain (Patel, 2006; Sherman, Cherkin, et al, 2005). Treatment access problems are still among the top barriers that exist in this and the US health system (Brennan, et al, 2007). Non-generic drugs are generally not available in the Indian Health Service and this includes certain long-acting formulations and the new abuse-resistant formulations that are helpful for treating patients with drug abuse issues (Fishman, 2007).

Barriers induced by drug regulating agencies. Pain sufferers are forced to negotiate a social climate where “war on drugs” has been declared (Gilson, 2010). This war encompasses legitimate prescription opioid analgesics due to the increase in the aberrant use of these drugs (Fishman, 2007). Most patients do not abuse their prescriptions but the social stigma that can result from chronic opioid therapy can complicate treatment efforts (Brennan, et al, 2007). In fact, less than 4% of patients who are prescribed opioid analgesics engage in aberrant use of these drugs (SAMHSA, 2010). It is acknowledged that the contacts of patients who obtain opioids legitimately may use these patients as a source to obtain drugs for abuse or diversion with or without the knowledge of the patient for whom the drug is intended (SAMHSA, 2010).

The global war on drugs is a societal issue that has negatively impacted access to pain treatment by causing concern about scrutiny from regulatory agencies (Brennan, et al, 2007). The International Narcotics Control Board (INCB) is responsible for reducing global drug abuse. Even this organization has declared that governments have gone too far in their attempts to control the illicit consumption of opioid medications and that control is an impediment that has resulted in the denial of adequate pain treatment (International Narcotics Control Board, 2004). Physicians, fearful of investigation, avoid appropriate treatment while switching patients from one ineffective medication to another. Widely publicized cases have caused fear of criminal prosecution further contributing to under-treatment (Brennan, et al, 2007). Over-regulation also causes problems for patients by stigmatizing the use of controlled drugs and generating concerns about privacy. Access has been markedly improved in some countries through evidence-based reforms in drug regulation (Joranson & Ryan, 2007). For example, India and Kerala facilitated an increase in community-based palliative care improved access to treatment by loosening licensing requirements for pharmacies. Romania and Italy have also successfully engaged in regulatory reform by streamlining administrative processes and improving access to strong opioids for patients with severe pain regardless of the underlying cause. Educational campaigns in Romania have been designed to inform the public, healthcare professionals, regulators and law enforcement officials. Access to pain care can be increased through regulation reform without increasing the misuse of drugs or diverting them to illegal markets (Joranson & Ryan, 2007).

Governments around the world are taking notice of the consequences of under treated pain and many have initiated policy changes related to pain control (International Narcotics Control Board, 2004). Both Europe and the United States have proposed national legislation to

review existing policies affecting access to strong opioids for the treatment of pain (National Pain Care Policy Act of 2009; The Open Minds Group, White Paper, 2005;). The U.S. National Pain Care Policy Act, signed into law in March 2010, requires the Secretary of Health and Human Services (HHS) to seek an agreement with the Institute of Medicine to convene a Conference on Pain to:

- (1) increase the recognition of pain as a significant public health problem in the United States;
- (2) evaluate the adequacy of assessment, diagnosis, treatment, and management of acute and chronic pain;
- (3) identify barriers to appropriate pain care; and
- (4) establish an agenda to reduce such barriers and significantly improve the state of pain care research, education, and clinical care in the United States. (3/30/2009, Section 2).

This Act also requires the Director of the National Institutes of Health (NIH) to continue and expand, through the Pain Consortium, an aggressive program of basic and clinical research on the causes of and potential treatments for pain and the establishment of an Interagency Pain Research Coordinating Committee that will:

- (1) Develop a summary of advances in federal pain care research relevant to the diagnosis, prevention, and treatment of pain and diseases and disorders associated with pain; and
- (2) Identify critical gaps in basic and clinical research on the symptoms and causes of pain. (03/30/2009, Section 409J).

As such, the National Pain Care Policy Act requires HHS to establish and implement a national pain care education outreach and awareness campaign to educate providers, consumers, patients, their families, and other caregivers.

Pain Treatment Modalities

Various CAM modalities are readily available at the Winslow tribal health center. The CAM modalities available on campus for treating pain are: Acupuncture, yoga, massage, tai chi, and a traditional healer. The available allopathic modalities are: Physical therapy, behavioral health, opioid and adjunctive medications, and specialty referral. Specialty referrals for painful conditions are made to orthopedic surgeons, neurosurgeons. Treatments provided by intervention specialists may include implantable devices such as spinal stimulators, or minimally invasive procedures such as epidural injections (American Pain Society, 2007).

Discussions with the providers at the Winslow IHS indicated they feel that patients tend to have a poor understanding of allopathic interventions and their intended outcomes. Providers reported that patients seem to mistrust medications and are particularly fearful of opioid analgesics. This likely results in poor medication compliance and, thus, poor response to prescribed medications (Lewis, et al, 2010). Patients often reported that they combine allopathic treatments with ceremonies and herbs prescribed by traditional healers, a practice that is common among NA populations (American Cancer Society, 2010).

Theoretical Framework

General systems theory is a theory of wholeness that was introduced by Ludwig Von Bertalanffy in the early 20th century. The major premise of this theory is that living systems are open, complex, and adaptive allowing for maintenance of a steady state in response to changes in

the internal and external environments. A system is defined as an interrelated set of elements and boundaries between dynamic systems are naturally blurred and fragmented (Bertalanffy, 1968). Closed systems are systems that are isolated from their environment; in contrast, all living things are dynamic, open systems that are constantly interacting with the environment. In a dynamic system, the whole is greater than the sum of the parts. The state of each unit within a system is continuously in motion and is dependent upon these interactions. Open complex systems display emergent, non-linear behaviors through the exchange of energy with the environment and evolve in complexity over time (Bell & Koithan, 2006).

There are persistent disparities in the health of indigenous populations in spite of efforts to curb rising rates of chronic disease (IOM, 2001). Worsening health has been correlated with deviations from traditional health practices among indigenous people that have occurred along with their assimilation into the dominant culture (IHS, 2009). Recent efforts to encourage a return to traditional lifestyles, while admirable, have not produced significant improvements in health (IHS, 2009). Furthermore, the failure of the government health system to fully integrate traditional and allopathic medicine limits the provision of effective healthcare services (World Health Organization, 2006). Traditional healing systems and the IHS medical model are parallel systems of health care delivery that are commonly used by indigenous people, often simultaneously (American Cancer Society, 2009). Systems theories can be used as a framework to improve the understanding of indigenous health systems and to develop strategies to improve their integration with the Western model that has been imposed by the IHS. It is imperative, therefore, to temper findings in the extant literature, practice recommendations, and the “evidence” related to chronic pain treatment with an increased understanding of cultural and

social influences on health in order to design interventions that can reverse the trends in worsening health disparities among indigenous people.

“Evidence based medicine” is the buzz phrase in 21st century allopathic medicine and hard evidence derived from rigorous randomized control trials (RCT) is the gold standard for generation of new knowledge (Perry & Kronenfield, 2009). In the real world, however, multiple influences in the natural environment produce outcomes that cannot be predicted by randomized control trials (Verhoef, Lewith, Ritenbaugh, Boon, Fleishman, & Leis, 2005). Further, the reductionistic approach to systems does not fit with the complexity of this real world of clinical practice and human health/illness. Hence, the very foundation on which allopathic medicine exists falls short in justifying many of its practices.

Complexity theory provides an explanatory model that can improve the understanding of how traditional healing and other WSM improve health (Litaker, Tomolo, Liberatore, Stange, & Aron, 2009). People are exposed to multiple elements and are subjected to multiple influences at any given time in their existence. Complexity theory attempts to explain how a number of different elements respond when exposed to multiple influences at the same time (Laszlo, 1996). Response to treatment is nonlinear and often unpredictable, people do not operate with machine-like precision, and context must be considered in all treatment-response patterns. Thus, pain treatments must be individualized, patient beliefs should impact pain treatment choices, and response should be monitored over time to assure that the treatment has been effective.

Studies about appropriate pain therapies must also be reconsidered. Methodological approaches to effectiveness research need to be examined in light of the principles of complexity science. The purpose of the randomized control trial (RCT) is to eliminate these influences

because they “distort” linear relationships between interventions and outcomes (Field, 2005). Since complexity science questions this linear response paradigm, RCTs, the foundation of allopathic medicine and outcomes research, fails to account for the nonlinear nature of the responses that real people existing in a complex world have to treatment.

Community-Based Participatory Research and Complex Systems

Community-based participatory research (CBPR) allows for the incorporation of mixed methods to explore interacting phenomena that are poorly clarified using either quantitative or qualitative methods alone. Relationships in complex systems are typically nonlinear and can be difficult to study using conventional research methods (Verhoef, et al, 2005). CBPR is a study approach that was chosen for this study. CBPR is defined as: “a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and what is practiced in communities to improve health” (AHRQ, 2004). The CBPR paradigm is based on inclusion and democracy and is a partnership between communities and academics to share knowledge production and to address community-driven research priorities. Thus, CBPR assumes that communities and researchers will engage in a co-learning process that leads to problem-solving and the building of community capacity. Knowledge that is gained from this process is beneficial to all partners (Minkler, 2005). It is actively used to improve lives of community members and the structure/function of the community as a whole while informing others, including scientists, about the nature of phenomena as they are experienced in the daily lives of communities members and ways that communities respond to issues and solve problems (Flicker, et al, 2007).

The ultimate goal of CBPR is to improve the lives of community members through the implementation of the three inter-related elements of this approach: participation, research, and action (Minkler, 2005). Study phases include: (a) a full needs assessment for the purposes of, (i) understanding the phenomenon of interest, (ii) delineating the current state of affairs as related to the phenomenon of interest, and (iii) describing issues that the community faces relative to the phenomenon of interest (formative assessment); (b) building community capacity; (c) identifying a plan to address the issues and concerns that have been identified by the community; (d) implementing the plan for change, and (e) disseminating results of the project (Minkler, 2005).

CBPR typically takes place in a natural setting and involves long-term commitments (Flicker, et al, 2007). When investigating phenomena within communities, investigators use CBPR to identify all relevant variables and how they influence the issue of concern. Communities are complex systems whose components are constantly interacting with each other and with the environment (Bell & Koithan, 2006). The phenomenon, its relevance, and the outcomes are defined from the community perspective because human health and disease have etiology that extends beyond the biology and behavior of individual human beings (Midgley, 2006).

CBPR involves communities at the grassroots level to identify and resolve health issues. Widespread involvement increases the ability to accurately measure the problem and to develop treatments that are acceptable to the local population (Flicker, et al, 2007). CBPR enables informed, contextually-based planning and decision-making that will contribute to program effectiveness and successful implementation (Midgley, 2006). This approach to addressing health issues has been shown to contribute to increased acceptance by the target population of

the resulting interventions (Gittelsohn, Evans, Helitzer, Anliker, Story, Metacalfe, et al, 1998). There are no distinct sampling and data collection/analysis methods ascribed to the CBPR approach; a variety of qualitative and quantitative methods can be incorporated into the design, with methods individualized to fit the purpose, aims, and needs of the target community (Examining Community-Institutional Partnerships for Prevention Research Group, 2006).

Summary

Chapter two has reviewed the literature about chronic pain, current treatments, and barriers to care. Pain is viewed as a multi-faceted, complex health issue that most primary care providers have not been adequately prepared to manage regardless of setting. Multidisciplinary pain management programs have been shown to be effective in addressing the many issues associated with the treatment of chronic pain. None of these models have been studied among NA people, however. Ethnic minorities, including Native Americans, continue to be under-represented in research studies. The consequences of underrepresentation include the failure to understand how specific health problems affect subgroups within the US population. Identification of culturally influenced treatment expectations provides a starting point for the creation of appropriate solutions to the problem of untreated and undertreated pain.

The problem of chronic pain is approached in this practice inquiry from an emic perspective. In order to reduce health care disparities among minority populations, it is first necessary to understand the problem. The barriers associated with effective pain care include cultural factors; misperceptions about pain medications, health provider barriers, health system barriers, and social stigmatization. A complex systems perspective acknowledges and embraces the interactions between the subsystems, allopathic and WSCAM. Complexity theory provides

explanatory models that can improve the understanding of how traditional healing and other WSM improve health either separately or in combination with allopathic treatments.

Theoretical framework for this practice inquiry was general systems theory and whole systems of medicine. The major premise of general systems theory is that living systems are open, complex, and adaptive allowing for maintenance of a steady state in response to changes in the internal and external environments. Whole systems of medicine such as Native American traditional healing encompass a range of treatments that are used by indigenous healers to provide holistic treatment for a multitude of acute and chronic health problems. People are exposed to multiple elements and influences in their environment and this often renders it difficult to study phenomenon of interest using conventional research methods. CBPR methods were chosen for this practice inquiry since this approach allows for the use of a variety of qualitative and quantitative methods that can be incorporated into the design to fit the purpose, aims, and needs of the target community.

CHAPTER 3: METHODS

Overview of Design

Community-based participatory research (CBPR) is the research approach that was chosen for this study. The research design was ethnographic in orientation, incorporating mixed methods to explore interacting phenomena that are typically limited using either quantitative or qualitative methods alone.

Application of Community Based Participatory Research in the Proposed Project

Since CBPR is an approach to research that typically unfolds over several years and includes several phases, it was necessary in this project to clearly delineate both long and short-term study goals and objectives. The long-term goal was to design and implement a pain management program, refining the program to meet the specific needs of Native American clients and then to evaluate program outcomes. The short-term goal focused on developing a knowledge base regarding issues around chronic pain and its treatment among Native American people within the Winslow community. Therefore, this project constitutes the first phase of the recommended longer-term CBPR that will ultimately lead to the development and refinement of an effective, culturally sensitive, interdisciplinary program for the management of chronic pain.

There are two communities of interest in this study. One community is the community of primary care providers who are responsible for evaluating and treating chronic pain. The second community is Native American people with chronic pain within the Winslow community. Community members with chronic pain are a population sub-group within this multi-ethnic border community; their reactions to pain are influenced by multiple factors including the allopathic healthcare system, cultural factors, traditional healing modalities and interactions with

the dominant culture. Outcomes are not linear in complex systems and cannot be adequately measured when examined out of context (Bar-Yam, 2006). CBPR acknowledges this limitation and preserves this context through inclusion and evaluation of issues from the community perspective.

Methods utilized in a CBPR approach are attractive to Native American tribes because they are more respectful to community knowledge, cultural beliefs and values; identify more relevant sampling, data collection, intervention, and evaluation methods that are accepted by the community within which the inquiry takes place (Strickland, 2006). This research approach was chosen for this practice inquiry because it capitalizes on the innate wisdom of the community to identify and describe issues around chronic pain management and ultimately to resolve problems and create new systems of management through a process that conveys respect for their culture, knowledge, and expertise (Garwick & Auger, 2003).

The CBPR approach engages communities at the grassroots level to evaluate locally relevant issues and to elicit information that is valid and sensitive to the many factors that influence outcomes for the involved subjects (Minkler, 2005; Strickland 2006). Thus, the assessment produced an emic perspective of issues around pain including the influences of patient/provider communication, treatment practices, self-management techniques, and the relationships of these perspectives to outcomes of pain control and wellbeing.

Three specific aims were identified for this inquiry:

1. Describe patient factors that influence the management of chronic pain
2. Describe provider factors that influence pain management.

3. Analyze similarities and differences between Winslow providers and providers in the Texas Pain Study by Weinstein, et al, (2000) related to factors that influence pain management.

Formative Assessment

Formative assessment is a preliminary step in developing effective programs to address community health issues. It is an evaluation of factors that influence an issue of concern for the purpose of planning an intervention to address that issue (Teufel-Shone, Siyuja, Watahomigie & Irwin, 2006). In this project, factors that influence the treatment and management of chronic pain in a sub-community of chronic pain sufferers who seek care at a rural IHS health center in Northern Arizona were examined and evaluated. Formative assessment involves identifying the problem, setting, population, and resources. A thorough knowledge of these factors is essential to designing successful programs to address community issues (Helman, 2006).

Methodological Approaches and Techniques

A mixed methods (qualitative and quantitative) approach was used to gain insight into the local factors that contribute to the self-management and treatment of chronic pain. Mixed methods were used because neither quantitative nor qualitative methods alone were sufficient to produce a rich description of the local factors that contribute to chronic pain management (Bell & Koithan, 2006). Mixed methods offer the potential for gaining a deeper understanding by elucidating facts that would not be uncovered using a single research method (Glesne, 2006). Patients with chronic pain treated at the Winslow Indian Health clinic were interviewed to address Aim 1 and the interviews were digitally recorded and analyzed for content. Healthcare

providers participated by responding to the survey, *Physician Factors Influencing Pain Management* (Cleeland, Cleeland, Dar, & Rinehardt, 1986), to address Aims 2 and 3.

According to Greene, et al (1989) and reinforced by Bazely (2004), there are five major advantages for the use of mixed methods designs: (1) *Triangulation* to test the consistency of findings; (2) *complementarity* to clarify and illustrate results from one method with the use of another; (3) *development* of results from one method to shape methods or steps that follow; (4) *initiation* to promote new research questions or to challenge results obtained through one method; and (5) *expansion* to provide richness and detail to the study (Greene, et al, 1989; Bazely, 2004). The use of mixed methods typically enables the researcher to produce results that have better quality and scope compared to using a single method alone (Bell & Koithan, 2006). Each method helps clarify data collected by the other method throughout the study (Bazely, 2004). The patient subjects were patients with chronic pain who lived in the community of Winslow and received treatment for their pain at WIHCC. Patients with chronic pain treated at the Winslow Indian Health clinic were interviewed to address Aim 1. Qualitative content analysis was used for these interview data. Providers, physicians, nurse practitioners and physician assistances who provide health care to patients seeking care at Winslow Indian Health Care Center, were surveyed to address Aims 2 and 3. Quantitative analytical strategies were used with the provider data.

Setting

Location

The inquiry took place in Winslow, Arizona, a small rural town adjacent to the southwestern corner of the Native American Indian reservation in northern Arizona.

Description

Winslow has a land mass of 12 square miles that lie within Native American County in northern Arizona along the historical US highway known as Route 66. It is comprised of a combination of cultures due to its location on the border of the Native American Indian reservation, the influence of the railroad industry, and its historic Route 66 legacy. European, Native American, Hispanic, Asian, Black, and Anglo American citizens are all blended together here and there is a strong sense of community.

Winslow is a town of stark contrasts not only in the cultures represented by its residents, but also in its architecture. Its edges are blighted on all sides by rotting buildings, junk yards and general neglect. The Santa Fe Railroad runs through the heart of the town and the familiar train horns can be heard at various intervals from one end of the town to the other 24 hours per day. Just like many small towns in the Southwest, Winslow was bypassed by Interstate 40 in the 1970s and this had a profound effect on the local economy and culture. The many shops that once thrived by selling Native American art and jewelry became less visible and less accessible to tourists. The hospitality industry floundered and several of the local hotels subsequently failed to thrive. Many of these hotels and abandoned businesses remain standing supplying cheap housing for indigents and creating crumbling eyesores.

Expensive modern homes coexist alongside tumble-down shacks throughout this small city. The center of town, however, has several beautifully preserved historical buildings occupied by thriving businesses that cater to visitors and townspeople alike. Winslow boasts the painstaking restoration of an elegant landmark hotel, the La Posada, designed in the early 1920s by

famous architect Mary Colter. The hotel was abandoned by the Santa Fe Railroad in 1994 and was slated for demolition prior to being purchased and restored by its current owner.

The community still attracts a fair number of the many international travelers of Old Route 66 and widespread recognition has been attained through the popular 1970s Eagles song that has the line most people of the baby-boomer generation will recognize: “Well, I’m a standin’ on a corner in Winslow, Arizona, such a fine sight to see. It’s a girl, my Lord, in a flat-bed Ford slowin’ down to take a look at me.” The hit song has helped this town create a new post-Route 66 identity. Local business owners have capitalized on the song’s popularity by promoting “Standin’ on the Corner Days,” by creating thematic displays, and through sale of related paraphernalia. The album containing this song’s lyrics are heard continuously via a loop recording that is projected through a speaker near a centrally-located statue of a young man with a guitar. The charred, salvaged remains of an historical building provide a backdrop complete with a mural depicting a flat-bed Ford with a girl inside. Hundreds of tourists stop by each year to be photographed with the statue and to take a step back in time in this quintessential American small town.

Population

The Winslow community is a center of commerce and a resource for medical care for people from throughout Navajo County which consists of 9,953 square miles of high desert. Native Americans represent 48% of the Navajo county population compared to 46% Caucasian, 8% Latino, and less than 1% Black. The population of Winslow is approximately 10,000 people and the population density according to the 2000 census was 773 people per square mile. Latinos represent 28% of the Winslow population; Native Americans 24%, Caucasians 40%, Blacks 5%,

Asians 1%. According to the Census Bureau (2000) there were 2,754 households and 40% of these had children under the age of 18. Fifty percent were married couples living together; 16% had a female head of household, approximately 24% were individuals, and 10% had a person who was 65 years of age or older living alone. The average household size was 2.86 and the average family size was 3.40. The median age in 2000 was 31 years; 10% were 65 or older and 30% were under the age of 18. Males represent the majority outnumbering females 135:100. The median household income was \$29,741 (national \$44,512) and 21% of the population was below the poverty line (U.S. Census, 2000).

Community Resources

The Winslow community has most of the amenities and resources that its residents and visitors require. There are three schools: Elementary, middle, and high school. Northern Pioneer College is located in Winslow and is a comprehensive community college serving Native American County. There are numerous small convenience stores with gas stations, several chain hotels, multiple chain and locally-owned restaurants, a Super Walmart, and one chain grocery store.

Healthcare Resources

The Winslow Indian Health Care Center (WIHCC) has a significant impact on the local economy and culture of Winslow, AZ. The health center is a major local employer that draws clients to the community from nearby towns and from deep within the reservation. The health center has 18 full-time healthcare providers that deliver primary care, urgent care, psychiatry, and surgical services. The campus also has a behavioral health clinic; an optometry clinic; physical therapy; traditional healing; an urgent care center; a diabetes program; a dietician; and a

variety of social services. Full-service laboratory and radiology departments are maintained and a non-affiliated tribal ambulance is stationed at the health center. Health center patients from the reservation contribute to the local economy by grocery shopping, eating at local restaurants, buying clothing, automobiles, and farm supplies. Some move from the reservation to the town to be closer to medical resources and other amenities while others move there to work or attend school. In addition to the health center, the tribe maintains a large dormitory in Winslow for Native American elementary and high school students; the dormitory employees and residents regularly seek health care at the Winslow tribal health center.

The health center retains the services of a traditional healer who has a Hogan-shaped “office” located on the campus. Traditional members of the Navajo tribe often seek the services of traditional healers to manage common health issues, including the management of chronic pain. According to WIHCC data, the annual numbers of client visits to the Winslow Indian Health Care Center have steadily increased over the past few years possibly indicating that local tribal members are increasingly incorporating allopathic treatments into their traditional health practices.

The small community hospital in Winslow has the designation of “critical healthcare access point,” a feature that results in financial support through tax dollars. IHS physicians provide the majority of in-patient care in this community hospital and the facility gleans significant financial benefits from their services. The hospital serves all local residents and as well as the residents of nearby communities, including the many patients who are transported from the tribal clinics and urgent care center. Routine surgeries and medical issues can be addressed at the hospital but any patient requiring intensive care or specialized procedures must

be transferred to Flagstaff Medical Center 50 miles away. The hospital maintains a medical helicopter and an ambulance service that serves the Winslow community. However, patients who reside across the nearby reservation borders must have their emergency transportation provided by tribal emergency medical services.

Other health resources within the community include two dentists, two chiropractors, and an optometrist. The hospital maintains a health clinic staffed by two physicians and a nurse practitioner and there is a community health center that offers sliding scale fees to uninsured people. A local medical supply company provides durable medical equipment including home oxygen delivery. There is a 120-bed skilled nursing facility, several group homes, and a monitored independent living facility to aide people who are vulnerable, disabled, or otherwise unable to manage without help.

Community health resource aides (CHRs) are members of the community who have been hired by the tribal health system to work with the locals to engage in health promotion activities. The Native American tribal health system is a separate entity from the private corporation Winslow Indian Health Care Center (WIHCC) but their staff work closely with WIHCC to bridge outpatient and home care. They check up on the elderly, make home visits with public health nurses, and facilitate a variety of community health initiatives. Most of the elderly, and even some middle-aged community members, speak only in their Native language and those who are bilingual often prefer to communicate in their Native tongue. CHRs are fluent in both the English and Native American language. They help reduce barriers to effective health care delivery by bridging the communication and cultural gaps between patients and their health care providers. They live within the Native American community but are able to effectively navigate

both the Native American and mainstream cultures. They translate health information in layman's terms using the language that is most comfortable for their clients. They also relate information given by their clients to professional healthcare providers to facilitate the communication of health and social issues that need to be addressed in order to improve or maintain the health and wellbeing of the patient.

Sample

Patients with chronic pain treated at the Winslow Indian Health clinic comprised the Native American patient sample, and physicians, nurse practitioners and physician assistances that provide health care to patients seeking care at Winslow Indian Health Care Center comprised the healthcare provider sample.

Sample Description and Sampling Process: Patients

A convenience sample was used to select the Native American patient sample. A Native American ethnic background was required; they were asked prior to intake into the study if they were eligible for health care at IHS and tribal health centers. (Establishing eligibility to receive healthcare at tribal and IHS health centers generally requires a Certificate of Indian Blood although there are some exceptions such as Public Health Service employment.) Participants were required to be over the age of 21 and to be able to communicate in the English language. They were required to be receiving pain care from a licensed allopathic health care provider at WIHCC.

Engaging the NA community and eliciting input and feedback from NAs can present difficult challenges, especially for outsiders who are unfamiliar with community norms. Gaining access to this community required intensive relationship building efforts on the part of the

researcher. NA communities are typically suspicious of research because past research and the subsequent reports have often been debasing, exploitive, and disrespectful of cultural mores. American Indian tribes have been extensively researched in the past by anthropologists, medical scientists, and other outsiders mostly for the purpose of gaining insight into their culture (American Indian Law Center, 1999). As a result, there are lingering and pervasive negative attitudes toward research and a perceived power imbalance interferes with their willingness to take an active role in any type of research. Involvement of a research assistant (RA) from the community facilitated the research process since the RA provided access to contacts that were not accessible to the researcher. It was thought that the involvement of a local Native American person in the recruitment process increased the comfort level of participants and helped mitigate the negative perceptions and anxiety regarding participation in this study.

Lita Scott, who is Native American and a member of the community, acted as the research assistant and community broker for this practice inquiry. At the time of this project Ms. Scott was a graduate student of nursing at the University of Phoenix and had human subject research training. Through her existing knowledge that has been obtained via membership in the Native American tribe, she assisted in identifying and approaching chronic pain sufferers and provided them with information about study participation. She informed the potential participant that a pain study was being conducted to improve pain care delivery to people who receive care at the tribal health center. If they were chosen to participate in an interview, they were told they would receive a gift card in the amount of \$20.00 as a token of appreciation. Once each of the potential participants had been located the RA reaffirmed inclusion/exclusion criteria by asking

them a series of questions (See Appendix E). If inclusion criteria had been met the study was then further explained and the person was added to a pool of potential participants.

Recruitment efforts were purposive so that the sample would be reflective of patients seen at WIHCC and a range of conditions that contribute to musculoskeletal pain. First, flyers were posted in the public library, in the offices of two local chiropractors, and in the office of a massage therapist (See Appendix C). These were not effective and no participants were recruited with this method. Next, an advertisement was placed in a free community newsletter that is distributed throughout Winslow. The ad was exactly the same as the poster. This advertisement recruited a few volunteers but only one person followed through and was subsequently interviewed. The advertisement was again placed two months after the first. The second advertisement succeeded in recruiting several volunteers and four were subsequently interviewed. The researcher and RA together selected five people from the pool of potential participants who were recruited into the project. Detailed information was then provided to the chosen participants about the study and informed consent.

Providers

A quota sample was used for provider participants at Winslow Indian Health Care Center. Consent was obtained prior to participation in 1:1 interviews with the RA.

Sample Description and Sampling Process

Inclusion criteria for provider participation were: (1) being employed by the Winslow Indian Healthcare Center, (2) being licensed and/or credentialed by the Winslow Indian Health Care Center to provide patient care as a physician, a nurse practitioner, or a physician's assistant, and (3) providing pain care to chronic pain patients at Winslow Indian Health Care Center.

Contracted providers who provide specialty services at the health center (e.g. nephrology, cardiology, and rheumatology) were excluded. *Locum tenens* providers were also excluded from this study.

The medical staff consists of 18 full-time health care providers but this number fluctuates due to high employee turnover rates. High participation rates among the provider staff were anticipated because of the concerns that have been expressed and the many discussions that have taken place during staff meetings on the topic of pain management. Talks around the creation of a pain management program have been widely supported at WIHCC. It is likely due to this virtually unanimous interest and support that 100% of the medical staff responded to the survey (n=18).

Recruitment was accomplished by sending an invitation and description of the study via secure email. Information about the survey was also presented at the monthly medical staff meeting and an information packet was handed out. Complete information about the study and written instructions for participation was outlined. Instructions for electronic participation (in lieu of a paper survey) were provided in the information packet. Participation was optional and providers who choose to complete the paper survey were instructed to return the anonymous forms to the researcher's mailbox.

Data Collection Procedures

Data Collection Procedures with Patient Participants

Patients were interviewed individually to address Aim 1. Volunteers who were selected for the final sample were provided with a detailed description of the study verbally over the phone by the Private Investigator (PI) and in writing via mail. A copy of the project description

and consent form can be found in Appendix A. Participants were instructed that they could withdraw from the study at any time, for any reason. A stamped self-addressed envelope was included with the project information and consent form that was mailed to the participant. The participant subsequently mailed the consent form back to the PI after signing it. Once the signed consent form was returned, the PI provided the name and contact information for the participant to the RA. An interview was scheduled by the RA with the participant at the location and time of their choosing. The RA contacted the participant the day prior to the interview to confirm the appointment and the participant's interest in participation.

Qualitative methods (specifically ethnographic methods) were used to collect data from community members with chronic pain to address Aim 1. Storytelling is the traditional method of passing information among NA people (Garwick & Auger, 2003). Ethnographic methods are consistent with the Native American tradition of storytelling since in the Native American culture storytelling has been the primary method of handing down knowledge and legends for thousands of years. These methods allowed participants to tell their story using their own words which is consistent with their cultural practices. The use of traditional methods to communicate information that is relevant to a study is less threatening than traditional research methods (Warne, 2006). Therefore, 1:1 interviews that incorporated story-telling were used to collect data from patient subjects recruited to this study.

Prior to the interviews the questions were reviewed with the RA and she was instructed in ethnographic methods. The 1:1 interviews were initiated using a series questions designed to elicit spontaneous descriptions by participants on the topic of pain. Spradley (1979) recommends five types of descriptive questions: Grand tour questions; mini-tour questions; example

questions; experience questions; and native-language questions. These methods were implemented and formed the basis of the ethnographic interview and led to a sample of expressions in the language of the informants. They comprised the majority of the questions that were asked. The interviews were loosely constructed to avoid influencing the voiced perspectives of the subjects and to allow them to guide the direction of the interview. New questions sometimes emerged as the interviews unfolded and this is a natural occurrence during the course of ethnographic interviews (Krauss, 2005). The RA attempted to incorporate these questions into the interview process to elicit rich descriptions from participants on the topic of pain. Once their interviews were completed, participants were each given a gift card in the amount of twenty dollars as a token of appreciation.

Immediately following the interviews Ms. Scott returned the recorder to the researcher and the contents were then forwarded for transcription. The transcriber was chosen from among those who were in use by Arizona University's College of Nursing at the time the need for transcription arose. The transcriptionist had human subject protection training and her certificates of training were on file with the College of Nursing Institutional Review Board. The recorded interviews were forwarded to the transcriptionist via secure email. Once the recordings had been transcribed the printed transcription was sent to the PI via secure email. The digital recordings were destroyed once they had been transcribed.

Data Collection Procedures with Provider Participants

Providers were surveyed to address Aims 2 and 3. Specifically, the anonymous survey *Physician Factors Influencing Pain Management* (Cleeland, Cleeland, Dar, & Rinehardt, 1986). Providers were asked to participate in the survey electronically housed in Survey Monkey, but

were given the option of paper and pencil if they did not feel comfortable with the electronic version. Survey Monkey is a secure website that allows researchers to construct password protected surveys for data collection. The researcher was the administrator for this survey and the only person with access to the data that was collected.

Informed consent. Complete information about the study was posted on the first page of the survey and participants agreed to participate by clicking on the appropriate response. They were not able to proceed with the survey if they did not agree to participate and were instructed to exit from the website by closing their web browser. Proceeding with the study indicated consent for participation.

In order to use a paper version of the survey participants could either print the hard copy that was attached to the recruitment email or request a printed copy by contacting the medical secretary via secure email. Complete information about the study was posted on the first page of the survey. Participants agreed to participate by checking the appropriate response on the survey indicating they agreed to participate. The included instructions advised them to stop the survey if they did not agree and that by continuing with the survey they indicated they consented and wished to participate. Participants placed their completed anonymous survey in a sealed manila envelope and then hand carried it to the secretary's office. This is a common method of communicating various types of information in this office; the submission of survey forms in this manner was not, therefore, conspicuous. The medical secretary subsequently forwarded the paper surveys to the PI.

The survey. The survey was originally designed in 1986 to evaluate physician factors that influence the management of cancer pain. The study by Cleeland, et al, (1986) was

conducted in response to various studies that showed most cancer patients had been provided poor pain management. No psychometric information regarding the survey was provided in the published report by Cleeland, et al. The survey results highlighted approaches to practice that are potentially relevant to adequate pain control.

The survey was subsequently used in the Texas Cancer Pain Initiative to measure physician factors that contribute to non-cancer pain management practices (Weinstein, et al, 2000). This study targeted rural clinics and randomly sampled physicians from all over Texas who practiced in various specialties. Construct validity was determined by factor analysis of three attitudinal subscales during the Texas study: Scale 1 - reluctance to prescribe opioids for chronic pain; Scale 2 - fear of patient addiction; Scale 3 - fear of DRA (drug regulatory agency) scrutiny. The survey was piloted with medical school students and at meetings of the Texas Cancer Pain Initiative meetings. The three scales of opiophobia with three attitudinal dimensions were created by summing the responses on items that had factor loadings $\alpha > 0.40$.

The first part of the survey following the consent process asked for information about the providers' licensure and/or credentials, and the respondent indicated whether they were a medical doctor, a doctor of osteopathic medicine, a nurse practitioner, or a physician's assistant. The survey itself was divided into six sections each of which was on a separate page. Participants moved from one page to the next by clicking on the "next" prompt at the bottom of the page. The survey only allowed participants to move forward; they could not move backward to a previous page. They were allowed to skip any question they did not wish to answer.

This survey was comprised of a series of statements that asked the provider to either agree or disagree. This produced nominal level data for analysis. The survey was comprised of

statements covering six scales that influence healthcare providers in the management of pain: Reluctance to prescribe opioids for chronic pain; fear of patient addiction; fear of drug regulatory agencies; knowledge about pain and pain treatment; psychological attributes related to pain and pain treatment; and bias about gender and age. Survey participants were asked to read statements and respond as to whether they agreed or disagreed. These responses were assigned a number to represent the answer (1= agree, 0= disagree). The survey required 30 to 45 minutes to complete.

After the surveys had been completed, the researcher constructed an Excel database using the Survey Monkey tools and this was then exported into computer files and the SPSS statistical software. A backup copy was stored on a compact disc in the PI's locked cabinet at her residence. The raw data was kept in Survey Monkey as a backup until the study had been completed. The hard copies of the survey were kept until all data had been entered and data analysis had been completed. These were also stored in the principal investigator's locked cabinet. The work computer used by the researcher while employed in Winslow was password protected and all study-related materials were accessible only to the researcher. A copy of the survey can be found in Appendix K.

Data Analysis

Qualitative Analysis of Patient Interview Data

The purpose of the qualitative analysis was to understand human experience and behavior associated with chronic pain from the point of view of the patient participants. Each of the patient interviews were transcribed into Word documents for analysis. Entire transcripts were read and re-read at least five times before coding proceeded in order to familiarize the analyst with the story of the individual patient. Glesne (2006) described this phase of analysis as follows:

“The coding, categorizing, and theme-searching process is.... a time when you think with your data, reflecting upon what you have learned, making new connections and gaining new insights, and imagining how the final write-up will appear.” (p.154)

According to Glesne (2006), this process allows the researcher to sort out what has been learned in order to concentrate on writing up the data.

Using an ethnographic process described by Spradley (1979), the transcripts were fractured into small data bits, words, and word groups that were developed based on the research aims. Once this first coding pass was completed, each of the individual coding units were further explored to more deeply comprehend the participants’ experiences, beliefs, and values regarding chronic pain and treatment preferences and outcomes. Raw data from these coding units were subjected to coding using an *emic* perspective, coding established from the participants’ perspective and with the participants’ own words. Subsequently, these *emic* descriptive codes were then reduced and abstracted to theoretical or *etic* codes that captured the beliefs, attitudes, pain experiences, pain treatment, and outcomes in language that is more theoretically driven that can be compared across subjects and studies. Further reduction of the *etic* codes created a culturally relevant individual story line that described the individual’s experience with chronic pain and their treatment preferences.

Finally, a culturally relevant “fingerprint” was created for each participant. This fingerprint captures the individual’s experience with chronic pain and their treatment preferences while using *etic* categories as the organizational framework. This process allows results across subjects to be compared and contrasted so that shared (convergent) as well as unique (divergent) experiences can be identified.

Each individual subject's story with relevant codes was entered into a first order data display or matrix that captured the individual's experience with chronic pain and addressed the various research aims (Miles & Huberman, 1994). Between subject comparison and analysis was then conducted by constructing second order comparative matrices for each of the research aims, identifying experiences, beliefs, and treatment preferences and outcomes that were shared and those that were unique across the patient subjects.

Quantitative Analysis of Provider Survey Data

Survey data were analyzed using SPSS. Once the data had been collected, it was exported from Survey Monkey into SPSS and a descriptive analysis was conducted.

Data management. Data management required several steps:

1. The data collected in Survey Monkey was converted and exported into Excel then transferred to a desktop computer for importation into SPSS.
2. Survey results from the participants who chose the paper and pencil format were then entered into SPSS.
3. The electronic Survey Monkey and the paper/pencil surveys were combined in SPSS.
4. The scores were changed to numeric values to accurately represent "agree" and "disagree" responses.
5. The researcher then ran a descriptive analysis by item for subscale scores and to determine if the data was logical.

Statistical analysis. Descriptive statistics were used to summarize the demographics of the respondents. Percentages were calculated for each of the items of the survey. Scores on each

of the attitudinal subscales were calculated and descriptive statistics were computed. The scores were then compared by provider type using Chi-square. The scores were then compared pairwise to identify provider types who were most in need of further education in pain management and to identify providers who were more knowledgeable and who may be most appropriate for providing pain care in a future pain management program. These analytical outcomes were used to address Aim 2. The survey questions were analyzed individually using a 2 x 2 contingency table and t-tests were used to compare Winslow providers to providers in the Texas Pain Study to explore similarities and differences between these two groups of rural healthcare providers and address Aim 3.

Resources

The health service unit for this population provided password protected computers and office space during the time the research was employed at WIHCC. Upon her resignation, the researcher deleted all study data from the work computers and transferred the information to her home computer which was password protected. This health service unit is comprised of a multidisciplinary staff that was consulted for input regarding local pain management practices and resources. These include physical therapists, pharmacists, behavioral health professionals, substance abuse counselors, allopathic healthcare providers, a traditional healer, a massage therapist, and an acupuncturist. This professional diversity contributed to the insight gained into a range of perspectives on pain management among providers at this facility. A better understanding of the practices and preferences of the community of chronic pain sufferers who receive care at this institution may lead to improved planning and resource utilization.

Summary

This study took place in Winslow, Arizona, a small rural town adjacent to the southwestern corner of the Native American Indian reservation in northern Arizona. Community-based participatory research (CBPR) was the approach that was chosen for this study. Mixed methods (qualitative and quantitative) were used to gain insight into the local factors that contribute to the self-management and treatment of chronic pain. Mixed methods were used because neither quantitative nor qualitative methods alone were sufficient to produce a rich description of the local factors that contribute to chronic pain management. Mixed methods offer the potential for gaining a deeper understanding of chronic pain experience and treatment by elucidating facts that would not be uncovered using a single research method. Data were collected from people living within the community and health care providers working with the community. Specifically, interviews with NA patients with chronic pain were analyzed using ethnographic methods described by Spradley (1979) and comparative analysis as described by Miles and Huberman (1994) to address Aim 1. Health care provider surveys were analyzed Interviews with health care providers to address Aims 2 and 3.

CHAPTER 4: RESULTS

Introduction

In 2007, the escalating use of prescription pain medications alerted the Winslow tribal health organization that community members were increasingly seeking care for chronic pain complaints. A short-term goal of CBPR approach to researching and intervening in NA chronic pain management was the formative assessment of this very small, but representative community of chronic pain patients and providers, constituted the first step in designing a pain management program to address the needs of Native American patients with chronic pain who receive care at Winslow Indian Health Care Center. This study specifically identified the problem, setting, population, and resources associated with the management of pain by IHS health care providers for a Native American population living in a border community.

Chapter four describes the results of the data analysis and identifies and compares the findings relative to the three research aims. Two study populations were recruited that represented two different sets of stakeholders at WIHCC. The patient subjects were patients with chronic pain who lived in the community of Winslow and received treatment for their pain at WIHCC. Patients with chronic pain treated at the Winslow Indian Health clinic were interviewed to address Aim 1. The provider group included physicians, nurse practitioners, and physician assistants who provide healthcare to the patients who seek care at Winslow Indian Health Care Center. Providers were surveyed to address Aims 2 and 3. Qualitative content analysis was used for the interview data with patients and quantitative analytical strategies were used with the provider data.

Results: Patient Experiences of Pain Treatment

Individual interviews with five patients who were treated for chronic pain at the Winslow Indian Health Care Center were conducted to understand their chronic pain treatment experience and address Aim 1. Patient factors that influence pain management including:

- a) Pain assessment and influences of patient/provider communication;
- b) Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
- c) Patient self-treatment practices and remedies for chronic and acute pain;
- d) Outcomes of pain management according to patient-centered goals;
- e) Perceptions of the risk for use and potential for abuse of prescription opioid medications were explored.

Patient Participant Demographics

The patient participants included four female and one male ranging in age from 25 to 61 years old. Three had back pain, one had neck pain, and one had arm pain. All subjects had chronic pain for more than two years and all had seen multiple healthcare providers for pain treatment.

TABLE 1. *Patient Demographics*

Participant	Gender	Age in Years	Pain Problem
A	Female	53	Low back pain
B	Female	32	Back pain/Herniated disc
C	Female	25	Neck pain/Headaches
D	Female	61	Arm pain/Congenital defect
E	Male	60	Low back pain/Compression fractures

Coding Result

Once the initial, holistic reading of the transcripts was complete, a coding structure was developed. Since the interviews progressed rather systematically across all subjects based on the research questions, coding categories that captured essential pieces of information were identified. Table 2 provides that initial coding structure as well as the coding definitions.

TABLE 2. *Initial Qualitative Coding Structure*

Code	Definition
Pain Assessment	The diagnostic studies, provider assessments, consultations, etc, undertaken to obtain a pain diagnosis
Patient/Provider Communication	Things a provider said or did not say related to pain. Things the patient said to the provider to communicate about pain. Knowledge sharing or lack of information sharing on the part of the provider that either helped or caused concern.
Beliefs/Attitudes	Personal beliefs or attitudes that contributed to the perception of the pain experience, the cause of pain, the acceptance or rejection of treatment, or the desire for more or less treatment.
Self-Treatment	The types of treatments the patient uses on their own. Examples are over-the-counter medications, altering activities, heat.
Outcomes	What happened after treatment such as change in pain, quality of life, and function.
Perceptions of risk, opioids	How the patient feels about using medication prescribed by an allopathic healthcare provider.
Allopathic Interventions	Mainstream interventions prescribed by WIHCC providers such as physical therapy, medications, surgeries.
Alternative Therapies	Complementary alternative therapies such as massage, acupuncture, chiropractic care that the patient used.
Family Influence re: pain	Statements or actions by family members that changed the way the patient managed or treated pain.

These eight coding categories were then used to fracture the data into word phrases and complete sentences. Appendix M provides an exemplar of the outcome of this coding process. Once this coding process was complete, data from each of the coding categories for each of the patient participants were examined in greater depth, using an inductive approach. *Emic* codes were identified within each larger coding category that provided more in-depth descriptive

information. These *emic* coded transcript segments were then reduced and abstracted to theoretical or *etic* codes that capture the beliefs, attitudes, pain experiences, pain treatment, and outcomes.

Matrix analysis techniques, as described by Averill (2002) and Koithan, et al (2007) were used to create this final turn of the data and create first order, descriptive matrices for each participant. These first order matrices (exemplar in Appendix N) provide a culturally relevant description of their pain and pain treatment experiences. For example, the following patient statements provided a summary of her outcomes from her perspective:

“Nothing’s really become better; it really limited my ability to do basic things.”

“... was successful with chiropractor for muscle spasms, pain management and orthopedic doctors were helpful.”

“Hydrocodone helps, I just wish it would be over.”

“Pretty much takes out my career.”

Second Order Matrices (Appendix O) were then constructed so that between-subject comparisons by response category could be identified. Convergent and divergent experiences were identified (Appendix P) and will be discussed below.

The Individual Stories of Chronic Pain in a Native Population

The individual stories of the chronic pain experience for each participant informs us about patient issues around pain management and provide insights as to potential practice innovations, patient preferences, and treatment alternatives. These results reveal individual aspects of chronic pain management that enlighten us about the day-to-day experience of living with chronic pain. These stories express the experiences of pain among participants including the impact on daily functional capacity and their quality of life. Patients described significant

burdens due to their pain including the limited ability to maintain employment and to participate in physical activities for pleasure or for their roles within their family. Their experiences in the allopathic setting have been unsatisfying and the general lack of knowledge regarding their particular problem has caused needless worry for some patients that extracts an additional toll on their overall wellbeing.

Participant A. This participant had chronic back pain that restricted her employment ability. She also had pain in her knees. She was not sure of the cause of her pain and had considered several possible explanations. She thought it might be due to an epidural she had during childbirth more than 30 years ago. She tied the worsening of her chronic pain to her obesity and implied that diabetes can cause pain although she knows she does not have diabetes. She expressed frustration that numerous diagnostic tests had been run but she still does not know why she is in pain.

“I’m not sure what to look for anymore (sounds frustrated) I don’t know what the heck is going on. Some do and some don’t [understand my pain]. I don’t know what’s going on with my legs either.”

“I’ve had MRIs, I’ve had everything done. They put me underneath the x-rays and everything and they said my whole body’s ok. So they don’t know what’s going on. And they did blood work and everything, but I don’t know.”

“There has to be something else, [sounding slightly agitate].”

She acknowledged that running all these tests is “the white way,” her tone reflecting concern that implied that although they did all these tests they must have missed something, that there must be a specific cause for her pain that can be found and treated. She said she had communicated openly with her providers about her pain and her attempts at self-treatment. She reported that medications caused adverse effects and had to be stopped. She still takes ibuprofen

when the pain is at its worst and has tried acupuncture which provided some temporary relief. As far as whether providers understand her pain she stated that “some do and some don’t.” When asked if she is satisfied with her pain care she simply replied, “No.” Her family members had no influence on her decisions around pain management. When asked if there was anything else she would like her healthcare providers to know she described the negative impact that pain has on her life including her ability to work and to take care of her family. Her desired outcome was to find a treatment that would reduce her symptoms to a point where she could stand longer and have the physical flexibility and stamina to perform her household chores.

Participant B. This participant had chronic low back pain and felt that she had to take extreme measures before providers would take her pain seriously. She had pain for many months when it became so severe she went to the emergency room where an MRI was finally ordered to diagnose the problem. Eventually, she was given the diagnosis of a herniated lumbar disc. She felt that providers at WIHCC initially brushed her off and that her chiropractor also did not understand the severity of her pain. When asked what else she would like her providers to know she had specific suggestions:

“I would like to tell him/her that it seems to me like a lot of the patients are just numbers that come across them and they just send you...well especially my healthcare provider, she seems to be typing at the computer a lot more often. She listens but....what would I like to tell her- that this pain is real. The referrals have been very helpful. I don’t know, I guess that’s a good question besides the pain is real”

At this point the interviewer pressed further: “What stops you from telling them?”

“Oh just the....I don’t know...the looking away from you, the eye-to-eye contact is not there and with some doctors it is with some doctors it’s not.”

The patient further recommended:

“...getting to know that person and what their past...what they used to do...and what they can and can't do would...could be a helpful tool to figure out if the pain...what types of pain there are...with the symptoms.”

It was her belief that chiropractors do not like pain medications and that she was expected to “work things out naturally.” She tried going to a traditional healer for manipulative therapy but combined with the chiropractic care “it was too much” so she opted to stay with the chiropractor only. She also believed that people have varying pain thresholds and need to be considered individually and holistically. Her attempts at self treatment included over-the-counter analgesics, topical preparations, thermal therapy, and exercise. Alternative therapies tried were massage, consultation with a traditional healer, and chiropractic care; of these she felt that massage worked the best. When asked how the pain affected her daily life she provided multiple examples:

“It really limited my ability to do the basic things- sweeping, well the necessities I guess- sweeping mopping. And the things I like to do it has limited me. Going out to the field to walk a long mileage to..for..dirt roads all over the Navajo Nation. And I can't sit for long periods of time, lay down or sit down or any of those”

She believed that, due to “side effects, “ opioid medications are potentially harmful, should be limited to short term use, and should only used when pain is severe. Other allopathic interventions included referral to a pain management specialist and another referral to an orthopedic surgeon. The people who influenced her decisions regarding pain management and treatment were her mother and her husband. Patient B responded that she was not satisfied with her pain care. When asked about her outcome goals she responded that she would like the quality of her life to be better:

“I’m just at a point of continuing pain, limiting activities, and at this point I just wish it would be over with.”

“It’s mostly been taken out of me.....the quality of life has been taken out of me.”

“And I’d like for the outcome for me...like in a year or so, I know it’s going to take time to recover, but in a year or so to really be a better person the quality of life because of the limiting activities. That pretty much takes out my career and the quality of life.....”

Participant C. This patient had chronic neck pain and migraines that interfered with her work as a dental assistant and with her daily activities.

“my muscles tense up really bad and gets so bad that sometimes it bothers me when I’m sleeping and I can’t sleep comfortably..... seems like it’s getting worse...”

“Sometimes it even affects me when I’m driving. I like to...I have hobbies, like I like to play softball. Sometimes that affects it as well. It also affects my job too. I get headaches on a constant basis,”

She received an exam at WIHCC but no diagnostic studies were ordered. She felt that she communicates her symptoms and self-treatment attempts with her provider and that she has had an adequate explanation of the cause and was given appropriate treatment options. She acknowledged that she could do more to communicate with her provider since she has not had an appointment for about a year although her symptoms are worsening. She believed that her job as a dental assistant was affecting her symptoms and that stress was the underlying problem that caused her muscles to tense. The physical therapy ordered by her providers was not helpful and she felt that her time could be better spent focusing on other treatments such as massage therapy. She refused to see a traditional healer although her grandmother attempted to influence her in that direction. Self-treatment attempts included thermal therapies, exercise, altering physical

activities, and topical analgesics. When the pain is “really bad” she takes medications prescribed by her provider.

“Like I said, I’m not a big fan of prescription drugs but if it’s there and I absolutely need it then I’ll take it. I don’t take anything else.”

“...when I’m assisting and I hold a certain position I can feel it starting to get numb so I have to put my arm down”

“I’ve tried icy hot. That helped. I’ve tried miloflex [Myoflex]. Miloflex didn’t help as much as icy hot. And then sometimes I’ll use heating pads I’ll put that on there just to try and relax it, get it to calm down.”

Her provider referred her to both physical therapy and massage therapy but she felt the massage therapy was more helpful than the other treatments prescribed. She did not like prescription pain medications and used them only when the pain was unbearable. Her goals for pain treatment are to obtain adequate relief to get through her work day and to engage in leisure activities such as softball,

Participant D. This patient mixed her English with Navajo and was more comfortable responding in her native Navajo language. Her responses were mostly brief and pointed. She had chronic left-sided arm pain from a congenital defect. When asked if she communicated with her healthcare providers about her pain, she indicated she had done so.

“I went to diabetic clinic, I asked for pain medicine.”

No specific diagnostic studies had been ordered to diagnose her pain; she apparently felt that the cause of her pain should be quite obvious to other people.

“....just look at my left side down to my ankle and see for yourself.”

She believed there is nothing more that can be done to help her.

“There’s nothing else to do; I was born this way. Just take the medicine.”

“I don’t think they can do anything about it.”

Self-treatment practices included over-the-counter analgesics and altering activities. It had been customary for her to make bread for her family, but she stopped doing this due to her pain. Now she “hauls bread from the store.” When asked if the pain interferes with her activities, she responded that it prevented her from working.

“Yes, I can’t wash dishes anymore; I had to change my dishes to plastic stuff now because I cannot lift more than 10 lbs”

She denied using complementary alternative medicines for pain, but subsequently stated that she had been many places seeking help and “even saw a German doctor.” She felt that strong pain medications should be prescribed for her pain and this was her advice to healthcare providers when asked what else she wanted them to know. She reported that she is not satisfied with her pain care. Her treatment goals are to be “free of pain.” She indicated that her family influenced her pain management by encouraging her to limit or modify her activities.

Participant E. Patient E was the only male subject in this study. He suffered from chronic low back pain and periodic exacerbations. He communicated with many provider types and felt he had adequately revealed the details of his pain as well as self-treatment attempts. He felt the providers understand his pain “to a point.”

“I don’t think they know the intensity of the pain I went through.”

He reported that the allopathic treatments he had received included physical therapy and painkillers. Alternative therapies included massage, chiropractic care, and consultation with the traditional healer. The traditional healer performed manipulative therapy, crystal gazing, and “mental” therapies. It was this patient’s belief that chiropractors work the best although he used

massage therapy with good results. He was very traditional in his beliefs and had integrated his own care using the modalities from each health paradigm that help the most.

“I like chiropractors the best. Initially I didn’t like it because you had to endure more pain to alleviate the pain that I had but now it works.”

“I consult with [traditional healer] and he’s done some mental and physical therapy with me. And he’s explained to me through crystal gazing what some of my problems are.”

“I am grateful that the pain has gone away. I am very appreciative of it now because I know what it’s like to have it and I enjoy life more today.”

Other self-treatments included distracting activities, over-the-counter medications, and activity modifications. The most important outcome for this patient was to alleviate pain adequately to permit participation in more physical activity for weight management. When asked if he was satisfied with his pain care he replied, “not really.” His advice to healthcare providers is to consider more treatment options.

“I wish they did more of it [pain care service]. That they had physical therapists at the clinic, or a referral to different chiropractors in Winslow, even Flagstaff. The chiropractic help that I got was more with my private insurance.”

“I’m satisfied with the pain that I don’t have as much anymore.”

“It was a conglomeration of the assistance and the help that I got from all these three facets of health [chiropractor, traditional healer, massage] that was available.”

When questioned regarding his perceptions around opioid therapy, he responded, “They scare me.”

“I don’t do pain pills anymore.I’ve take pain killers and it was like being under the influence and not having control over my affairs and it really weirded me out. I rather deal with the pain than that loss of control.”

He reported that his wife strongly influences his choices in the management of his chronic and recurrent exacerbations of chronic back pain.

“I myself wouldn’t go normally so through the urging of my wife I finally went and saw a chiropractor.”

“.....my wife works on me....she’s a massage therapist.”

The Shared Chronic Pain and Treatment Experience in this Native Population

It is important to identify and describe both convergent and divergent perceptions in order to paint a rich description of the pain experience. Convergent perceptions represent emergent themes that form patterns in the data. Several experiences were shared among the participants. Their self-reports of communication to their providers were similar as were the self-treatments used to cope with pain. All made negative remarks regarding provider communication and information sharing with them. They shared openness to the use of alternative therapies but typically combined these with mainstream therapies. All reported that pain had a significant impact on their activities and quality of life.

Pain assessment and influences of patient provider communication. Patients believed they communicated information about pain and pain self-treatment to their healthcare providers. Four patients made negative remarks reflecting experiences with provider communication. Some of their comments on this topic were:

“I’m not sure what to look for anymore [sounds frustrated] I don’t know what the heck is going on.... I don’t know what’s going on with my legs either.”

“it seems to me like a lot of the patients are just numbers that come across them...Oh just the....I don’t know...the looking away from you, the eye-to-eye contact is not there and with some doctors it is with some doctors it’s not.”

“Whenever I mention pain they just prescribe painkillers and um I tell them, I do not want painkillers, they weird me out. I consult with [traditional healer]he’s explained to me ...what some of my problems are...I’ve been pretty much open with them, telling them what works and what don’t.”

Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care. All of these patients attempted to use complementary alternative therapies for pain treatment but none relied on alternative therapies alone. The most commonly used alternative therapy was massage. Acupuncture and chiropractors were also used and two participants utilized the services of a traditional healer. Three of the five participants felt that family members influenced how they managed their pain. Examples of relevant comments were:

“But ironically going to the traditional healer....to me the first couple of visits it just seemed like chiropractic services- pulling the joints here, pulling the fingers- exactly what a chiropractors would do. it just seemed like I was seeing two chiropractors...And the massage therapist, boy it felt really good....she really targeted the problem...but it was only a temporary fix... I don't necessarily like the pain medications I'm taking.”

“I like chiropractors the best. Initially I didn't like it because you had to endure more pain to alleviate the pain that I had but now it works. I consult with [traditional healer] and he's done some mental and physical therapy with me. And he's explained to me through crystal gazing what some of my problems are.... I've taken pain killers....”

Patient self-treatment practices and remedies for chronic and acute pain. All patients in this inquiry used a variety of over-the-counter medications for pain including topical analgesics, ibuprofen, Excedrin, and acetaminophen. They also used thermal treatments such as heating pads and warm baths to relieve pain symptoms. All patients had at some time altered their physical activities to varying degrees in an effort to reduce pain symptoms. Patient comments included the following:

“I just take ibuprofen, that's what the doctors have been giving me because I didn't know how to deal with this...I take ibuprofen or naproxen and now Excedrin.”

“I tried in the beginning icing it, heating it, exercising it, stretching it, and took Motrin for the muscle pain inflammation and I've tried that on my own.”

“I just find something else to do. Read a book, go out for a drive, go to the rez. Just a number of things get my mind off the pain. I just take it easy, take an aspirin maybe.”

Outcomes of pain management according to patient-centered goals. As a group they were not satisfied with their pain care. All patients reported that pain interfered with their employment and/or activities of daily living. Patient reported goals of treatment included relief of pain, improved quality of life, the ability to return to work, the ability to perform household chores, and the ability to participate in more physical leisure activities. Patient remarks on outcomes included:

“There has to be something else, [sounding slightly agitated] you know. I can’t stand long periods, I can’t stand up too long because my back starts hurting and then I feel like I’m bending over like this and it feels like I have to straighten up.....it doesn’t go away.”

“It really limited my ability to do the basic things- sweeping, well the necessities I guess- sweeping mopping. And the things I like to do it has limited me. That pretty much takes out my career and the quality of life....the quality of life has been taken out of me.”

“....sometimes it even effects me when I’m driving. I like to...I have hobbies, like I like to play softball. Sometimes that affects it as well. It also affects my job too. I get headaches on a constant basis,”

“I can’t wash dishes anymore; I had to change my dishes to plastic stuff now because I cannot lift more than 10 lbs.”

“It has pretty much put a limitation to my physical activities and I’ve gained weight as I result of it.”

The Unique Chronic Pain and Treatment Experiences in this Native Population

The divergent experiences of these patients help to understand the range of perceptions they had regarding pain and pain treatment. Only one patient remarked positively about her provider’s communication skills. There was inconsistency in the range of diagnostic evaluations for their pain problems; each patient with back pain had a different workup. All patients had

different beliefs about the cause of their pain but only one commented on cultural differences and the influence on pain treatment.

Pain assessment and influences of patient provider communication. Only one patient felt satisfied that her provider understands her pain and that the provider has given an adequate explanation of the cause. Two of the five patients had undergone recent diagnostic studies (magnetic resonance imaging) in an effort to diagnose their problem. One patient felt that the lack of eye contact indicated that providers do not listen well.

‘It’s been awhile since I’ve seen anybody over there (IHS) Cause they don’t know that it’s gotten that further... the last time I’d seen them they were able to explain everything.’

“Oh just the....I don’t know...the looking away from you, the eye-to-eye contact is not there...”

Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care. The study patients had varying beliefs regarding the cause of their pain but, contrary to the stereotyping, none of these beliefs involved supernatural causes. One patient indicated that the physical therapy ordered by her provider was a waste of time. One patient pointed out that the pain experience is individualized and should be approached as such. The same patient remarked that her CAM providers did not approve of allopathic treatments. One patient commented on cultural influences in the allopathic setting:

“you know, they do everything the White way [self-conscious chuckle]. They don’t know what’s going on....I don’t know if this has anything to do with the shots, the epidurals with the kids, I don’t know.”

“I think it mainly entails with my assisting. I think with me constantly having to look down all the time.”

“I think there’s better areas where I could focus more on [besides PT]. I think I need to be more consistent about going to them [massage therapy]. ” [massage] allows me to do what I need to do throughout the day.”

“Well, I was born with a short arm, left side. It has sharp, drilling pain. There’s nothing else to do; I was born this way. Just take the medicine. I don’t think they can do anything about it.”

“....seems like chiropractors they seem to have a dislike for you to go anywhere else to get relief.”

“Chiropractors, do not like pain medications, they want to work everything out naturally just like a traditional healer.”

“A lot of people have different levels of pain, thresholds of pain. Some people can handle it more than others so I think it is on a person to person basis.”

Results: Provider Factors Affecting Pain Management

A previously validated survey entitled *Factors Influencing Physician Management of Cancer Pain* (Cleeland, et al, 1986) was administered to health care providers to address Aims 2 and 3. Provider factors that influence pain management; and similarities and differences between Winslow providers and providers in another rural setting related to factors that influence pain management were examined in this project phase.

Provider Demographics

The provider participants (n=18) included healthcare professionals who provide primary care, including pain management, to patients who seek healthcare at WIHCC. One hundred percent participation was achieved among the provider staff including five nurse practitioners, three physician assistants, six osteopathic physicians, and four medical doctors. Eight of the providers were female and 10 were male. Average number of years in practice ranged from 2.5 to 36 yrs with a mean of 14.6 years. Years at WIHCC ranged from 2 to 30 with a mean of 7.4 years. Three of the 18 providers had received any past training in pain management.

TABLE 3. *Provider Demographics*

Participant	Profession	Gender	Yrs in Practice	Yrs at WIHCC	Specialized Pain Training
1	DO	Female		2.5	None
2	PA	Male	36	2	None
3	PA	Male	33	8	None
4	MD	Male	10		None
5	MD	Male		14	None
6	MD	Female	15	6	10 hrs CME/ 2 yrs
7	DO	Male	16	8	None
8	PA	Male	15	1.5	None
9	NP	Female	12	3	self-learning modules
10	NP	Female	20	11	None
11	DO	Female	14	5	None
12	DO	Male	30	30	None
13	NP	Female	2.5	2	None
14	MD	Male			None
15	NP	Female	20	2.5	None
16	DO	Female	36	16	None
17	NP	Male	5	3	Online CMEs, previous hospice experience as an RN, and lectures at conferences.
18	DO	Female		2.5	None

NP = nurse practitioner, PA= physician assistant, DO= osteopathic physician, MD= medical doctor

Survey Results

The provider survey queried six basic content areas that influence pain management, addressing provider factors that influence pain management. The content areas were:

1. Reluctance to prescribe opioids for chronic pain
2. Fear of patient addiction
3. Fear of drug regulatory agencies
4. Knowledge about pain and pain treatment
5. Psychological attributes related to pain and pain treatment
6. Bias about gender and age

Item responses from the Winslow provider population were analyzed for percent of total responses for each response item. The survey items that addressed knowledge were then further analyzed using quantitative methods to identify provider groups who were most in need of pain education. This also identified providers who were more knowledgeable and who may be appropriate for management of patients within the planned pain management program. The Winslow survey responses for all items were then compared to the responses of the providers in the Texas Pain Study (Weinstein, Laux, Thornby, Lorimor, Hill, Thorp, & Merrill, 2000) on the content areas listed above to address Aim 3.

Descriptive analysis results. Once the data were collected, they were exported from the Survey Monkey database into SPSS and a descriptive analysis was conducted. These results are reported in Table 4.

TABLE 4. *Results of Provider Survey Questions (n = 18)*

SUB-SCALE 1: RELUCTANCE TO PRESCRIBE OPIOIDS FOR CHRONIC PAIN	Agree - n	Disagree -n	Agree %	Disagree %
Chronic pain of unknown cause should not be treated with narcotic even if this is the only way to obtain pain relief	2	14	11.8	76.5
It is appropriate to escalate a dose of narcotics above the usual range if the prognosis is less than 1 yr	13	3	70.6	17.6
If a chronic pain patient is active on the job there is no possible justification for prescribing narcotics for pain	1	16	5.9	88.2
Narcotics should be restricted to treatment of severe intractable pain	5	12	29.4	64.7
Persons who fit the "profile" of a likely drug abuser should never be treated with narcotics	1	16	5.9	88.2
Prognosis should be the primary factor in deciding whether a patient should receive opiates	1	16	5.9	88.2
Patients who complain of pain out of proportion to its cause are usually drug abusers	1	14	5.9	76.5
Using narcotics to relieve the pain of benign conditions is ill-advised	3	13	17.6	70.6
Even if patients have severe chronic pain, they should be treated with narcotics only when their illness has reached a terminal phase	1	17	5.9	94.1
The presence of a physiologic basis for pain should be the primary factor when deciding to prescribe opiates	6	10	35.3	52.9
I would never prescribe narcotics for a patient with chronic pain who is able to work.	0	17	0	94.1

SUB-SCALE 2: FEAR OF PATIENT ADDICTION	Agree - n	Disagree-n	Agree %	Disagree %
Any patient who is given narcotics for pain relief is at significant risk for addiction	2	15	11.8	82.4
I would be extremely concerned about possible addiction if a member of my family were given morphine for chronic pain	6	11	35.3	58.8
I must exercise caution when prescribing potentially addictive medications to patients with chronic pain	17	0	94.1	
When narcotics are used to control chronic pain, addiction is a common outcome	11	6	58.8	35.3
More than 5% of patients who receive narcotics for pain subsequently become addicts	8	6	47.1	35.3
SUB-SCALE 3: FEAR OF DRUG REGULATORY AGENCIES	Agree - n	Disagree -n	Agree %	Disagree %
If I prescribe opiates for several months for a patient with chronic pain due to cancer, I am violating state law	2	16	12	88
My colleagues are more willing to give narcotics for cancer pain than I am	2	15	12	82
Prescribing narcotics for patients with chronic pain is likely to trigger a drug enforcement agency investigation	0	17		94
Too many narcotic prescriptions lead to utilization reviews	11	5	59	29
Pharmacists who receive several opiate prescriptions from a doctor are likely to report the doctor to a state review board	3	14	18	77
If I follow the same prescribing practices as other doctors in my field, I will not be investigated by a regulatory agency	10	7	53	41
There are limits to the number of narcotics tablets a patient should be prescribed	15	2	82	12
I give patients a limited supply of pain medications to avoid being investigated	16	2	88	12
SUB-SCALE 4: KNOWLEDGE ABOUT PAIN AND PAIN TREATMENT	Agree - n	Disagree -n	Agree %	Disagree %
The majority of patients having chronic pain are under medicated. (True)	8	6	44	33
Psychological dependence on narcotics very frequently results from legitimate prescriptions. (False)	12	5	66	27
Suicide with an overdose of narcotics prescribed for pain occurs very frequently. (False)	1	16	5	88
The best judge of pain intensity is the patient. (True)	16	1	88	5
The health care provider is the best judge of pain intensity. (False)	1	16	88	5.9
Pain in a cancer patient is most likely due to treatment. (False)	2	15	5.9	83
The tumor itself is most likely the cause of pain in a cancer patient (True)	12	4	66	22
Preexisting conditions not related to the cancer cause the most pain for cancer patients (False)	2	15	5.9	83
Increasing requests for analgesics indicate unrelieved pain (True)	12	4	83	22
Increasing requests for analgesics indicate tolerance to the analgesic. (False)	12	3	83	1.2
Almost all cancer patients suffer pain. (True)	7	10	38	55
Almost all cancer patients should receive opiates to relieve chronic pain (True)	10	6	55	33

SUB-SCALE 5: PSYCHOLOGICAL ATTRIBUTES	Agree - n	Disagree -n	Agree %	Disagree %
Compliant patients are entitled to more of my time than noncompliant ones	0	17	0	94
Those who contribute the most to society should get better health care.	5	12	29	65
I do not like being referred patients with doubtful diagnosis	1	16	5.6	88
Life would be better if homosexuals and IV drug abusers were segregated into special groups	2	15	12	82
If I knew that a prospective patient had an untreatable disease, I would avoid taking that patient if I could	3	12	18	65
I resent tax money being spent on patients with self-inflicted diseases	3	12	18	65
A doctor who practices has few surprises have a lot to be grateful for.	0	17	0	94
It "bugs" me if a consultant I am working with after carefully reviewing a patient says, "I'm not sure."	3	14	18	76
When laboratory reports give conflicting information, I get upset	0	17	0	94
Conscientious patients deserve better health care than those with self-inflicted problems	5	10	29	53
It bothers me when even a pathologist cannot find the cause of death.	0	17	0	94
More healthcare dollars should be spent on those who contribute most to society	5	11	29	59
I do not enjoy treating patients whose illness is unlikely to respond to treatment	6	11	35	59
I get irritated by inconsistent medical reports.	0	17	0	94
When the time comes that medical care will have to be rationed, those with high IQs should get the best care.	2	15	12	82
I dislike having patients whose outcomes "don't follow the book."	5	11	29	59
Undiagnosable illnesses are something I'd rather not get involved with.	0	17	0	94
SUB-SCALE 6: BIAS ABOUT GENDER AND AGE	Agree - n	Disagree -n	Agree %	Disagree %
It is easier for a male patient to become addicted to narcotics than a female	0	17	0	94
Men are less likely to report pain to their doctor than women.	8	7	47	41
Females are more likely to experience pain than males	4	13	24	71
Young adults are more likely to become addicted to narcotics than the elderly	2	15	12	82
Older patients are less likely to report pain than younger patients	7	8	41	47

Scale 1: Reluctance to prescribe opioids for chronic pain. Seventeen percent would withhold pain medication if prognosis were > 1 year. Twenty-nine percent of the Winslow sample thought opioids should be restricted to patients with severe intractable pain.

Scale 2: Fear of patient addiction. This scale measured whether providers feared that prescribing opioids leads to patient addiction. Forty-seven percent of Winslow providers thought that prescribing opioids could lead to addiction. Thirty-five percent would be concerned about addiction if a member of their family were prescribed opioids for severe pain. Ninety-four percent thought that extreme caution should be used when prescribing opioids for chronic pain.

Scale 3: Fear of drug regulatory agencies. Scale 3 measures provider fear of scrutiny from drug regulatory agencies when prescribing opioids. Fifty-nine percent of Winslow providers thought that prescribing too many opioids can trigger utilization reviews and 82% thought the number of pills should be limited to avoid scrutiny. Fifty-three percent thought they could avoid scrutiny by following prescribing practices of other providers.

Scale 4: Knowledge about pain and pain treatment. Sixty-five percent of Winslow providers incorrectly believed that psychological dependence occurs when opioids are used to treat chronic pain. Sixty-five percent believed that increasing requests for medications indicates tolerance also incorrect since this usually indicates inadequate treatment. Only 41% recognized that most pain can be successfully treated. Forty-seven percent correctly identified that chronic pain is generally undertreated. Physician assistants demonstrated the highest need for pain education. Nurse practitioners had the most knowledge about pain management although the score differences compared to DO or MD providers were not statistically significant.

The Winslow responses on the knowledge questions were scored since, unlike the other questions, these questions do have right or wrong answers. These questions test provider's knowledge about pain management and provide clues as to what the content of future educational programs at Winslow might include. The scores were compared by profession to

ascertain whether there were large discrepancies in knowledge. This may help determine which provider types will be most appropriate to participate in future pain management programs.

Scale 5: Psychological attributes related to pain and pain treatment. Thirty percent did not like being referred patients with an unclear diagnosis and did not enjoy taking care of them. None of the Winslow respondents thought that conscientious patients deserved better care or that more healthcare dollars should be spent on those who contribute most to society. Thirty-five percent were irritated by inconsistent medical reports.

Scale 6: Bias about gender and age. Forty-seven percent of Winslow providers thought that women were more likely than men to report pain compared to 41% who disagreed with this statement. Forty-one percent thought older patients are more likely to report pain than younger patients compared to 47% who disagreed with this statement. No one thought it was easier for males to become addicted than females.

Knowledge differences by provider type. The provider scores on the knowledge test were compared based on provider type. A chi-square test by profession produced $X^2(3) = 8$, $p < .05$, $r = .123$ which is statistically significant; this means that there were significant differences in knowledge scores by profession. Winslow providers scores on the knowledge questions ranged from a minimum score of 46.2% to a maximum score of 92.3% ($M = 65.9$, $SD 12.9$) as shown in Table 5. Physician assistants (PA) scored the lowest with a median score of 61.5% out of 100% and nurse practitioners (NP) scored the highest with a median score of 76.9%.

TABLE 5. *Knowledge Scores by Provider Type* (n=18)

PROVIDER TYPE	NUMBER OF PROVIDERS	MEDIAN SCORE FOR GROUP	Number of questions with 100% correct for group
NP	5	76.9	10
PA	3	61.5	8
DO	6	69.2	9
MD	4	73.1	9.5

Minimum 46.2%, Maximum 92.3%, Mode 69.2, Mean 65.9, Median 69.2, SD 12.9

Provider scores were then paired by profession and analyzed using the chi-square statistical test. This information was explored to help identify whether certain provider types need priority for educational activities once the appropriate instruction materials have been identified. Pairwise chi-square test of PA and NP scores produced $X^2(3) = 7.22$, $p < .05$ which is statistically significant. The chi-square test of PA and medical doctor (MD) scores produced $X^2(3) = 3.93$, $p < .05$ which is again statistically significant. The chi-square tests of all other possible professional pairs (Table 6) were not statistically significant.

TABLE 6. *Pairwise Comparison of Provider Scores* (n=18)

PAIRWISE COMPARISON	Chi Square	p-value (0.05)
NP:PA	7.22	.007*
NP:DO	1.95	.086
NP:MD	.51	.474
PA:DO	1.69	.192
PA:MD	3.93	.047*
DO:MD	.46	.494

*Denotes results that are statistically significant $p < 0.05$

Comparison of Winslow Results to Texas Pain Study Results

Survey results from the Winslow providers were compared to responses generated by primary care providers in the Texas Pain Study population (n=386) in order to address Aim 3. The Texas Pain Study was conducted by Weinstein, et al (2000) using this survey to evaluate physician factors in the management of chronic non-cancer pain. The purpose of this comparison

was to determine whether Winslow providers had characteristics that influence pain management that were similar to Weinstein’s Texas Pain Study providers. If this hypothesis was supported, then the recommendations in the Weinstein study are transferrable.

A 2 x 2 contingency table was constructed for each of the 59 questions using the number of “agree” and “disagree” survey responses from the Winslow providers and the survey responses from the Texas providers. Then the data were analyzed using a t-test (Fisher’s exact test). An example of this comparison analysis is provided in Table 7 using the first survey question.

TABLE 7. *Exemplar: 2 x 2 Contingency Table*

QUESTION: Chronic pain of unknown cause should not be treated with narcotic even if this is the only way to obtain pain relief.

	Agree	Disagree	Total
Texas	88	256	344
Winslow	2	14	16
Total	90	270	360

Note: The two-tailed $p = 0.3759$

Tables 8 through 13 show the results of the comparison of the survey results from both the Winslow and Texas providers. The percentages provided in the Texas survey by Weinstein were converted to real numbers for analysis in a 2 x 2 contingency table. The number conversions used in the contingency tables are shown and statistically significant differences between the two groups are identified with asterisks.

Reluctance to prescribe opioids. Winslow providers differed significantly in their response to two questions related to the reluctance to prescribe opioids. Specifically, the Winslow providers are less likely than the Texas providers to suspect that patients who complain of pain out of proportion to its cause are usually drug abusers. They are also less likely to believe

that using narcotics to relieve the pain of benign conditions is ill-advised. The specific questions where there were statistically different responses between the Winslow providers and the Texas Pain Study providers are identified with asterisks in Table 8.

TABLE 8. *Winslow and Weinstein Texas Pain Study Survey Results Compared – Reluctance to Prescribe Opioids*

RELUCTANCE TO PRESCRIBE OPIOIDS FOR CHRONIC PAIN	WIN A	WIN D	TPS A	TPS D	p-value
Chronic pain of unknown cause should not be treated with narcotic even if this is the only way to obtain pain relief	2	14	88	256	.3759
It is appropriate to escalate a dose of narcotics above the usual range if the prognosis is less than 1 yr	13	3	298	41	0.693
If a chronic pain patient is active on the job there is no possible justification for prescribing narcotics for pain	1	16	41	308	0.4328
Narcotics should be restricted to treatment of severe intractable pain	5	12	118	249	.5722
Persons who fit the "profile" of a likely drug abuser should never be treated with narcotics	1	16	101	253	0.0743
Prognosis should be the primary factor in deciding whether a patient should receive opiates	1	16	56	284	0.4455
Patients who complain of pain out of proportion to its cause are usually drug abusers	1	14	84	229	0.0007*
Using narcotics to relieve the pain of benign conditions is ill-advised	3	13	122	222	0.0161*
Even if patients have severe chronic pain, they should be treated with narcotics only when their illness has reached a terminal phase	1	17	37	317	>0.999
The presence of a physiologic basis for pain should be the primary factor when deciding to prescribe opiates	6	10	164	160	0.2124
I would never prescribe narcotics for a patient with chronic pain who is able to work.	0	17	34	305	0.6923

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance p<0.05

Fear of patient addiction. Winslow providers had less fear than Texas providers (12% versus 28%) that any patient who is given narcotics for pain relief is at significant risk for addiction but more fear (47% compared to 22%) that patients who receive narcotics for pain subsequently become addicts (see Table 9.)

TABLE 9. Winslow and Weinstein Survey Results Compared - Fear of Patient Addiction

FEAR OF PATIENT ADDICTION	WIN A	WIN D	TPS A	TPS D	p-value
Any patient who is given narcotics for pain relief is at significant risk for addiction	2	15	108	249	0.0055*
I would be extremely concerned about possible addiction if a member of my family were given morphine for chronic pain	6	11	151	206	0.0667
I must exercise caution when prescribing potentially addictive medications to patients with chronic pain	17	0	358	20	0.3884
When narcotics are used to control chronic pain, addiction is a common outcome	11	6	159	190	0.1904
More than 5% of patients who receive narcotics for pain subsequently become addicts	8	6	85	172	0.0005*

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance $p < 0.05$

Fear of regulatory agencies. Table 10 shows that on questions related to fear of regulatory agencies a significantly higher percentage of Winslow providers than Texas providers (82% versus 53%) believed that their peers were not any more willing than themselves to prescribe opioids.

TABLE 10. Winslow and Weinstein Survey Results Compared - Fear of Drug Regulatory Agencies

FEAR OF DRUG REGULATORY AGENCIES	WIN A	WIN D	TPS A	TPS D	p-value
If I prescribe opiates for several months for a patient with chronic pain due to cancer, I am violating state law	2	16	9	338	0.4297
My colleagues are more willing to give narcotics for cancer pain than I am	2	15	39	203	0.0023*
Prescribing narcotics for patients with chronic pain is likely to trigger a drug enforcement agency investigation	0	17	102	229	0.068
Too many narcotic prescriptions lead to utilization reviews	11	5	191	87	0.139
Pharmacists who receive several opiate prescriptions from a doctor are likely to report the doctor to a state review board	3	14	87	173	>0.999
If I follow the same prescribing practices as other doctors in my field, I will not be investigated by a regulatory agency	10	7	184	72	0.2556
There are limits to the number of narcotics tablets a patient should be prescribed	15	2	259	84	0.6094
I give patients a limited supply of pain medications to avoid being investigated	16	2	92	207	0.6102

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance $p < 0.05$

Knowledge of pain and pain treatment. Interestingly, in spite of the fact that providers were not concerned about addiction, 58% incorrectly responded that psychological dependence on narcotics very frequently results from legitimate prescriptions. They correctly answered that preexisting conditions not related to the cancer do not cause the most pain for cancer patients and they scored significantly higher on this question than the Texas group (see Table 11.)

TABLE 11. *Winslow and Weinstein Survey Results Compared – Knowledge*

KNOWLEDGE (<i>*denotes most troublesome for Winslow</i>)	WIN A	WIN D	TPS A	TPS D	p-value
<i>*Almost all chronic pain can be relieved with treatment. (True)</i>	7	10	261	102	0.789
The majority of patients having chronic pain are under medicated. (True)	8	6	218	85	0.4397
<i>*Psychological dependence on narcotics very frequently results from legitimate prescriptions. (False)</i>	12	5	208	144	0.1047
Suicide with an overdose of narcotics prescribed for pain occurs very frequently. (False)	1	16	38	285	>0.999
The best judge of pain intensity is the patient. (True)	16	1	306	54	0.3579
The health care provider is the best judge of pain intensity. (False)	1	16	51	294	0.4316
Pain in a cancer patient is most likely due to treatment. (False)	2	15	15	324	0.7052
The tumor itself is most likely the cause of pain in a cancer patient (True)	12	4	259	83	>0.999
Preexisting conditions not related to the cancer cause the most pain for cancer patients (False)	2	15	29	252	0.0494*
Increasing requests for analgesics indicate unrelieved pain (True)	12	4	209	119	0.4928
Increasing requests for analgesics indicate tolerance to the analgesic. (False)	12	3	241	95	0.1278
<i>*Almost all cancer patients suffer pain. (True)</i>	7	10	208	119	0.2815
<i>*Almost all cancer patients should receive opiates to relieve chronic pain (True)</i>	10	6	148	143	>0.999

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance $p < 0.05$

Psychological attributes related to pain and pain treatment. When asked about provider psychological attributes that influence pain management 94% of Winslow providers disagreed that conscientious patients deserve better health care than those with self-inflicted problems compared to only 53% of Texas providers. A significantly higher percentage of

Winslow providers disagreed that conscientious patients deserve better care than patients with self-inflicted problems. Likewise, a higher percentage of Winslow providers disagreed that people with high intelligence should get better care or that they disliked having patients who “don’t follow the book.” Again, this may reflect the psychological traits that drew these providers to Winslow to care for the medically underserved patients at WIHCC (see Table 12.)

TABLE 12. *Winslow and Weinstein Survey Results Compared - Psychological Attributes*

PSYCHOLOGICAL ATTRIBUTES	WIN A	WIN D	TPS A	TPS D	p-value
Compliant patients are entitled to more of my time than noncompliant ones	2	15	179	149	0.4434
Those who contribute the most to society should get better health care.	0	17	75	236	0.3884
I do not like being referred patients with doubtful diagnosis	5	12	82	211	0.1699
Life would be better if homosexuals and IV drug abusers were segregated into special groups	1	16	63	254	0.6241
If I knew that a prospective patient had an untreatable disease, I would avoid taking that patient if I could	2	15	35	305	0.5943
I resent tax money being spent on patients with self-inflicted diseases	3	12	194	134	0.1404
A doctor who practice has few surprises has a lot to be grateful for.	3	12	134	166	0.0831
It "bugs" me if a consultant I am working with after carefully reviewing a patient says, "I'm not sure."	0	17	32	284	0.0971
When laboratory reports give conflicting information, I get upset	3	14	107	197	>0.999
Conscientious patients deserve better health care than those with self-inflicted problems	0	17	127	205	0.0044*
It bothers me when even a pathologist cannot find the cause of death.	5	10	136	160	>0.999
More healthcare dollars should be spent on those who contribute most to society	0	17	101	214	0.284
I do not enjoy treating patients whose illness is unlikely to respond to treatment	51	38	29	59	0.2737
I get irritated by inconsistent medical reports.	42	35	35	59	0.3808
When the time comes that medical care will have to be rationed, those with high IQs should get the best care.	4.1	81	0	94	0.001*
I dislike having patients whose outcomes "don't follow the book."	20	52	12	82	0.0118*
Undiagnosable illnesses are something I'd rather not get involved with.	32	48	29	59	0.2374

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance p<0.05

Bias about gender and age. Table 13 shows there were no statistically significant differences between the Winslow and Texas providers on any of the questions related to gender and age bias.

TABLE 13. *Winslow and Weinstein Survey Results Compared - Bias Regarding Gender and Age*

BIAS REGARDING GENDER & AGE	WIN A	WIN D	TPS A	TPS D	p-value
It is easier for a male patient to become addicted to narcotics than a female	0	17	15	251	0.451
Men are less likely to report pain to their doctor than women.	8	7	185	126	0.7046
Females are more likely to experience pain than males	4	13	89	174	0.4858
Young adults are more likely to become addicted to narcotics than the elderly	2	15	93	187	0.4852
Older patients are less likely to report pain than younger patients	7	8	119	149	0.1915

A = agree, D= disagree

WIN = Winslow Study (n=18)

TPS = Texas Pain Study (n=386)

*Denotes statistical significance $p < 0.05$

Summary

This chapter reports the results of the five patient interviews to address Aim 1, and the results of the provider survey to address Aims 2 and 3. Patients' pain problems were representative of the types of patients seen for chronic pain at Winslow Indian Health Care Center. Eighteen providers participated in the survey representing 100% participation.

Native American patients (n=5) residing within the Winslow community participated in digitally recorded interviews to gain insight into their perceptions regarding chronic pain management. The results show that Winslow patient participants were generally dissatisfied with the pain care practices at Winslow Indian Health. All participants reported that their pain interfered with their activities of daily living including employment. There were wide variances among participants in the types of diagnostic work up and in patient education. Self-treatment

consisted of over-the-counter medications such as ibuprofen, acetaminophen, and topical preparations. They also used thermal treatments and activity modification to manage symptoms. All of these patients attempted to use complementary alternative therapies for pain treatment but none relied on alternative therapies alone. The most common effective treatment for these patients was massage. Patient reported goals of treatment included relief of pain, improved quality of life, the ability to return to work, the ability to perform household chores, and the ability to participate in more physical leisure activities.

The previously validated survey entitled *Factors Influencing Physician Management of Cancer Pain* (Cleeland, et al, 1986) was administered to Winslow health care providers (n=18). The results of the provider survey showed there were negative psychological attributes and bias. They also had significant fears regarding scrutiny from drug regulating agencies and nearly one-third thought opioids should be restricted to patients who have severe pain. There were high levels of fear regarding patient addiction and providers lacked knowledge regarding the risks for psychological dependence and the fact that most chronic pain can be effectively treated.

Fifty of the survey items showed no statistically significant differences between Winslow providers and the results of the Texas Pain Study. There were nine items on the 59 item survey that had statistically significant differences in response between these two provider groups.

CHAPTER 5: DISCUSSION OF FINDINGS

Introduction

The purpose of this practice inquiry was to develop a knowledge base about issues associated with chronic pain and its treatment among Native American people. The results of this inquiry will be used to make recommendations for the development of a pain management program within an institution that provides health services to this Native American community. In this chapter, results will be discussed and interpreted. Implications and recommendations for clinical practice will be presented. Study strengths and limitations will be summarized and recommendations for future studies will be provided.

Interpretation of Findings

The Experience of Chronic Pain: The Patient Perspective

Dissatisfaction with pain care at WIHCC was the overarching theme among patient participants. Patients reported poor outcomes following treatment for chronic pain and continued to have significant symptoms that interfered with daily functioning and quality of life. Although patients felt they communicated their pain and self-treatments to their provider, they also made comments indicating that provider communication was poor. They expressed frustration with their ongoing symptoms and the lack of understanding about their condition and treatment options. Obviously, cultural factors contribute to misperceptions and communication issues between patients and providers at WIHCC and this leads to suboptimal outcomes for patients with chronic pain. People from different cultures respond differently to the pain experience. Since less than half (44%) of WIHCC providers have worked with this population for five years

or more a general deficiency in cultural competency can be expected. This is consistent with the literature concerning cultural competency and complex health issues such as chronic pain.

The influences of culture on symptoms, patient/provider relationships, and adherence to treatment have been well-documented (Cuffe, Waller, Cuccaro, Pumariega, & Garrison, 1995; Helman, 2000; Pumariega, Johnson, Sheridan, Cuffe, 1996; Saha, 1999). Culture in healthcare is an important factor that encompasses the values, beliefs, and behaviors of a person or group and the influence of these characteristics on health care practices (Suh, 2008). Cultural competence is, therefore, a critical factor in Winslow since the majority of health care providers are non-Native. A study by Kramer (2002) found that Native Americans tend to understate their pain levels and that this often leads to misperceptions and under treatment. The influence of culture on communication in the health care setting has been well documented (Palos, Ashing-Giwa, 2007).

Health and illness behavior is determined by how people identify and respond to their symptoms (Lenz, 1984). One model that informs this process is the Symptom-Action-Time-Line model proposed by Buehler, Malone, and Majerus-Wegerhoff (2006). Buehler, et al, found that Native American women in Montana used the symptom-action-time-line (SATL) process to respond to health symptoms. Knowledge and past experience with illness, severity and duration of the symptoms, and the extent to which this interfered with function were factors that influenced the perceived need for action. Seeking help from professional resources is the final stage of the SATL. Professional resources were utilized only after self-care and lay resources had been implemented and failed. The literature suggests that men tend to delay seeking professional

help as long as possible and may have very different, longer time-lines; however, most of the studies focus on women.

During the 1:1 interviews Winslow patients described their shared and unique experiences with chronic pain and their perceptions of pain treatment at WIHCC. According to these descriptions three of the five patient subjects had back pain but each had different diagnostic workup ranging from a simple physical exam to MRI and consultant referrals. This is discrepancy is common at WIHCC where diagnostic workup is highly dependent upon each provider's experience with chronic pain issues, familiarity with the diagnostic value of specific studies, and ingrained practice behaviors. Clinical practice guidelines for back pain do not recommend expensive testing initially because it is not generally necessary, but a basic x-ray may offer some useful information to share with the patient regarding the cause of their pain and its treatment. X-ray services are readily available on site at WIHCC, and this is the least expensive initial step in identifying problems that lead to chronic pain. In spite of the availability of guideline materials, these are not consistently implemented within this clinic. Clinical practice guidelines for back pain, for example, are readily available and implementation of these guides has the potential to reduce costs and streamline care. Chronic pain clinical practice experts recommend that diagnostic work ups should proceed in a stepwise fashion according to published guidelines to avoid unnecessary testing and duplication of services and to improve quality of care (American Society of Anesthesiologists, 2010).

Two of the five patients in the Winslow study were poorly informed regarding their pain diagnosis, the cause of their pain, or their treatment options. Their comments included:

“They don't know what's going on....I don't know if this has anything to do “with the shots, the epidurals with the kids, I don't know.”

“There’s nothing else to do; I was born this way. Just take the medicine. I don’t think they can do anything about it.”

Both of these patients expressed frustration and dissatisfaction with their pain care and one of these women verbalized the following:

“There has to be something else, [sounding slightly agitated] you know. I can’t stand long periods, I can’t stand up too long because my back starts hurting and then I feel like I’m bending over like this and it feels like I have to straighten up.....it doesn’t go away.”

All participants in this project had suboptimal treatment outcomes and continued to have pain that significantly impacted their lives. Clearly the lack of patient provider communication regarding the cause of their pain and the omission of frank discussions about prognosis, treatment options, and realistic treatment expectations impacts these patients’ perspectives around pain and pain treatment.

Patient education has been shown to increase compliance, improve outcomes, and increase patient satisfaction with care. Mutual trust and rapport are a natural consequence of the continuous interactions over time between the patients and healthcare providers (Institute for Patient- and Family –Centered Care 2010). At the time of this study, only a small fraction of patients in the Winslow IHS service area had been assigned a primary care provider. As a result, patients often see a different provider each time they go to the clinic. They receive different and often conflicting advice from multiple providers that leaves them confused and frustrated. The assignment of a primary care provider creates consistency and continuity of care. Consistent messages about health issues and treatment options promote trust and reduce confusion for patients. This is especially important with complex health issues such as chronic pain where provider knowledge and comfort with management is highly variable. Patients in Winslow have

expressed frustration by fragmented care; the “new patient” phenomenon, wherein providers see patients they have never seen previously. This occurs day after day in a very high proportion of all patient/provider encounters at WHICC. This phenomenon contributes to both patient and provider frustrations with pain care and compromises the quality of healthcare delivery.

Outdated, paternalistic models of healthcare have been proven to be ineffective and this is reflected in IHS statistical data (IHS, 2009). The concept of patient-centered care is central to the nursing paradigm but this concept has only recently been introduced into the medical healthcare model taught in medical schools. The hallmarks of patient-centered care are patient/provider partnerships that promote informed, shared decision making, development of patient knowledge, self-management skills, and preventive behaviors (Rosenthal, 2008). The healthcare providers’ knowledge of patients’ home life, employment, cultural background, family relationships and other factors are used to inform health promotion and treatment decisions. Studies have shown that patient-centeredness produces better clinical outcomes and patient satisfaction with care (Wagner, Austin, Davis, Hindmarsh, Schaefer, and Bonomi, 2001).

Patient treatment choice and options. There are many available treatment options for chronic pain management that include pharmacological support (non-steroidal anti-inflammatory drugs [NSAID] and opioids), complementary therapies (body work, mind-body interventions, and energy modalities), and alternative medical systems (Native healing practices or Traditional Chinese Medicine). There is abundant literature about the effectiveness of various pharmacological treatments and emerging support (systematic reviews, meta-analyses) for complementary and alternative therapy choices (American Pain Foundation 2010; American Pain Society, 2007; American Society of Anesthesiologists, 2010; Ernst, 2005; National Centers for

Complementary and Alternative Medicine, 2010; Patel, 2006; Porsche, 2010; Warne, 2008; Weiner, et al, 2006; World Health Organization, 2006).

Use of prescription medications. The patient participants in this inquiry generally did not like or want to use opioid analgesics. They had serious concerns about the safety of opioids as well as the adverse effects associated with long-term NSAID use. Although these medications were helpful to varying degrees, they were not very effective as standalone treatments for their chronic pain. Patients routinely combined these therapies with complementary treatments that were, for the most part, self-selected and self-referred. Only one patient had succeeded (after more than a decade of seeking and self-referring) in integrating a near optimal pain treatment plan that included a combination of allopathic and complementary alternative therapies. He expressed his fear of and dissatisfaction with opioid analgesics and his frustration that healthcare providers continued to order them.

Four of the five patients in the study were reluctant to use opioid medications, believed they should be used sparingly, and that they were associated with significant adverse effects.

They made comments such as:

“It seems like it just relieves it for a little bit but I have to take it a lot. But I just try to take one or two a day.”

“I don’t want to be taking those for the rest of my life because of the side effects. But it helps.”

“Like I said, I’m not a big fan of prescription drugs but if it’s there and I absolutely need it then I’ll take it.”

“They scare me.”

Delaying the use of prescribed medications until the pain is unbearable makes it more difficult to regain control of symptoms (Fishman, 2007). The literature consistently supports

unfounded anxiety about adverse side effects of opioids and concerns about addiction, tolerance, and over-medication when using opioids for chronic pain management. Among patients, negative attitudes about opioid use are associated with older age, lower socioeconomic status, and lower levels of education (O'Rorke, et al, 2007).

Beliefs and attitudes about treatment options. All patient participants in this study used some type of complementary alternative therapy in conjunction with allopathic treatments. The therapies used by patients were consultations with a traditional healer, massage therapy, chiropractic care, and acupuncture.

Although the statistics are unknown, many members of tribes in the Southwest continue to use the traditional Native American whole system of medicine to manage their health issues either alone or in combination with allopathic medicine (Warne, 2008). Therefore, the treatment choices found in this sample did not mirror the population as a whole and in congruent with the literature. A study of patients who live on the reservation, and who may be engaged in more traditional practices, would likely produce findings that are more consistent with the literature. Beuhler, et al., (2006) found that Native American women in Montana believed that some symptoms were due to supernatural forces and sought the help of a medicine man. However, none of the patients in this study implied that their pain was a consequence of supernatural forces. Patients in this inquiry attributed their pain to mechanical problems with their musculoskeletal system. Again, these patients live in Winslow and have integrated with mainstream culture; their perceptions may not reflect those of more traditional NA people who live on the reservation. Two patients reported they had consulted a traditional healer for pain and only one patient had used the traditional healer who is on staff at WIHCC. The one patient who

consulted with the traditional healer on staff subsequently withdrew from his care in favor of chiropractic care for which she paid out of pocket. This low number of consultations with the staff traditional healer may surprise some leaders at WIHCC. The researcher's conversations with several people from the Navajo tribe revealed that they typically have one medicine man that treats the entire family throughout life. They report that their healer knows them well and they do not typically consult other traditional healers.

Massage was used by three of the five participants and was perceived as more effective than all therapies tried by one of the subjects who used it. Massage is readily available at WIHCC, but only one patient had been referred for this therapy by a provider; another patient was treated by his wife who is a massage therapist and a third self-referred to the massage therapist at WIHCC. Although patients did not specifically comment on the lack of provider referral to complementary therapies that worked, this does lend to the potential for reduced confidence in the allopathic health system when effective therapies are not offered. The lack of provider awareness regarding effective complementary alternative therapies for pain treatment is not surprising. Providers who were trained in the allopathic paradigm have traditionally not been exposed to CAM and are not likely to refer these therapies even when they are available in the same clinic. A Cochrane review of the literature supports the use of massage as a therapy that can be helpful for chronic back pain (Furlan, Imamura, Dryden, & Irvin, 2008). Therefore, increasing provider awareness of the literature/evidence of the effectiveness of massage as well as increasing the professional dialogue between providers (allopathic and massage therapists) might increase the use of massage for patients with chronic pain.

Only one patient reported using acupuncture which is also readily available in the clinic. Clinical practice guidelines set forth by the American Pain Society and the American College of Physicians (2007) recommend acupuncture as a CAM therapy that physicians should consider when patients with chronic low-back pain do not respond to conventional treatment. Providers at WIHCC are not fully utilizing this available, proven therapy and are missing valuable opportunities to educate patients regarding non-pharmacologic treatment options that can be incorporated into their chronic pain treatment plan.

Patient self-treatment practices. All patients in this practice inquiry used self-treatment modalities such as thermal treatments, over-the-counter analgesics, and activity modification to relieve pain symptoms. This corresponds to the second stage, which is the self-care stage, of the symptom-action timeline (SATL) described by Beuhler, et al., (2006). The self-care stage involved self-initiated activities such as over-the-counter medications or heating pads, getting more rest or consciously watching for further symptoms. According to Beuhler (2006), the timeline for this stage is mostly dictated by the intensity of the symptoms and ranged from seconds to days. Furthermore, by the time patients have reached the fourth stage of the SATL, they have already exhausted their own treatment resources and are in need of advice. It is at this stage that Winslow patients typically seek allopathic care for their symptoms.

Although all of the self-treatment measures that these patients used can be useful as adjunctive treatment in chronic pain management, there is the potential for self-harm. Over-the-counter medications may also be part of the prescribed therapy resulting in duplications, overuse, and significant adverse effects. As Beuhler (2006) described, by the time a patient seeks care in the allopathic setting they have generally already exhausted these resources and require more

aggressive treatment. The literature supports the provider assisted design of an individualized, patient-centered, multimodality treatment plan for chronic pain management that may or may not include these self-treatment measures (American Society of Anesthesiologists, 2010; American Pain Society, 2010; Fishman, 2007; Weiner, et al, 2006).

Outcomes of pain management: The patient perspective. All subjects indicated that their pain had significant impact on their daily activities, including the ability to work, the ability to engage in leisure activities, and the ability to perform household tasks. The goals of treatment for patients in this study were realistic and likely attainable with proper treatment. Patients identified goals that included relief of pain, improved quality of life, the ability to return to work, the ability to perform household chores, and the ability to participate in more physical leisure activities. Current literature supports the appropriateness of these goals; the American Association of Anesthesiologists (2010) claim that when using multidisciplinary treatment modalities for chronic pain there is effective reduction of pain symptoms for time periods ranging from four to 12 months and an eventual increase in activity level and ability to participate in activities of daily living (American Association of Anesthesiologists, 2010). While chronic pain is expected to wax and wane, these periods of improvement have the potential to significantly impact the ability of patients with chronic pain and allow them to participate in activities that are important to them such as employment, leisure activities, household management, and family activities.

The evidence links inadequate treatment of acute pain to maladaptive behaviors and pathologic neural alterations that evolve into chronic pain syndromes. All types of pain can result in decreased mobility; sleep disturbance, impaired immune system functioning, depression, and

medication dependence. Pain undermines the quality of life and impairs social functioning, including the ability to maintain employment. Chronic pain causes huge social and economic burden and is clearly linked to low socioeconomic status (American Pain Society, 2009; Brennan, et al, 2007).

Factors that Influence Pain Management: The Provider Perspective

This section addresses provider factors that influence pain management. Factors known to influence the way providers treat pain include the attitudes they have toward opioid prescribing; fears regarding patient addiction, fears regarding scrutiny from drug regulatory agencies, their knowledge and beliefs around pain treatment, psychological factors, and bias regarding gender and age. The results of this inquiry and implications for patients in Winslow are discussed below.

Opioid prescribing. Winslow providers differed significantly in their response to two questions related to the reluctance to prescribe opioids. Specifically, the Winslow providers are less likely than the Texas providers to suspect that patients who complain of pain out of proportion to its cause are usually drug abusers. They are also less likely to believe that using narcotics to relieve the pain of benign conditions is ill-advised. This would imply that these providers are more willing to prescribe necessary opioids for chronic pain. However, prescribing practices are influenced by complex local issues around the potential for addiction.

Opioids and addiction. Winslow providers appear ambivalent regarding the prescribing of opioids for chronic pain. They had less fear than Texas providers that any patient who is given narcotics for pain relief is at significant risk for addiction but more fear that those patients who receive narcotics for pain subsequently become addicts. The impressions of the Winslow

providers may be influenced by the higher than average addiction rates among their Native American patients. The percentage of American Indian or Alaska Native adults who needed treatment for an alcohol or illicit drug use problem in the past year was higher than the national average for adults (18.0 vs. 9.6%) (SAMHSA, 2010). This is a legitimate concern that reinforces the need for pain management practice that include screening for abuse risk, pain management agreements, intensive patient education, and regular blood and/or urine drug screening for patients who are prescribed opioid analgesics as well as some family members. These are time consuming tasks that may be better managed through the development of a multidisciplinary pain management program.

Apprehension regarding drug regulating agencies. On questions related to fear of regulatory agencies, a significantly higher percentage of Winslow providers than Texas providers believed that their peers were not any more willing than themselves to prescribe opioids. Fifty-three percent of the Winslow providers also believed that if their prescribing practices were similar to their peers they would be at less risk for scrutiny by drug regulating agencies. These perceptions impact the willingness to prescribe opioids for pain and imply that Winslow providers are not fearful of drug regulating agencies or of prescribing these drugs. Providers in WIHCC, as in all IHS facilities, are covered by the Federal Tort Act making it difficult for them to be personally liable in a malpractice claim compared to providers who are covered by commercial malpractice policies. This may account for their increased willingness to prescribe high risk medications such as opioids and their lack of concern about lawsuits and personal liability.

Knowledge and beliefs. Four of the knowledge questions were particularly problematic for the Winslow providers. They believed that patients who receive narcotics for pain were at risk for becoming addicts. Sixty-six percent agreed with the false statement that psychological dependence on narcotics very frequently results from legitimate prescriptions. These beliefs regarding the dangers of psychological dependence on narcotics may reflect their experiences with higher addiction rates among Native Americans compared to the general population. This can lead to under-prescribing and, when prescribed, limitations on the amount of medication provided to patients. This can create a cycle of under-treated pain and requests for more medication that reinforce provider misperceptions about drug-seeking and abuse. The risks for the occurrence of this cycle are reinforced by the fact that 83% of providers agreed with the false statement that increasing requests for analgesics indicate tolerance to the analgesic (it usually indicates under treatment.) Unfortunately, 66% of the Winslow providers did not know that, in cancer patients, the tumor itself is most likely the cause of pain and 55% did not know that most cancer patients suffered from pain. Interestingly, the same number (55%) agreed that nearly all cancer patients should have opiates for pain. The implications of this finding are not clear and require further study. The lack of provider knowledge on important aspects of pain management helps to explain the patients' experiences and suboptimal pain outcomes.

Nurse practitioners scored higher than medical doctors, osteopathic physicians, and physician assistants on the knowledge scale. This is not surprising giving the emphasis in nursing on patient comfort and focused education that nurses receive about health management and patient-centered care. Nursing curriculums promote the knowledge of a global perspective on healthcare that “includes clinical, scientific, decision making, and humanistic skills, including

preparation in community health, patient education, and nursing management and leadership.” (American Association of Colleges of Nursing, 2008, p. 3). This particular skill set is unique to the nursing profession and serves them well in today’s complex healthcare environment.

Physician assistants scored the lowest on the knowledge scale, indicating this group has the most immediate need for education on pain treatment. Overall, the findings on the knowledge scores were similar between the Winslow and Texas Pain Study providers. There was a statistically significant difference between the two groups of providers on only one item: Preexisting conditions not related to the cancer cause the most pain for cancer patients (False). Eighty-three percent of Winslow providers responded correctly compared to 65% of the Texas Pain Study providers. This finding has little if any relevance to the prescribing practices of Winslow providers for chronic non-cancer pain.

Psychological attributes. A higher percentage of Winslow providers disagreed that people with high intelligence should get better care or that they disliked having patients whose pathophysiology “does not follow the book.” Again, this may reflect the psychological traits that drew these providers to Winslow to care for the medically underserved patients at WIHCC. Overall, providers at WIHCC had a lack of knowledge about pain and psychological traits that are known to be barriers to pain management. These findings are similar to providers in the Texas Pain Study by Weinstein, et al, (2003) and other studies confirm that these findings are common among healthcare providers (Bertakis, et al, 2004; Cleeland, et al, 1986; Craine, 2003; O’Rorke, et al, 2007).

Gender and age bias. There were no statistically significant differences between Winslow and Texas providers on any of the questions related to gender and age bias. It is not

surprising that Winslow providers believed that men and elders are less likely than women to report pain, since stoicism is the norm in Native American culture. Elders are more likely than younger patients to be traditional in their beliefs and, therefore, more adherent to cultural traditions (Morgan, 2008).

Representativeness of the Sample

Two populations were included in the sample representing local stakeholders in the treatment of chronic pain. Both populations were representative of the conditions found at WIHCC. This representativeness allowed the researcher to adequately address Aims 1-3 for the purposes of this formative assessment.

Patient sample. The patient sample included four females ranging in age from 25 to 61 years and one male age 60 years were interviewed. Three participants had chronic back pain, one had arm pain, and one had neck pain and headaches. In the United States there are four common types of chronic pain: Low back pain is the most common (27%), followed by severe headache or migraine pain (15%), neck pain (15%) and facial ache or pain (4%) (National Institute of Health, 2006). These are also common chronic pain complaints at WIHCC. Therefore, this sample is representative of chronic pain patients seen at this health center.

Provider sample. At the time of the provider survey there were 18 healthcare providers on the medical staff at Winslow Indian Health Care Center. One hundred percent of the target population responded to the survey. Therefore, this sample is definitely representative of this community. The high participation rate was likely reflective of the local concern about chronic pain and the issues that complicate providing treatment.

Among the provider respondents there were five nurse practitioners, three physician assistants, six osteopathic physicians, and four medical doctors. Eight of the providers were female and 10 were male. Average number of years in practice ranged from 2.5 to 36 yrs with a mean of 14.6 years. Years at WIHCC ranged from 2 to 30 with a mean of 7.4 years. Three of the 18 providers had received any past training in pain management.

Tribal health centers are typically staffed with non-Native health care providers who have been educated within an allopathic model. Generally speaking, providers in the IHS have limited or no knowledge of how local culture impacts patient/provider interactions (Northwest Federation of Community Organizations, 2009). Demographic information regarding ethnic background was not collected in the survey. However, it is known that there was only one NA healthcare provider on staff at WIHCC; the researcher is very familiar with the facility and medical providers on staff at the time of this inquiry. Cultural differences between patients and providers are compounded by the transient nature of the providers in the IHS. Although some providers remain in the IHS system for many years, most fulfill their two-year obligation for student loan repayment and then leave the system (Indian Health Service, 2009). Less than half (44%) of the Winslow providers had worked at WIHCC for five years or more. Therefore, it can be concluded that less than half of the providers have remained at the facility long enough to have the opportunity to develop cultural competency with this particular population. Cultural competency requires interaction over time and the motivation to gain knowledge of the culturally influenced belief system that influence healthcare behaviors. Providers who know they will leave in two years are not likely to be highly invested in this endeavor. The lack of cultural

competency impedes the ability of providers to deliver effective pain care and contributes to the suboptimal outcomes described by the patients in this inquiry.

Summary

The patient results indicated they had suboptimal treatment outcomes and continued to have inadequately treated pain that significantly impacted their lives. Poor patient/provider communication impacted these perceptions since patients had knowledge neither of the range of available treatment options nor of realistic treatment expectations. They continued to have symptoms that significantly impacted their ability to go about their daily lives and this negatively influenced their quality of life. They continued to struggle with unclear prognoses, inadequate knowledge and capacity for self-care, and frustration with the allopathic system of care.

Provider results indicated there were psychological barriers that are known to negatively influence chronic pain treatment such as authoritarianism, intolerance of ambiguity, reliance on technology, and locus of control that are known barriers to effective pain care. There was a lack of knowledge regarding pain and pain management among the Winslow providers as well as perceptions and fears related to drug regulatory agencies. These findings are similar to providers in the Texas Pain Study and to various other published studies.

Winslow providers care for a population that has higher addiction rates than the general population and this may influence their perceptions regarding the risks of addiction when prescribing opioid analgesics. Their experiences and propensity for working with underserved populations may account for slight differences between Winslow and Texas Pain Study survey results. Specifically, Winslow providers may be more tolerant of patient behaviors that may undermine health.

Project Strengths and Limitations

Strengths

Community-based participatory action research (CBPR) involves communities at the grassroots level to identify and resolve health issues and the use of these methods was a major strength of this project. Widespread involvement increases the ability to accurately measure the problem and to develop treatments that are acceptable to the local population. CBPR enables informed, contextually-based planning and decision-making that will contribute to program effectiveness and successful implementation. This approach to addressing health issues has been shown to contribute to increased acceptance by the target population of the resulting interventions (Gittelsohn, Evans, Helitzer, Anliker, Story, Metacalfe, Davis, & Iron Cloud, 1998). As such, an effective pain management program can be developed, decreasing the waste of scarce healthcare resources.

Patient interviews. Ethnographic interviews allowed the researcher to elicit patient perspectives around chronic pain. It allowed patients the opportunity to tell their stories about their pain experiences. Storytelling is a traditional Native American method of communicating important information. Utilizing this familiar method of information sharing was more comfortable for patients than other possible methods such as surveys and this enhanced the data collection process. The Native American research assistant was an invaluable asset to the study due to her ability to connect with the participants in a way an outsider would not have been capable of doing. The interview questions used by the RA were adequate to extract useful and relevant information for this formative assessment.

Provider survey. One-hundred percent participation was achieved on the provider survey. This is a testament to the level of concern Winslow providers have for the problems around pain management within the community. High participation rates enabled the researcher to detect a few statistically significant findings and improved the relevance and validity of findings. The ranges of patient characteristics such as age and pain problem strengthen the study and were representative of the pain issues typically seen by providers at WIHCC.

Limitations

Limitations of this study included difficulties the researcher encountered with patient recruitment and with the RA's inexperience with ethnographic interview methods. The provider survey was another issue since these methods have inherent limitations. Small samples are common issues in clinical studies with which researchers must contend.

Limitations with patient participants. The limitations associated with recruitment difficulties and the inaccessibility to patients who reside on the reservation are acknowledged. Proficiency with ethnographic interview techniques is gained with experience. The PI's choices in selecting an interviewer from the community were limited and resulted in the selection of a RA who had very little experience in conducting this type of interview.

The patient sample was limited to patients living in Winslow. The exclusion of patients who reside on the nearby reservation is an additional limitation of this study. The inclusion of patients living on and off the reservation would likely have provided additional culturally relevant information around patient experiences related to pain. Obviously, Native Americans who reside in Winslow are more assimilated into mainstream culture than reservation residents and there may be significantly different perspectives on the experience of pain.

Likewise, it was not feasible to administer a survey to Native American patients to address Aims 1 since no pain related surveys have been validated with this population. Although surveys themselves have significant limitations, it may have been useful to utilize this method to reach a larger pool of patient participants; surveys can be mailed or filled out in the clinic while patients are waiting for appointments.

Another limiting factor is that recruitment of an adequate sample pool was difficult and this limited purposive sampling methods. Although the sample was fairly representative of the range of problems seen at WIHCC, there was only one male perspective. Patient interviews may have been considered uncomfortable for potential participants and this information may have inhibited recruitment efforts. They may not have wanted to discuss pain issues or to have their voices digitally recorded.

Some of the patients were minimally forthcoming with their responses and opportunities for further questioning were missed. The inexperience of the research assistant in interviewing for the purpose of ethnographic research resulted in the limited data bits that were available for analysis. Further probing during the interviews would likely have elicited a higher volume of relevant data.

The ability to communicate in English was one of the inclusion criteria. However, it was impossible to prevent participants from lapsing into their native language once an interview had gotten underway. It was necessary to retain the services of a bilingual transcriptionist for one of the interviews since the interviewee frequently responded using her Navajo language. This language conversion is recognized as an additional limitation of the study since meaning can be lost in the translation.

Limitations with provider participants. There were many inherent problems with survey data collection methods and the context of the needs assessment. However, all studies have limitations that are often unable to be controlled by the researcher. These are frequently recognized once a study has been completed and provide valuable insight for future inquiries. Survey methods and associated issues for this inquiry are described in the following paragraphs. The small sample size is a further limitation but this is a common issue in clinical studies.

The inherent limitations associated with survey methods are acknowledged in this study. To enhance validity more than one measure for each domain should be used for confirmation when self-report measures are used in studies. Combining research methodologies is a type of triangulation that is used to view an issue from multiple perspectives to obtain a rich description of the phenomenon under study and increase the validity of results (Trochim, 2006). Ideally, providers should have had interviews and the resulting data should be compared to the survey data to provide confirmation of at least some findings. However, it was impossible for the researcher to conduct interviews with providers due to cost and time factors. Also, since the researcher was an “insider” member of the staff at the time of the study it would likely have been impossible to remain objective. Strategies for overcoming this would be to expand the size of the research team, incorporate debriefing, and to use triangulated data where more options can be explored. The researcher had neither the financial or human resources available to incorporate these strategies. Thus, the results of the survey analysis alone were compared to the results of the Weinstein (date) data to validate observations concerning provider factors that influence effective pain management.

The small sample size is a limitation of this study since nonparametric tests such as the t -test have little power to detect differences with small samples. Nonparametric are less powerful than the parametric tests; p values tend to be higher in non-parametric tests making it more difficult to detect differences as being statistically significant. When large samples are measured, the difference in power is minor. The chi-square test results only in approximate P values. The Yates correction used with the chi-square test goes too far and the P may be calculated as too high. Fortunately, nonparametric tests are not reliant on the estimation of parameters describing the distribution of the variable of interest in the population. In this study, the use of nonparametric tests enabled the processing of data from a small sample on variables where nothing is known about the distribution.

State of the Practice in Winslow Indian Health Care Center (WIHCC)

The importance of the therapeutic patient/provider relationship cannot be overstated when dealing with complex health issues such as chronic pain. In order to provide effective patient-centered healthcare it is essential to get to know a patient including care preferences, social situation, family and support systems, and a multitude of other factors that influence the development of a treatment plan.

The current clinical practice guidelines and expert panel recommendations emphasize the importance of having one primary healthcare provider to oversee integrated, multimodality pain management and treatment plans, especially when opioids are involved (ASA, 2010; APS, 2010, Fishman, 2007; Weiner, et al, 2006). At the time of this study, only a small percentage of patients at WIHCC had been assigned a primary care provider. Consequently, patients typically saw numerous providers for their health issues. This has resulted in fragmented care and a

perpetual “every patient is a new patient” phenomenon that causes frustration among both patients and providers. Reports in the literature support the fact that healthcare providers’ knowledge of patients’ home life, employment, cultural background, family relationships and other factors should be used to inform patient-centered health promotion and treatment decisions (Helman, 2006). It is impossible to develop therapeutic relationships when patients see a different provider each time they seek care. End with a statement that summarizes the issues and why this is so important.

Leaders at WIHCC are working to establish primary care assignments for all patients but the process is slow. The paternalistic IHS model of care persists and attempts to adopt newer models are fraught with resistance and bureaucracy (Northwest Federation of Community Organizations 2009). Entrenchment in the outdated, paternalistic models of healthcare delivery traditionally employed by the IHS can inhibit the adoption of health policies and newer models of care that have been shown to positively impact patient care (Rosenthal, 2008).

The availability of multimodality pain treatment options facilitates the care of the person with chronic pain (American Society of Anesthesiologists, 2010; American Pain Society, 2010; Weiner, et al, 2006). While the lack of availability of certain pain treatments is a problem that exists in some health systems, the Winslow tribal healthcare system is fortunate to have multiple resources in place that have been shown in studies to provide good results in the treatment of pain (ASA, 2010). Unfortunately, only one patient in this study had been referred for non-pharmacologic therapies for pain. A multidisciplinary staff is already on hand, and they are capable of offering a wide array of interventions that have the potential to improve pain care at this facility. The available types of professionals that can contribute to pain care are allopathic

physicians, nurse practitioners and nurses, behavioral health professionals, pharmacists, physical therapists, a traditional healer, an acupuncturist, and a massage therapist. There are also classes for yoga and tai chi both of which have been shown in studies to have positive results in the management of chronic pain (Patel, 2006; Sherman, et al, 2005).

There appears to be a mismatch in what patients want and need, what is available, and what providers do and recommend. Patients were open to non-pharmacologic strategies to treat pain and did not like using opioid medications. Yet, they did not use the services of the traditional healer on staff at WIHCC. Previous conversations between the researcher and NA people in this community revealed that they typically have one medicine man that treats the entire family throughout life. They report that their healer knows them well, and they do not typically consult other traditional healers. Further, in order to see the traditional healer of their choice they must pay for this service out of pocket; payment for the in-house healer is covered under the IHS health care system. This contention between patients' wishes and providers' treatment contributes to the suboptimal outcomes and patient dissatisfaction with care found in this practice inquiry.

Nearly one-third of the providers thought opioids should be restricted to patients who have severe pain, and there were high levels of fear regarding patient addiction. Patients concurred; four of the five patients in this practice inquiry did not like using opioids and thought they should be used sparingly. However, only one patient had been referred by a provider to any of the available complementary alternative therapies to address their pain concerns. Even more concerning, one patient indicated that providers continued to prescribe opioids in spite of his rejection of these medications.

The providers in this inquiry had significant fears regarding scrutiny from drug regulating agencies and this has an impact on prescribing practices that may influence patients' ability to obtain relief from chronic pain. They also showed some attitudes and bias that could create further barriers to effective pain treatment. The majority of Winslow providers lacked knowledge regarding the risks for psychological dependence and the fact that most chronic pain can be effectively treated. They are worried about prescribing opioids yet they lack the knowledge and/or referral skills to adequately address their patients' concerns about pain management. The result of this situation is reduced quality of care, suboptimal outcomes, dissatisfied and undertreated patients, and health care providers that are eternally frustrated! All of these factors are known to increase the financial burden of pain care for the healthcare system and to extract a huge toll on patients who typically are affected physically, socially, emotionally, and financially by their chronic pain.

On a positive note, the results of the provider survey imply high levels of tolerance among Winslow providers toward patients who have health behaviors that are different from mainstream society. Their propensity for serving in a mission-oriented work environment with an underserved population may represent psychological characteristics that contribute to this trait. Tolerance is a favorable psychological trait related to cultural competence. The favorable psychological traits of the Winslow providers along with their concern about the problem of pain deem this a receptive environment for presenting new approaches to pain management. Leaders in Winslow can capitalize on these positive findings by incorporating more extensive education for providers regarding traditional NA practices around pain and also by formulating new educational programs on the topic of other effective CAM therapies. Since patients seem equally

willing to try new approaches to pain treatment this creates the perfect climate for the implementation of pain education activities. Both patients and providers can be provided with useful information about therapies that have been shown to be helpful in managing pain including massage therapy, acupuncture, yoga, and Tai chi. The readiness for change among both patients and providers is perhaps the most important outcome of this community needs assessment.

Implications for Practice Innovation at Winslow Indian Health Care Center (WIHCC)

In order to address patient concerns and needs for adequate and evidence-based chronic pain management, a formalized multidisciplinary pain management program is recommended, maximizing the many available resources at WIHCC. Coordination of care through a pain management program will help ensure equitable, evidence-based pain care and will reduce the waste and expense associated with duplicate and unnecessary diagnostic testing (American Pain Society 2007; American Society of Anesthesiologists, 2010). Pain management programs typically include protocols that reduce the risks associated with the prescribing of opioid analgesics such as abuse, addiction, and diversion. Most importantly, these programs have been shown to improve patient outcomes and satisfaction with care (Weiner, et al, 2006).

Clinical practice guidelines (CPGs) for chronic pain should be incorporated into WIHCC policies to improve patient outcomes, increase patient satisfaction with care, preserve scarce health resources, minimize treatment risks, and reduce social and economic costs associated with untreated chronic pain (American Pain Society, 2007). The CPGs, set forth by the American Society of Anesthesiologists (2010) and endorsed by the American Pain Society, includes the use of opioid analgesics as *one* component of a multimodal treatment plan for chronic pain. It is

recommended that when these drugs are used long term, a monitoring and management strategy should be in place for side effects, adverse effects, and compliance. Monitoring and management strategies can be more efficiently incorporated into a pain management program than in primary care where time constraints limit the ability to address complex, multi-faceted issues such as pain treatment (Goldman, 2010).

Pain assessment and management are indicators of quality care that are frequently examined by health care facility accreditation organizations (Porsche, 2010). More effective pain management practices are indicated, and efforts to heighten the awareness of personal biases that interfere with clinical judgment are needed at WIHCC. Only three of the 18 healthcare providers in this study reported they had received any education in pain management. Education on pain management principles should be offered to all providers and the knowledge obtained must be applied rationally and scientifically utilizing multimodal therapies. Standards for quality improvement in chronic pain management have been written and are readily available both electronically and in hard copy (American Society of Anesthesiologists, 2010; Fishman, 2007). One way to assist healthcare providers in providing quality pain care is to create guideline-specific task forces to develop well-planned implementation processes and provide guideline summaries to providers. By including the providers in this process buy-in is fostered which ultimately leads to improved likelihood for the incorporation of the CPGs into practice (Quiros, Lin, & Larson, 2008). Newly hired providers should be routinely provided with pain management education and information about institutional pain policies as part of their orientation process at WIHCC.

Awareness and consideration of the patients' patterns of self-treatment that have been identified should be reflected in patient and provider education to help avoid potential interactions between allopathic, over-the-counter, and alternative therapies. For instance, one patient was using both a chiropractor and a traditional healer for manipulative therapy. With some types of back problems manipulative therapy is contraindicated and can cause serious harm (Ernst, 2005). Also, patients in this study frequently used over-the-counter preparations, such as acetaminophen, that are found in combination prescription opioid products. Ibuprofen is a frequently used over-the-counter medication that is marketed under various trade names. This medication is also prescribed in its generic form by healthcare providers creating the potential for overdose in patients who do not recognize that the generic and commercial formulations are the same drug. Provider knowledge regarding unsafe or duplicate therapies may prompt discussions about overtreatment or drug interactions.

Knowledge of patient preferences and experiences can enhance the ability to design and incorporate culturally appropriate standardized protocols into future pain management policies to assure equitable care for patients who seek pain care at the tribal facility in Winslow. The services of the traditional healer on staff in Winslow were not utilized by the subjects in this practice inquiry. Past discussions with community members revealed that they typically have one medicine man that treats the entire family throughout life and they do not typically consult other traditional healers. Perhaps it would be more appropriate to provide patients with vouchers or an alternative system of provider reimbursement that can be redeemed with the traditional healer that provides care to *their* family.

The influences of culture on symptoms, patient/provider relationships, and adherence to treatment have been well-documented (Cuffe, Waller, Cuccaro, Pumariega, & Garrison, 1995; Helman, 2000; Pumariega, Johnson, Sheridan, Cuffe, 1996; Saha, 1999). Purnell and Paulanka (1998) defined cultural competence as:

“developing an awareness of one’s own existence, sensations, thoughts, and environment without letting it have an undue influence on those from other backgrounds; demonstrating knowledge and understanding of the client’s culture; accepting and respecting cultural differences; and adapting care to be congruent with the client’s culture.” (p. 62)

Measures to better educate providers in cultural competency should be improved since this has been shown to positively influence the patient/provider relationship and to impact health outcomes (Lopez, Soto-Green, 2010). Retention strategies should be implemented to decrease the provider turnover rates at WIHCC and to increase the potential that providers will gain cultural competency over time. Efforts should be made to elucidate factors that contribute to the high provider turnover rates locally and steps should be taken to reduce or eliminate negative influences. According to one study of providers in the Navajo area, factors that push providers to leave tend to be specific to the institution and are potentially amenable (Kim, 2000).

Policy Recommendations

This project supports the need for policies that address pain as a public health issue. Standardized institutional policies are needed that ensure patient education regarding securing, disposing of, and the proper use of medications will help reduce the potential for abuse and diversion (Fishman, 2007). The IOM (2007) six essential elements of quality care (safety, timeliness, effectiveness, efficiency, patient-centeredness, and equity) should be incorporated into future policies and programs for chronic pain management. Development of a

multidisciplinary pain management program is highly recommended. Multidisciplinary pain programs have been shown to help contain the costs associated with the treatment of chronic pain, to improve the quality of care, and to improve outcomes while also improving patient satisfaction with their pain treatment (Weiner, et al, 2006). They have been shown to be effective in educating patients about pain management and appropriate medication use balanced with non-pharmaceutical treatments. Pain programs reduce the waste of scarce health resources and improve patient satisfaction with their healthcare. These programs generally integrate allopathic and complementary alternative therapies to create individualized treatment plans for patients with chronic pain. Among the professional disciplines typically represented in pain management programs are nurses, physicians, physical therapists, behavioral health providers, and pharmacists. While nurses, nurse practitioners, and physicians usually represent the core of the program, there are many variations in team composition. Programs should be tailored to meet the needs of the specific population for whom they are intended.

Consideration should be given to implementing institutional policies that require referral of patients with chronic pain to a pain management program. This is especially recommended for patients who are prescribed opioid analgesics. Patient education regarding treatment options and the appropriate use of opioids should be required as part of the institutional pain management agreement. Organizational policies should require the collection of outcomes data to monitor the quality of pain care delivered and performance improvement measures should be implemented. Clinical practice guidelines for chronic pain such as those provided by the American Society of Anesthesiologists (2010) should be implemented by providers to ensure that safe, equitable, and evidence-based pain care is provided to all patients who present with chronic pain.

The growing prevalence of chronic pain and the rising burden of caring for patients with chronic pain have merely just begun to influence policy at the national level. The National Pain Care Policy Act was signed into law March 2010. This Act contains three key provisions to promote better pain care:

1. Mandates an Institute of Medicine conference on pain to address key medical and policy issues affecting the delivery of quality pain care;
2. Establishes a training program to improve the skills of health care professionals to assess and treat pain; and,
3. Enhances the pain research agenda for the National Institutes of Health (NIH).

Unfortunately, abuse issues may lead to policies that limit access to effective treatment. The FDA recently proposed the controversial Risk Evaluation and Mitigation Strategy (REMS) for long-acting and extended-release opioids. This proposal includes recommendations for mandatory prescriber and patient education in order to prescribe these medications. There are concerns that this policy may decrease access to effective pain care since providers may simply refuse to comply with these requirements and instead resort to prescribing only short-acting opioid analgesics (American Pain Society, 2010). Providers need to provide input to legislators and remain informed regarding these potential policy changes related to opioid prescribing and pain management.

Recommendations for Future Native American Community-Based Participatory Action

Research Projects

The most important recommendation for the improvement of future projects with Native Americans is for high levels of control and participation by tribal members using CBPR methods

to further study patient factors related to pain management. Ideally, the impetus for future research will be perpetuated by community members themselves rather than an “outsider.” Residents of surrounding tribal lands should be included in future studies to adequately reflect the patient population served at WIHCC. Research is particularly difficult with tribes due to the history of issues with opportunistic researchers who have shown disrespect for their culture and values. Dr. June Strickland of the University Of Washington School Of Nursing reported that “we are merely in the formative phase of learning how best to form CBPR partnerships in transcultural research” (Strickland, 2006, p. 231). Dr. Strickland has been engaged in CBPR research with Native American tribes in the Pacific Northwest for more than a decade. Her recommendations for CBPR with this population are to gain a good understanding of cultural values and the ebb and flow of tribal life and to invest time in the community working with tribal experts to guide the planning. Establishing these partnerships requires that all parties have a vested interest and also requires ample funding to assure grassroots participation.

Future Studies

In order to elucidate specific patient issues that influence pain management within the Winslow community, further studies are needed. Future research is recommended to determine the education needs of Native Americans around pain management and best methods to educate patients about their problems and treatment options. Further studies are needed to explore perceptions of pain experience among patients living *on* the reservation. Outcomes research is necessary once the Pain Management Program has been implemented.

Gaining access to this population is difficult, especially for outsiders. Research on tribal lands is subject to complex tribal Institutional Review Board processes and this can significantly

extend the length of time required to complete research projects. A partnership that begins at the proposal stage between tribal community members and academic institutions is recommended for technical support and assistance in conducting additional pain research. Collaboration is essential to the process because this promotes buy-in that will increase community participation and this will, in turn, influence the reliability and validity of the results. Communities are more likely to accept the recommendations that result if they have ownership in the project. CBPR methods are recommended for future studies because Native American communities have shown less resistance to these research methods. Shared research partnerships between communities and academics to address community-driven research priorities benefit both the community and academic researchers; these partnerships increase the potential that the research will be relevant, useful, and sensitive to community concerns (Flicker, et al, 2007).

Summary

Pain is a growing national public health problem that contributes to spiraling health care costs and significant societal burden in the United States. It is the most common reason for seeking health care services, and is the leading cause of disability (CDC, 2008). Ethnic background has been shown to have an effect on pain treatment and outcomes (Green, 2003). Further research into cultural factors that influence pain management at WIHCC is needed. Pain is a major health issue in this country and under-treatment results in significant individual, community, and societal burden. Multiple factors contribute to the problem of inadequate pain management including cultural issues and health system factors. The growing problem of prescription drug abuse is an added dimension that further complicates the provision of quality pain care. Native Americans and other minority populations are especially vulnerable to the

problem of under-treatment and the subsequent negative outcomes associated with chronic pain. Although more research is needed, it is difficult for outsiders to gain research access to this population. Therefore, future studies should ideally be conducted by tribal members through collaborative relationships with researchers who are affiliated with academic institutions.

Winslow patient participants were generally dissatisfied with the pain care practices at Winslow Indian Health Care Center and voiced the desire for more effective treatment. They reported wide variances among participants in the types of diagnostic work up and in patient education. Self-treatment consisted of over-the-counter medications such as ibuprofen, acetaminophen, topical preparations, thermal treatments, and activity modification to manage symptoms. All of these patients attempted to use complementary alternative therapies for pain treatment, but none relied on alternative therapies alone. The most common effective treatment for these patients was massage. Massage was more effective than all other treatments tried for two participants and was an important component of a self-integrated pain management plan for one patient. All participants reported that, at the time of the study, their pain interfered with their activities of daily living including employment. Four of the five patients had negative perceptions of opioid pain medications and thought their use should be limited due to the adverse effects. One patient wanted the strength of the analgesics prescribed to her to be increased indicating under treatment of her pain. Patient reported goals of treatment in this study included relief of pain, improved quality of life, the ability to return to work, the ability to perform household chores, and the ability to participate in more physical leisure activities.

Data from providers in Winslow showed that there were attitudinal biases that could create barriers to effective pain treatment. They had some fear regarding scrutiny from drug

regulating agencies, although they were less fearful than the Texas Pain Study providers. Winslow providers were more concerned about psychological addiction than the Texas Pain Study providers, however, and this has an impact on prescribing practices and patients' ability to obtain relief from chronic pain. Nearly one-third thought opioids should be restricted to patients who have severe pain and there were high levels of fear regarding patient addiction. Providers lacked knowledge regarding the risks for psychological dependence and the fact that most chronic pain can be effectively treated. Winslow providers were highly tolerant of patients whose health beliefs did not conform to mainstream culture, including those who engaged in behaviors that undermine health.

Pain management is a challenging and multifaceted problem that is further complicated by cultural differences between patients and providers. The current political climate where billions of dollars have been poured into the failed "war on drugs" has instilled irrational fears in both patients and providers around the country (Brennan, et al, 2007). Further complicating an already complex problem is the fact that over the past ten years the abuse of prescription pain medications has risen along with improved efforts to relieve pain (SAMHSA, 2010). The push for better pain management has increased awareness of the problem and the number of opioid prescriptions written in the United States has risen dramatically. Most people who abuse or divert opioids obtain them from family members who have legitimate prescriptions (SAMHSA, 2010).

Both patients and providers demonstrated readiness for change that can be capitalized upon to formulate new approaches to pain treatment for this community. Patients were interested and receptive to the use of CAM therapies but providers were not ordering the CAM therapies

that are available on campus. The evidence is accumulating in the literature that treatments such as acupuncture, massage, and movement therapies can be effective components of a multimodal pain management plan. The time is ripe for introducing educational programs to both patients and providers to increase awareness of the benefits of these therapies.

Future studies around chronic pain management in Native Americans are recommended and the use of CBPR is strongly recommended. Research should be geared toward reducing disparities and improving the quality of pain care delivered to NA patients. CBPR should be used for most, if not all, research conducted with this population. This method provides increased validity over other research methods and is more accepted by tribal members. A complex systems perspective should guide future research since this approach acknowledges and embraces the interactions between the subsystems, allopathic and WSCAM. Complexity theory provides explanatory models that can improve the understanding of how traditional healing and other WSM improve health either separately or in combination with allopathic treatments.

APPENDIX A: INFORMED CONSENT – PATIENT PARTICIPANTS

Informed Consent

Chronic Pain Management in a Rural Reservation Border Town

Introduction

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you. This research study is being conducted by the University of Arizona. Results will be shared with Winslow Indian Health Care and be used to improve care of patients who have chronic pain. No names will be included when these results are shared. Your individual responses and your identity as a participant will remain confidential.

What is the purpose of this study?

The purpose of this study is to identify, explore and describe how chronic pain is treated in Native American people living in the Winslow area. This study will:

1. describe the experience of chronic pain as reported by Native American people;
2. describe perceived causes of their chronic pain;
3. describe pain treatment that they have received or that they used;
4. identify how Native American people in the Winslow area would prefer that their pain be treated; and
5. explore attitudes and beliefs about the treatment of chronic pain among health care providers in the Winslow area.

Why are you being asked to participate?

You are being asked to participate because you

- Are being treated for chronic pain in your muscles or bones that has been present for more than six months.
- Can establish Native American ancestry as evidenced by eligibility for health care and contracted services at Winslow Indian Health Care Center.
- Are over the age of 21.
- Are able to speak and understand English.
- Are able to participate in a 1-1.5 hour interview.
- Are receiving pain care from a health care provider at the WIHCC.
- Are living in Winslow.

How many people will be asked to participate in this study?

Five Native American people with chronic pain will be asked to be interviewed. The healthcare providers at WIHCC who treat chronic pain will also be asked to participate in this study.

What will happen during the study?

1. Once this informed consent is signed and returned to the principal investigator, she will call to schedule a face-to-face personal interview at a place and time of your choice.
2. The interview will be conducted by a Navajo research assistant who is able to speak English and Navajo fluently. The interview will last approximately 1-1 ½ hours and will be audio-recorded. These tapes will be transcribed for analysis and review by the study personnel and research advisors.
3. During the interview, you will be asked questions about your pain. You will be asked to tell your personal story about your pain, what you believe caused the pain to occur and why it continues. You will also be asked about the ways you have tried to get relief from pain. You will be asked about your experiences in getting treatments from doctors and other healthcare providers. You will be asked about the kinds of treatments you have used on your own to decrease the pain. You will have a chance to describe what works best and what does not work for your pain and the types of treatments you would prefer.
4. Once all of the interviews have been completed and analysis has taken place, you may be called by the investigator to participate in an additional 30-60 minute interview to discuss and confirm findings from the study and to help explain some of the findings from your perspective.

How long will I be in this study?

About 1-1 ½ hours will be needed to complete this study if you participate in only 1 interview. If you are asked to participate in a second interview about 2-2 ½ hours will be needed to complete this study. If a second interview is needed, the interviews should take place about six weeks apart.

Are there any risks to me?

The things that you will be doing have no more risk than you experience by giving this information to your health care provider. Although your identity as a participant in this research might be revealed, strict measures will be taken to prevent this. For example, we will only report group responses to questions and not individual responses. Although we have tried to avoid risks, you may feel that some questions may be stressful or upsetting. If this occurs you can stop participating immediately. We can give you information about individuals who may be able to help you with these problems.

Are there any benefits to me?

You will not receive any immediate benefit for participating in this study. You may benefit from better understanding about the experience and treatment of chronic pain.

What are the alternatives for participating in this study?

The alternative is not to participate in this study.

Will there be any costs to me?

Aside from your time there are no costs to participate in this study.

Will I be paid to participate in the study?

You will be given a \$20 Walmart gift card for each interview.

Will video or audio recordings be made of me during the study?

We will make an audio recording during the study so that we can be certain that your responses are recorded accurately only if you check the first box below. If you do not want to be audio recorded you may choose to not participate in this study.

I give my permission for audio recordings to be made of me during my participation in this study.

Will the information that is obtained from me be kept confidential?

The only persons who will know that you participated in this study will be the principal investigator and research personnel. Your records will be confidential. You will not be identified in any reports or publications resulting from the study. Your name will not be on the interview recording or transcription and no information that can be connected to you will be shared with anyone. It is possible that representatives of the National Institute of Health/National Center for Complementary and Alternative Medicine, the sponsor that supports the research, will want to come to The University of Arizona to review your information. Representatives of regulatory agencies including the University of Arizona Human Subjects Protection Program may access your records.

What if I am harmed by the study procedures?

No harm to you is expected from participating in this study. If talking about pain causes you to have any problems (stress, anxiety, emotional reaction), you will be given information about a healthcare professional that can help with these problems. In addition, you should contact the PI if you feel you have been harmed by this study.

May I change my mind about participating?

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Your refusing to participate will have no effect on your medical care or treatment

within the Indian Health Services or at WIHCC. You can discontinue your participation with no effect on your medical care or treatment.

Whom can I contact for additional information?

You can contact the Principal Investigator to tell her about a concern or complaint about this research study. The Principal Investigator, Cynthia Farrell, DNP candidate, MSN, FNP-BC can be reached at 928-289-4646. You may also contact the Principal Investigator's advisor, Dr. Mary Koithan, PhD, RN, CNS-BC, at 520-626-2036. For questions about your rights as a research subject; or if you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721 or visit their website (this can be anonymous) at <http://orcr.vpr.arizona.edu/irb/contact>.

Your signature:

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part. I do not give up any of my legal rights by signing this form.

Printed Name

Signature of participant

Date signed

Statement by person obtaining consent

I certify that I have explained the research study to the person who has agreed to participate, and that he or she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

Name of study personnel

Study personnel signature

Date signed

APPENDIX B: PROVIDER PARTICIPANT DISCLOSURE STATEMENT

Provider Participant Disclosure Statement

Title of Project: Chronic Pain Management in a Rural Border Town

You are being invited to voluntarily participate in the above-titled research study. The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Native American people in the Winslow area. This study will (a) describe the experience of chronic pain as reported by Native American people; (b) describe perceived causes of their chronic pain; (c) describe pain treatment that they have received or that they used; (d) identify how Native American people in the Winslow area would prefer that their pain be treated; and (e) explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area.

You are eligible to participate because you are currently employed by WIHCC; you are licensed and credentialed to provide patient care as a physician, a nurse practitioner, or a physician's assistant at WIHCC; and you provide pain care to chronic pain patients at WIHCC.

If you agree to participate, your participation will involve an anonymous survey about pain management. The survey will take place online using a secure website and will last approximately 30 to 45 minutes. You may choose not to answer some or all of the questions. Your name will not appear on these questionnaires.

Any questions you have will be answered by contacting the PI at the email address used in the study invitation. You may withdraw from the study at any time. There are no known risks from your participation. There are no direct benefits from your participation. You will receive a Cross® pen for your participation.

Only the principal investigator will have access to the information that you provide. In order to maintain your confidentiality, your name will not be asked during any portion of this data collection and no identifying information will be requested or captured by the online survey service. Your refusing to participate or your decision to discontinue your participation will have no effect on your involvement with employment.

You can call Cynthia Farrell, FNP, DNP(c), the Principal Investigator of this study, at (928)310-2578 if you have a concern or complaint about this research study. If you have questions about your rights as a research subject you may alternatively contact the Principal Investigator's advisor, Dr. Mary Koithan, PhD, RN-C, CNS-BC at 520-626-2036. If you have questions and wish to contact the University of Arizona Human Subjects Protection Program office, you may do so by visiting their website at www.irb.arizona.edu.

By completing the survey, you are giving permission for the investigator to use your information for research purposes.

Thank you.

Cynthia Farrell

APPENDIX C: PATIENT PARTICIPANT RECRUITMENT FLYER(S)

DO YOU HAVE

chronic pain?

Would you like to tell your story about your experience with muscle, joint, or bone pain and the treatments you have tried?

If so, you are invited to call to find out more about the Chronic Pain Study that will be conducted in Winslow. Participation will involve an interview and a follow up discussion. These will take about an hour each. You will be paid for your time.

You may be eligible for this study if:

You live in Winslow

You have had pain for at least six months (except cancer pain)

You are Native American and eligible for care at Winslow Indian Health

You are at least 21 years old

Call the Chronic Pain Study personnel at 928-310-2578 for more information and to enroll.

APPENDIX D: PROVIDER PARTICIPANT EMAIL ANNOUNCEMENT

Email Announcement to Recruit Provider

Dear Healthcare Provider:

You are invited to participate in an electronic survey on the topic of chronic pain management. Please copy and paste the link below into your web browser. The URL for this survey is:

http://www.surveymonkey.com/s.aspx?sm=DGO4phvOe5sQ2INqeuT2MA_3d_3d

This anonymous survey is part of a study I am conducting on chronic pain management in the Winslow community. The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Native American people in the Winslow area. This study will:

1. Describe the experience of chronic pain as reported by Native Americans;
2. Describe perceived causes of their chronic pain;
3. Describe pain treatment that they have received or that they used;
4. Identify how Native people in the Winslow area would prefer that their pain be treated; and
5. Explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area.

The survey will take about 30 minutes to complete the survey and it is requested that you allow enough time to do this in one sitting. The survey is housed on a secure, on-site website. Your responses will be collected without identifying who you are.

You are **eligible** to participate in this study if you are:

- Currently employed by WIHCC;
- Licensed and credentialed to provide patient care as a physician, a nurse practitioner, or a physician's assistant at WIHCC; **AND**
- Provide pain care to patients with chronic musculoskeletal pain at WIHCC.
- You are **not eligible** to participate in this study if you are a: Contracted provider who provides specialty services at the health center (e.g. nephrology, cardiology, and rheumatology) **OR**
- Locum tenens provider at WIHCC.

A small token of appreciation will be made available to each participant. I will be happy to answer any questions you may have about the study. If you prefer to discuss the study privately you may call me at 928-310-2578 or email me at: cfarrell@nursing.arizona.edu

Thank you in advance for your participation!

Sincerely,

Cynthia Farrell

APPENDIX E: VERBAL RECRUITMENT STATEMENT – PROVIDER PARTICIPANTS

Script for Verbal Announcement to Provider Participants

I am conducting a study on chronic pain management in the Winslow community. This research is being conducted through the University of Arizona.

The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Native American people in the Winslow area. This study will:

1. Describe the experience of chronic pain as reported by Native American people;
2. Describe perceived causes of their chronic pain;
3. Describe pain treatment that they have received or that they used;
4. Identify how Native people in the Winslow area would prefer that their pain be treated; and
5. Explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area.

I am asking the healthcare providers at WIHCC to participate by filling out an anonymous survey. The information you provide will be used to help plan a pain management program at WIHCC. You are **eligible** to participate in this study if you are:

- Currently employed by WIHCC;
- Licensed and credentialed to provide patient care as a physician, a nurse practitioner, or a physician's assistant at WIHCC; **AND**
- Provide pain care to patients with chronic musculo-skeletal pain at WIHCC.

- You are **not eligible** to participate in this study if you are a: Contracted provider who provides specialty services at the health center (e.g. nephrology, cardiology, and rheumatology) **OR**
- Locum tenens provider at WIHCC.

An electronic invitation and instructions to participate in this study will be sent to your WIHCC email. A small token of appreciation will be made available to each participant.

I will be happy to answer any questions you may have about the study. If you prefer to discuss the study privately you may call me at 928-310-2578 or email me at: cfarrell@nursing.arizona.edu

APPENDIX F: EMAIL REMINDER NOTICE – PROVIDER PARTICIPANTS

Email Survey Reminder

Dear Healthcare Provider:

The Chronic Pain Management study will end in two weeks. If you would like to participate there is still time. The URL for this survey is:

http://www.surveymonkey.com/s.aspx?sm=DGO4phvOe5sQ2INqeuT2MA_3d_3d

This anonymous survey is part of a study I am conducting on chronic pain management in the Winslow community.

The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Native American people in the Winslow area. This study will:

1. Describe the experience of chronic pain as reported by Native American people;
2. Describe perceived causes of their chronic pain;
3. Describe pain treatment that they have received or that they used;
4. Identify how Native people in the Winslow area would prefer that their pain be treated;
and
5. Explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area.

The survey will take about 30 minutes to complete and it is requested that you allow enough time to do this in one sitting. The survey is housed on a secure, on-site website. Your responses will be collected without identifying who you are.

A small token of appreciation will be made available to each participant. I will be happy to answer any questions you may have about the study. If you prefer to discuss the study privately you may call me at 928-310-2578 or email me at: cfarrell@nursing.arizona.edu

Thank you in advance for your participation!

Sincerely,

Cynthia Farrell

APPENDIX G: SCRIPT FOR PRE-SCREENING AND ENROLLMENT – PATIENT
PARTICIPANTS

Thank you very much for calling about this study. I am the principal investigator for this study and have responsibility for its conduct.

The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Native American people in the Winslow area. This study will:

1. Describe the experience of chronic pain as reported by Native American people;
2. Describe perceived causes of their chronic pain;
3. Describe pain treatment that they have received or that they used;
4. Identify how Native people in the Winslow area would prefer that their pain be treated; and
5. Explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area.

I have a few questions that I need to ask before I am able to determine if you qualify to participate in this study. I will not be recording your responses or any of your identifying information for the purposes of this screening process.

Please respond to the following screening questions.

1. Are you over the age of 21 years?
2. Are you eligible to receive healthcare services at Winslow Indian Health Care Center?
3. Do you have pain in your body that has been with you for at least six months?
4. Is your problem being treated by a healthcare provider at WIHCC?
5. Are you able to talk to an interviewer for 1 to 1½ hour about your pain?
6. Can you communicate and read using the English language?

For those qualifying I will then say:

I have just a few more additional questions to ask if you don't mind.

1. Are you male or female?
2. What is your age?
3. Do you live in the Winslow community?
4. What is the cause of your pain?
5. Where do you hurt?

If they qualify and I intend to enroll them, I will then say that they are eligible to participate.

APPENDIX H: SITE APPROVAL LETTERS FOR PATIENT PARTICIPANT FLYERS

Site Authorization Letter

Date Oct 22, 2009

Dear Cynthia Farrell:

I have reviewed your request regarding your study and am pleased to support your research project on chronic pain management in the Winslow community. Your request to use our organization as a recruitment site is granted. The recruitment method will include displaying a study announcement on a bulletin board, or other area of our choosing, that can be viewed by our patrons. This authorization covers the time period of November 1st, 2009 to November 1, 2010. We look forward to working with you.

Sincerely,

Doia Blalock
Printed Name

Doia Blalock

Signature

City Librarian
Title

Winslow Public Library
Business or Organization Name

Site Authorization Letter

Date 10/20/09

Dear Cynthia Farrell:

I have reviewed your request regarding your study and am pleased to support your research project on chronic pain management in the Winslow community. Your request to use our organization as a recruitment site is granted. The recruitment method will include displaying a study announcement on a bulletin board, or other area of our choosing, that can be viewed by our patrons. This authorization covers the time period of November 1st, 2009 to November 1, 2010. We look forward to working with you.

Sincerely,

Liz Blackgoat, RN, LMT
Printed Name

Liz Blackgoat, RN, LMT
Signature

Owner
Title

Shepherd Massage
Business or Organization Name

Site Authorization Letter

Date 10 / 22 / 09

Dear Cynthia Farrell:

I have reviewed your request regarding your study and am pleased to support your research project on chronic pain management in the Winslow community. Your request to use our organization as a recruitment site is granted. The recruitment method will include displaying a study announcement on a bulletin board, or other area of our choosing, that can be viewed by our patrons. This authorization covers the time period of November 1st, 2009 to November 1, 2010. We look forward to working with you.

Sincerely,

M. Elizabeth Hawker, DC
Printed Name

[Handwritten Signature]
Signature
President

Hawker Chiropractic Center, PC
Title
Business or Organization Name

Site Authorization Letter

Date Oct. 22, 2009

Dear Cynthia Farrell:

I have reviewed your request regarding your study and am pleased to support your research project on chronic pain management in the Winslow community. Your request to use our organization as a recruitment site is granted. The recruitment method will include displaying a study announcement on a bulletin board, or other area of our choosing, that can be viewed by our patrons. This authorization covers the time period of November 1st, 2009 to November 1, 2010. We look forward to working with you.

Sincerely,

Ity E. Decker, DC

Printed Name

[Handwritten Signature]

Signature

President

Title

DECKER CHIROPRACTIC, P.C.

Business or Organization Name

APPENDIX I: SITE APPROVAL LETTER – WINSLOW INDIAN HEALTH CARE CENTER

(WIHCC) –

ACCESS TO PROVIDER PARTICIPANTS AND RECRUITMENT PROCESSES



Frank Armao, M.D.
Clinical Director

Winslow Indian Health Care Center, Inc.

500 North Indiana Avenue
Winslow, Arizona 86047

February 22, 2010

Cynthia Farrell
PO Box 1079
Ash Fork, AZ 86320

Dear Cynthia

I have reviewed your request regarding your study and am pleased to support your research project entitled *Chronic Pain Management in a Rural Reservation Border Town*. Your request to use Winslow Indian Health Care Center as a research recruitment site is granted. The research will include recruitment of healthcare providers for participation in a survey. The survey will consist of a series of questions about pain management practices and beliefs. This authorization covers the time period of March 1, 2010 to March 1, 2011. We look forward to working with you.

Sincerely,


Frank Armao, MD
Chief Medical Officer

Phone: (928) 289-6233

Fax: (928) 289-6223

APPENDIX J: PARTICIPANT INTERVIEW GUIDE

Interview Guide – Patients

1. Tell me about your pain: What do you think is the cause of your pain? How long have you had this pain?
2. Does your pain prevent you from doing things you like or need to do? Ask the participant to describe these activities.
3. Many people use alternative therapies to treat all kinds of problems. Do you treat your pain yourself? If so, what kinds of treatments do you use? How well do they work?
4. Do you tell your healthcare provider at WIHCC about all the treatments you use? Why or why not?
5. Some people like to go to chiropractors, traditional healers, massage therapists and other types of providers who treat pain. Do you use any of these types of providers?
6. Who else treats your pain? What kinds of treatments have they recommended?
7. How do you decide what kinds of treatments to use for pain?
8. Do the people around you (family, friends) influence your decisions about pain treatment? Who? How?
9. What kinds of treatments do you like best for treating your pain? Why?
10. What are the most important outcomes of treatment for you? (e.g., cure, symptom relief, quality of life) Why?
11. Do you think your health provider at WIHCC understands your pain?
12. Are you satisfied with the pain treatment prescribed by your health provider at WIHCC?
13. (If applicable) How satisfied are you with the pain treatment recommended by your traditional healer/chiropractor/massage therapist (ask about all complementary/alternative treatment strategies that apply from question #5)?
14. How do you feel about using prescriptions medications for pain?
15. What would you like to tell your (allopathic) healthcare provider about your pain that you have not been able to tell him/her?
16. What stops you from telling them?
17. Is there anything else you would like to tell me?

APPENDIX K: PROVIDER PARTICIPANT SURVEY –
FORMAT UPLOADED TO SURVEY MONKEY

1. Study Eligibility

*** 1. Are you employed by Winslow Indian Health Care?**

Yes

No

*** 2. Are you a contracted healthcare provider for Winslow Indian Health (specialty services such as rheumatology, cardiology, nephrology, etc.)?**

Yes

No

*** 3. Are you a locum tenens healthcare provider at Winslow Indian Health?**

Yes

No

Survey monkey will be programmed to advance people answering yes to Question 1 and no to Question 2 and 3 to page 3 and to proceed with the survey. Those answering in other ways would be directed to page 2 which tells them they are not eligible to participate based on their answers.

2. Not Eligible for the Study

Thank you for your interest in participating in this survey. Based on your answers to the previous questions, you are not eligible to participate in this study. If you feel that you have been excluded from this study incorrectly, please contact the Principal Investigator at 928-310-2578 or email cfarrell@nursing.arizona.edu

3. Disclaimer

Title of Project: Chronic Pain Management

You are being invited to voluntarily participate in the above-titled research study. The purpose of this study is to identify, explore and describe factors that impact the treatment of chronic pain in Navajo people in the Winslow area. This study will

1. describe the experience of chronic pain as reported by Navajo people;
2. describe perceived causes of their chronic pain;
3. describe pain treatment that they have received or that they used;
4. identify how Navajo people in the Winslow area would prefer that their pain be treated; and
5. explore attitudes and beliefs about the treatment of chronic among health care providers in the Winslow area

You are eligible to participate because you are currently employed by WIHCC; you are licensed and credentialed to provide patient care as a physician, a nurse practitioner, or a physician's assistant at WIHCC; and you provide pain care to chronic pain patients at WIHCC.

If you agree to participate, your participation will involve an anonymous survey about pain management. The survey will take place online and will last approximately 30 to 45 minutes. You may choose not to answer some or all of the questions. Your name will not appear on these notes.

Any questions you have will be answered and you may withdraw from the study at any time. There are no known risks from your participation and no direct benefit from your participation is expected. There is no cost to you except for your time and you will receive a Cross @ pen for your participation.

Only the principal investigator will have access to the information that you provide. In order to maintain your confidentiality, your name will not be revealed in any reports that result from this project. You may decide to not begin or to stop the study at any time. Your refusing to participate or your decision to discontinue your participation will have no effect on your involvement with employment. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

You may be removed from the study by the investigator for these reasons: If there is insufficient usable data from your survey.

If you quit the study early, you may be asked to complete the following activities: N/A

You can call the Principal Investigator to tell him/her about a concern or complaint about this research study. The Principal Investigator, Cynthia Farrell, FNP, DNP Candidate can be called at (928)310-2578. If you have questions about your rights as a research subject you may call the University of Arizona Human Subjects Protection Program office at (520) 626-6721. If you have questions, complaints, or concerns about the research and cannot reach the Principal Investigator; or want to talk to someone other than the Investigator, you may call the University of Arizona Human Subjects Protection Program office. (If out of state use the toll-free number 1-866-278-1455.) If you would like to contact the Human Subjects Protection Program via the web (this can be anonymous), please visit <http://www.irb.arizona.edu/contact/>.

By participating in the survey, you are giving permission for the investigator to use your information for research purposes.

Thank you.

Cynthia Farrell

*** 1. Do you certify that you have read the information explaining this study and that you are willingly participating in this research? By clicking on the "yes" box below you are consenting to participate in this anonymous survey. If you do not wish to participate please exit by closing your browser now.**

YES

NO

Survey Monkey will be programmed to go back to page 2 for participants who answer no to this question. Page 2 informs them that they are not eligible to participate based on their answer.

4. Instructions

This survey consists of a series of statements and is divided into six parts. After reading each statement please indicate whether you agree or disagree by clicking on the appropriate answer button. Right click on the "next" button to advance to the next page once you have entered your answers to all the questions on the current page.

Please be sure you are finished before proceeding to the next page. This survey moves forward only. If you choose to skip questions you will not be able to go back and answer them later. There are no "right" or "wrong" answers to the statements presented. Please allow thirty minutes to complete the survey and try to complete it in one sitting.

7. Patients who complain of pain out of proportion to its cause are usually drug abusers.

- Agree
 Disagree

8. Using narcotics to relieve the pain of benign conditions is ill-advised.

- Agree
 Disagree

9. Even if patients have severe chronic pain, they should be treated with narcotics only when their illness has reached a terminal phase.

- Agree
 Disagree

10. The presence of a physiologic basis for pain should be the primary factor when deciding to prescribe opiates.

- Agree
 Disagree

11. I would never prescribe narcotics for a patient with chronic pain who is able to work.

- Agree
 Disagree

5. SURVEY - I

1. Do you agree or disagree with this statement:

Chronic pain of unknown cause should not be treated with narcotics even if this is the only way to obtain pain relief.

- Agree
 Disagree

2. Do you agree or disagree with this statement:

It is appropriate to escalate a dose of narcotics above the usual range if the prognosis is less than 1 year.

- Agree
 Disagree

3. If a chronic pain patient is active on the job, there is no possible justification for prescribing narcotics for pain.

- Agree
 Disagree

4. Narcotics should be restricted to treatment of severe intractable pain.

- Agree
 Disagree

5. Persons who fit the "profile" of a likely drug abuser should never be treated with narcotics.

- Agree
 Disagree

6. Prognosis should be the primary factor in deciding whether a patient should receive opiates.

- Agree
 Disagree

6. SURVEY II

1. Any patient who is given narcotics for pain relief is at significant risk for addiction.

- Agree
 Disagree

2. I would be extremely concerned about possible addiction if a member of my family were given morphine for chronic pain.

- Agree
 Disagree

3. I must exercise caution when prescribing potentially addictive medications to patients with chronic pain.

- Agree
 Disagree

4. When narcotics are used to control chronic pain, addiction is a common outcome.

- Agree
 Disagree

5. More than 5% of patients who receive narcotics for pain subsequently become addicts.

- Agree
 Disagree

7. SURVEY - III

1. If I prescribe opiates for several months for a patient with chronic pain due to cancer, I am violating state law.

- Agree
 Disagree

2. My colleagues are more willing to give narcotics for pain than I am.

- Agree
 Disagree

3. Prescribing narcotics for patients with chronic pain is likely to trigger a drug enforcement agency investigation.

- Agree
 Disagree

4. Too many narcotic prescriptions lead to utilization reviews.

- Agree
 Disagree

5. Pharmacists who receive several opiate prescriptions from a doctor are likely to report the doctor to a state review board.

- Agree
 Disagree

6. If I follow the same prescribing practices as other doctors in my field, I will not be investigated by a regulatory agency.

- Agree
 Disagree

7. There are limits to the number of narcotics tablets a patient should be prescribed.

- Agree
 Disagree

8. I give patients a limited supply of pain medications to avoid being investigated.

- Agree
- Disagree

8. SURVEY - IV

1. Almost all chronic pain can be relieved with treatment.

- Agree
 Disagree

2. The majority of patients having chronic pain are undermedicated.

- Agree
 Disagree

3. Psychologic dependence on narcotics very frequently results from legitimate prescriptions.

- Agree
 Disagree

4. The health care provider is the best judge of pain intensity.

- Agree
 Disagree

5. The best judge of pain intensity is the patient

- Agree
 Disagree

6. Suicide with an overdose of narcotics prescribed for pain occurs very frequently.

- Agree
 Disagree

7. Pain in a cancer patient is most likely due to treatment.

- Agree
 Disagree

8. The tumor itself is most likely the cause of pain in a cancer patient

- Agree
 Disagree

9. Preexisting conditions not related to the cancer cause the most pain for cancer patient.

- Agree
 Disagree

10. Increasing requests for analgesics indicate unrelieved pain.

- Agree
 Disagree

11. Increasing requests for analgesics indicate tolerance to the analgesic.

- Agree
 Disagree

12. Almost all cancer patients suffer pain.

- Agree
 Disagree

13. Almost all cancer patients should receive opiates to relieve chronic pain.

- Agree
 Disagree

9. SURVEY - V

1. Compliant patients are entitled to more of my time than noncompliant ones.

- Agree
 Disagree

2. Conscientious patients deserve better health care than those with self-inflicted problems.

- Agree
 Disagree

3. When laboratory reports give conflicting information, I get upset.

- Agree
 Disagree

4. It "bugs me" if a consultant I am working with after carefully reviewing a patient says, "I'm not sure."

- Agree
 Disagree

5. A doctor whose practice has few surprises has a lot to be grateful for.

- Agree
 Disagree

6. I resent tax money being spent on patients with self-inflicted diseases.

- Agree
 Disagree

7. If I knew that a prospective patient had an untreatable disease, I would avoid taking that patient if I could.

- Agree
 Disagree

8. Life would be better if IV drug abusers were segregated into special groups.

- Agree
 Disagree

9. I do not like to treat patients with doubtful diagnoses.

- Agree
 Disagree

10. Those who contribute the most to society should get better health care.

- Agree
 Disagree

11. It bothers me when even a pathologist cannot find the cause of death.

- Agree
 Disagree

12. More "health-care dollars" should be spent on those who contribute most to society.

- Agree
 Disagree

13. I do not enjoy treating patients whose illness is unlikely to respond to treatment.

- Agree
 Disagree

14. I get irritated by inconsistent medical reports.

- Agree
 Disagree

15. When the time comes that medical care will have to be rationed, those with high IQs should get the best care.

- Agree
 Disagree

16. I dislike having patients whose outcomes "don't follow the book."

- Agree
 Disagree

17. Undiagnosable illnesses are something I'd rather not get involved with.

- Agree
- Disagree

10. SURVEY - VI

1. It is easier for a male patient to become addicted to narcotics than a female.

- Agree
 Disagree

2. Men are less likely to report pain to their doctor than women.

- Agree
 Disagree

3. Females are more likely to experience pain than males.

- Agree
 Disagree

4. Young adults are more likely to become addicted to narcotics than the elderly.

- Agree
 Disagree

5. Older patients are less likely to report pain than younger patients.

- Agree
 Disagree

11. SURVEY INFORMATION

Source: Cleeland, C, Cleeland, L., Dar, R., Rinehardt, L. (1986). Factors influencing physician management of cancer pain. *Cancer*. 58, 796-800.

Professor Charles S. Cleeland
Chair, Symptom Research CAO
MD Anderson
Houston, TX

This survey has also been used in more recent studies to evaluate provider management of pain:

Winsteln, S., Laux, L., Thornby, J., Lorimor, R., Hill, C., Thorpe, D., Merrill, J., . (2000). Physicians' Attitudes Toward Pain and the Use of Opioid Analgesics: Results of a Survey from the Texas Cancer Pain Initiative. *Southern Medical Journal*, 93(5), 479-487.

12. Demographics

1. What is your professional title?

NP

PA

MD

DO

Other (please specify)

2. What is your gender?

Male

Female

3. How many years have you been in active practice?

4. How many years have you worked at WIHCC?

5. Have you had any special training/education in the treatment of chronic pain?

Yes

No

If yes, please describe

6. This is the end of the survey. Thank you for your participation! Please see the medical staff secretary to claim your Cross pen. If you would like to comment on the study or survey a space is provided below for this purpose.

APPENDIX L: CONFLICT OF INTEREST DISCLOSURE

REPORT OF FINANCIAL INTERESTS RELATED TO RESEARCH
University of Arizona

INSTRUCTIONS: This form is to be completed by all Covered Individuals (www.uci.edu/office_of_integrity) when entering into new sponsored research agreements, changing existing personnel, acquiring new interests, or entering into new subcontracts or purchase agreements. Completion of this form is in accordance with the UA Policy on Conflict of Interest and Commitment. The information provided herein may be released to the sponsor upon request, and per the Arizona Public Records Act (ARS 39-101-161 and ARS 15-1640), may be released to the public upon request.

Please scan and submit the signed form to: coi@email.arizona.edu

NAME (LAST)	(FIRST)	TELEPHONE	E-MAIL ADDRESS
Farrell	Cynthia	028-310-2578	cfarrell@nursing.arizona.edu
ACADEMIC UNIT OR DEPARTMENT		MAIL BOX#	PI'S NAME (if different)
College of Nursing			
TITLE OF RESEARCH PROJECT			
Chronic Pain Management in a Reservation Border Town			

Sponsor (check one):

- Public Health Service/NIH
 National Science Foundation
 Other agency: _____
 American Heart Association
 American Cancer Society
 Subaward (Indicate prme sponsor below): _____
 Private entity: Winslow Indian Health Care Center

Reason for disclosure (check ALL that apply):

- New proposal
 Involves human subjects
 New interest related to ongoing project
 New investigator for project
 Continuing/added support
 New subcontract
 Purchase/service order with private entity related to the research
 Other: _____

I do NOT have any financial interest in any entity related to the research to be conducted for this project.

I DO have a financial interest in an entity related to the research to be conducted for this project, as described below:

NAME OF ENTITY with which I have a financial interest and its primary business (submit only one entity per report): _____

A. Are you or your Relative (defined below*) a director, officer, partner, trustee, consultant, employee, or a member of a scientific or technical advisory board or board of directors for the entity funding your research or related to your federally-sponsored research? No Yes
 If yes, specify the position: _____

B. Do you or your Relative (defined below*) have an investment of any value (including stock options) in the entity funding your research or related to your federally-sponsored research? No Yes
 If yes, the value of the investment is: _____
 If yes, do you own more than 0.1% of the entity's shares? (% owned: _____) No Yes

C. Have you or your Relative (defined below*) received any income this year from the entity funding your research or related to your federally-sponsored research? No Yes
 If yes, the annual income was: \$83,600

D. Have you or your Relative (defined below*) received gifts, in cash or in kind, exceeding \$400 from the entity funding your research or related to your federally-sponsored research? No Yes
 If yes, what was the nature of the gift? _____
 What was the estimated value of the gift? _____

Certification: I certify that I have used all reasonable diligence in preparing this statement and that it is true to the best of my knowledge. I certify under penalty of perjury under the laws of the state of Arizona that the foregoing is true and correct.

Signature: Cynthia Farrell Date: 10/19/09
 (Must be signed by the person to whom it pertains and may not be signed by a Designee)

* **Definition of Relative:** A spouse or domestic partner, child, child's child, parent, grandparent, siblings and their spouses, or if the parent, sibling or child of your spouse.

APPENDIX M: QUALITATIVE ANALYSIS – LEVEL 1 MATRIX

Subject A

Aims – patient perspective:

1. Pain assessment and influences of patient/provider communication;
2. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
3. Patient self-treatment practices and remedies for chronic and acute pain;
4. Outcomes of pain management according to patient-centered goals;
5. Perceptions of the risk for use and potential for abuse of prescription opioid medications.

CATEGORY	EMIC CODES	QUOTES
Pain Assessment	x-ray, MRI, blood work	I've had MRIs, I've had everything done. They put me underneath the x-rays and everything and they said my whole body's ok. So they don't know what's going on. And they did blood work and everything, but I don't know.
Patient/Provider Communication	I don't know (says this x 4). Not sure	I'm not sure what to look for anymore [sounds frustrated]. I don't know what the heck is going on. Some do and some don't [understand my pain]. I don't know what's going on with my legs either.
Beliefs/Attitudes	The "white" way Not sure what the pain in my back is Not diabetic, I'm overweight	They did x-rays and, you know, they do everything the "white" way [lowers voice, laughs]. I think it's the epidural from having kids And I'm not diabetic, I know I'm overweight but... I don't know.
Self-Treatment	Excedrin, hot showers	they had to cut me off [IBU, naproxen] because I was taking... I've been taking it too long ...still comes back ...it feels like my back is tensed all the time. And you know it just hurts my back and I think it's going down to my legs.
Outcomes	Not satisfied with treatment Yes (pain limits ADLs) pain is coming back	There has to be something else, [sounding slightly agitated] you know. I can't stand long periods, I can't stand up too long because my back starts hurting and then I feel like I'm bending over like this and it feels like I have to straighten up. It doesn't go away.
Perceptions of risk, opioids	it gets me sick	It seems like it just relieves it for a little bit but I have to take it a lot. But I just try to take one or two a day. They cut me off because my liver is getting all messed up
Allopathic Interventions	Ibuprofen, naproxen Knee surgery	I just take ibuprofen, that's what the doctors have been giving me because I didn't know how to deal with this because I was working. I had knee surgery
Alternative Therapies	"pins" (acupuncture)	I just....umm... where they did the pins. They did that and it helped for a little bit but the pain is coming back again. It doesn't go away.
Family Influence re: pain	No	[Response to question: Do the people around you, your family your family members, your friends influence your decisions about pain treatment?]

Subject B

Aims – patient perspective:

1. Pain assessment and influences of patient/provider communication;
2. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
3. Patient self-treatment practices and remedies for chronic and acute pain;
4. Outcomes of pain management according to patient-centered goals;
5. Perceptions of the risk for use and potential for abuse of prescription opioid medications.

EMIC CODES	QUOTES
MRI	Eventually it took me to go to the emergency room where the doctor there said ok we really need to get an MRI done.
<p>Yes. (Tells providers about all treatments used) initially they would just send me home with ibuprofen Yes to a point (providers understand the pain). doctors they just kind of brushed it off I wish he (chiropractor) would understand more patients are just numbers eye-to-eye contact is not there getting to know that person... could be a helpful tool</p>	<p>At first, I'd say maybe the first two doctors they just kind of brushed it off...you know exercise and do all that. Eventually it took me to go to the emergency room where the doctor there said ok we really need to get an MRI done. I don't how much more I can express how much pain I'm in to the doctor ...you'd figure that a chiropractor would understand. I wish he would understand more of the pain and the severity of it, I don't know what else he would have done for me, the traditional healer, I would like to tell him/her that it seems to me like a lot of the patients are just numbers that come across them and they just send you...well especially my healthcare provider, she seems to be typing at the computer a lot more often. She listens but....what would I like to tell her- that this pain is real. The referrals have been very helpful. I don't know, I guess that's a good question besides the pain is real [I: What stops you from telling them?] P: Oh just the....I don't know...the looking away from you, the eye-to-eye contact is not there and with some doctors it is with some doctors it's not. getting to know that person and what their past...what they used to do...and what they can and can't do would...could be a helpful tool to figure out if the pain...what types of pain there are...with the symptoms.</p>
<p>muscle spasms herniated discs chiropractors do not like pain medications chiropractors/traditional healers want to work everything out naturally Traditional healer seemed like chiropractic services The referrals have been very helpful.</p>	<p>For almost 2 years now we thought it was muscle spasmsfigured out what it was in December 2009, which was herniated disks ...that MRI made a difference. chiropractors, do not like pain medications, they want to work everything out naturally just like a traditional healer. But ironically going to the traditional healer....to me the first couple of visits it just seemed like chiropractic services- pulling the joints here, pulling the fingers- exactly what a chiropractors would do. it just seemed like I was seeing two chiropractors. seems like chiropractors they seem to have a dislike for you to go anywhere else to get relief A lot of people have different levels of pain, thresholds of pain. Some people can handle it more than others so I think its is on a person to person basis</p>
Ice, heat, exercise, stretching, Motrin	I tried in the beginning icing it, heating it, exercising it, stretching it, and took Motrin for the muscle pain inflammation and I've tried that on my own
<p>Yes it does (prevent from doing things you like or need to do) Massage targeted the problem Successful with chiropractor for muscle spasms</p>	<p>It really limited my ability to do the basic things- sweeping, well the necessities I guess- sweeping mopping. And the things I like to do it has limited me. Going out to the field to walk a long mileage to..for..dirt roads all over the Navajo Nation. And I can't sit for long periods of time, lay down or sit down or any of those. ...eventually I had to get help for it. They seemed to be just temporary fixes [self treatment].</p>

<p>nothing's really become better (seeing chiropractor 2 yrs) Pain management, orthopedic surgeon helpful Just wish it would be over Quality of life Be a better person Pretty much takes out my career Hydrocortone helps</p>	<p>I've been successful with the chiropractor for the muscle spasms. I've been seeing him [chiropractor] every week for the past 2 years and nothing's really become better of it. But...he does help in other ways. And the massage therapist, boy it felt really good for the massage therapist. She really targeted the problem, also in the neck area which was really tense. And helped me out but like I said it was only a temporary fix. And he [chiropractor] helps me to get back into alignment and catches me when I'm not in alignment and helps out with other problems. I was able to go see the pain management in Flagstaff, orthopedic surgeon. So that was helpful. I'm just at a point of continuing pain, limiting activities, and at this point I just wish it would be over with. It's mostly the quality of life because of the limiting activities That pretty much takes out my career and the quality of life. ...the quality of life has been taken out of me. And I'd like for the outcome for me...like in a year or so, I know it's going to take time to recover, but in a year or so to really be a better person. And the hydrocortone helps in certain ways but then it wears off and then I have to rely on another drug too to help with the pain.</p>
<p>I don't necessarily like the pain medications</p>	<p>I don't necessarily like the pain medications I'm taking, it does have side affects. I don't necessarily feel like I should be taking those for the rest of my life. I don't want to be taking those for the rest of my life because of the side effects. But it helps</p>
<p>pain management in Flagstaff, orthopedic surgeon back surgery</p>	<p>I was able to go see the pain management in Flagstaff, orthopedic surgeon. ...we are talking with orthopedic surgeons, they are talking about doing a back surgery</p>
<p>Chiropractor, traditional healer, massage</p>	<p>I do use a chiropractor. I have gone to a traditional healer. I've had massage therapy done</p>
<p>Mom</p>	<p>yes, my mom especially does [influence decisions about pain management]. She was a healthcare worker when she was younger in an old folk's home and she knows much about medicine so she's been making sure that I'm taking care of myself. So she does take care of me, as well as my husband does. They're all concerned about my health.</p>

Subject C

Aims – patient perspective:

1. Pain assessment and influences of patient/provider communication;
2. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
3. Patient self-treatment practices and remedies for chronic and acute pain;
4. Outcomes of pain management according to patient-centered goals;
5. Perceptions of the risk for use and potential for abuse of prescription opioid medications.

CATEGORY	EMIC CODES	QUOTES
Pain Assessment	Exam	I went to IHS and they examined me I would like an overall exam to see what other options I have...see if there's anything else I could do to where it doesn't get to that point to where I can't stand the pain sometimes.
Patient/Provider Communication	: Yes. (<u>Tells provider about all treatments used</u>) I would say so (<u>providers understand pain</u>).	I went to IHS ... told me I had a pinched nerve under my shoulder blade so they said that that could be affecting it as well. The doctor was showing me nerve points too and said that's all related. They just told me that physical therapy was mainly to strengthen my muscles that I'm not used to working with. It's been awhile since I've seen anybody over there [HIS]. Cause they don't know that it's gotten that further... the last time I'd seen them they were able to explain everything. I haven't made the appointment. They told me that it was a pinched nerve too and that it affected my arm as well.
Beliefs/Attitudes	(pain) "entails with my assisting" I need to be more consistent there's better areas (besides PT)	I've had this pain for a little over a year. I think it mainly entails with my assisting. I think with me constantly having to look down all the time. I think there's better areas where I could focus more on. [besides PT]. I think I need to be more consistent about going to them [massage therapy]. ...when my muscles tense up is when I can feel it the worst, or when I'm under a lot of stress is when I become more tense and it's when it hits me the worst. So a massage therapist is the one I go to.
Self-Treatment	Exercise I have to put my arm down. I don't take anything else Icy Hot, Myloflex Heating pads	I try to do those exercises. Like I said, I'm not a big fan of prescription drugs but if it's there and I absolutely need it then I'll take it. I don't take anything else. When I'm assisting and I hold a certain position I can feel it starting to get numb so I have to put my arm down. I have to put my arm down. I've tried icy hot. That helped. I've tried miloflex. Miloflex didn't help as much as icy hot. And then sometimes I'll use heating pads I'll put that on there just to try and relax it, get it to calm down when I feel it getting worse I know what to take or what to do before it reaches that point.

Outcomes	<p>: I'm not sure <u>(satisfaction with pain treatment)</u>.</p> <p>(Physical therapy) not as good as I was hoping</p> <p>(massage) It gets me through the day</p>	<p>My muscles tense up really bad and gets so bad that sometimes it bothers me when I'm sleeping and I can't sleep comfortably..... seems like it's getting worse...</p> <p>Sometimes it even effects me when I'm driving. I like to...I have hobbies, like I like to play softball. Sometimes that affects it as well. It also affects my job too. I get headaches on a constant basis,...it feels like whenever my neck starts hurting I feel sharp pains above my eye too.</p> <p>Naproxen seems to help.</p> <p>Not as good as I was hoping it would work [physical therapy] [massage] allows me to do what I need to do throughout the day.</p> <p>When I see the massage therapist it relieved a lot of stress, a lot of tension. I am able to focus more on work. It gets me through the day.</p> <p>Sometimes I get a tingling experience in my hand and sometimes numbness like when I'm assisting and I hold a certain position I can feel it starting to get numb.</p> <p>And like I said a couple of weeks ago it was so bad that I was limited on how much I could turn my neck, that's how painful it was and that's the worst that it's gotten.</p> <p>And then sometimes I'll use heating pads I'll put that on there just to try and relax it, get it to calm down and that sometimes helps.</p>
Perceptions of risk, opioids	I'm not a big fan of prescription drugs	<p>I don't want to take a lot of medication.</p> <p>Like I said, I'm not a big fan of prescription drugs but if it's there and I absolutely need it then I'll take it.</p>
Allopathic Interventions	Physical therapy Naproxen	<p>They sent me to physical therapy a couple times.</p> <p>They also prescribe naproxen.</p> <p>...they set me up with the physical therapist and the massage therapist.</p> <p>They were able to help me with what they could.</p>
Alternative Therapies	massage	A massage therapist, I tried going to.
Family Influence re: pain	I just stick to my own reasons.	Me and my grandmother have talked about going to a medicine man but I haven' done that.

Subject D

Aims – patient perspective:

1. Pain assessment and influences of patient/provider communication;
2. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
3. Patient self-treatment practices and remedies for chronic and acute pain;
4. Outcomes of pain management according to patient-centered goals;
5. Perceptions of the risk for use and potential for abuse of prescription opioid medications.

CATEGORY	EMIC CODES	QUOTES
Pain Assessment	Look...and see	just look at my left side down to my ankle and see for yourself
Patient/Provider Communication	Yes. (Tells provider about all treatments used) Yes (Dr. knows about the pain)	I went to diabetic clinic, I asked for pain medicine. Interviewer (I): Does the doctor know about the pain? Pt: Yes, I don't think they can do anything about it.
Beliefs/Attitudes	Short arm...has sharp drilling pain. there's nothing else to do.	I: Tell me about your pain, what do you think is the cause of your pain? Pt: Well, I was born with a short arm, left side. It has sharp, drilling pain. That's it, I was born with it. Just use medicine given me; there's nothing else to do. There's nothing else to do; I was born this way. Just take the medicine. I don't think they can do anything about it.
Self-Treatment	Ibuprofen 800 I just buy and haul store bread	I have been many places seeking help.
Outcomes	can't wash dishes anymore Bread making, esp. tortilla, is hard to do; it's painful. it's every day and I can't work not really satisfied	I: Does your pain prevent you from doing things you like or need to do? Pt: Yes, I can't wash dishes anymore; I had to change my dishes to plastic stuff now because I cannot lift more than 10 lbs. I: Does it work? Ibuprofen 800. Pt: Yes, just a little bit. It comes back when the medicine wears off. [I: Are you satisfied with the pain treatment prescribed by your healthcare providers?] Pt: Not really, not really satisfied with it because...they just say that "you are just going to have to live with the pain.." I want stronger medicine than Ibuprofen 800 I even went to Show Low to a German doctor. I paid \$40 for that but it did not help. I just wish to be free of pain.
Perceptions of risk, opioids	Prescribe strong medicine to use.	I: How do you feel about using prescription medication for pain?...like narcotics? Pt: Prescribe strong medicine to use.
Allopathic Interventions	Ibuprofen	I want stronger medicine than Ibuprofen 800.
Alternative Therapies	: No. (denies using alternative therapies). went to Show Low to a German doctor	I even went to Show Low to a German doctor. I paid \$40 for that but it did not help.
Family Influence re: pain	Yes. (Others influence decisions around pain)	

Subject E

Aims – patient perspective:

1. Pain assessment and influences of patient/provider communication;
2. Beliefs and attitudes about treatment options, including allopathic and/or alternative systems of care;
3. Patient self-treatment practices and remedies for chronic and acute pain;
4. Outcomes of pain management according to patient-centered goals;
5. Perceptions of the risk for use and potential for abuse of prescription opioid medications.

CATEGORY	EMIC CODES	QUOTES
Pain Assessment		
Patient/Provider Communication	Yes (<u>tells provider about all treatments</u>). He explained to me yes and no (providers understand) I've been pretty much open	Yes [<u>tells provider about all treatments</u>]. Whenever I mention pain they just prescribe painkillers and um I tell them, I do not want painkillers, they weird me out. I consult with [<u>traditional healer</u>] ...he's explained to me ...what some of my problems are. I don't think they know the intensity of the pain that I went through. Yes, in the form in which they prescribed painkillers for me. I've been pretty much open with them, telling them what works and what doesn't.
Beliefs/Attitudes	I had an accident back in the summer of 1986 (cause) "don't like it" (wt gain) It takes a long time I guess. (benefit from chiropractor) I like chiropractors the best I enjoy life more today I am grateful I am very appreciative	I had an accident back in the summer of 1986 which I had two mildly compressed disks and I have recurrent pain. In 2001 I got hit by an 18-wheeler. It totaled my car and aggravated my lower back pretty much I've gained weight as I result of it and I don't like it. I like chiropractors the best. Initially I didn't like it because you had to endure more pain to alleviate the pain that I had but now it works. I consult with [<u>traditional healer</u>] and he's done some mental and physical therapy with me. And he's explained to me through crystal gazing what some of my problems are. I am grateful that the pain has gone away. I am very appreciative of it now because I know what it's like to have it and I enjoy life more today
Self-Treatment	I treat it by going to chiropractors find something else to do Aspirin Take it easy continue some of the contraction of muscles that I have	I just find something else to do. Read a book, go out for a drive, go to the res. Just a number of things get my mind off the pain. I just take it easy, take an aspirin maybe. Even that I don't use as much.
Outcomes	pain for about three years pain started to recede I'm very much limited It worked very well (<u>chiropractor</u>) Yes (<u>massage helps</u>). Alleviating the pain Not really (satisfied with pain care)	I was in pain for about three years. But that pain started to recede from therapy, from going to chiropractors, and pain pills and so on. I used to be physically active, run, bike and stuff like that. It has pretty much put a limitation to my physical activities and I've gained weight as I result of it It worked very well [<u>chiropractor</u>]. Initially for about a year it wasn't making much advance but finally it started to work. It takes a long time I guess.

	I don't have as much (pain) anymore. Become more physically active.	Alleviating the pain. (most important outcomes of treatment for you?) Like right now I pretty much don't have as much pain anymore. The pain was so intense back in the days, it was unbearable. But now I have maybe .5 pain. The only time I get pain is late in the day at the end of the week, after working all week my back starts to hurt a bit I wish they did more of it. [pain care services]. That they had physical therapists at the clinic, or a referral to different chiropractors in Winslow, even Flagstaff. The chiropractic help that I got was more with my private insurance. I'm satisfied with the pain that I don't have as much anymore. It was a conglomeration of the assistance and the help that I got from all these three facets of health [chiropractor, traditional healer, massage] that was available. . . .continue some of the contraction of muscles that I have, in my hamstrings and so on, and continue working on it and eventually become more physically active again.
Perceptions of risk, opioids	They scare me	I don't do pain pills anymore. I've take pain killers and it was like being under the influence and not having control over my affairs and it really weirded me out. I rather deal with the pain than that loss of control.
Allopathic Interventions	physical therapists Pain killers	And I was in pain for about three years. But that pain started to recede from therapy, from going to chiropractors, and pain pills and so on. I wish they did more of it. That they had physical therapists at the clinic, Whenever I mention pain they just prescribe painkillers
Alternative Therapies	Yes I do Chiropractor, traditional healer (crystal gazing) (physical therapy) (mental therapy) Massage	I consult with [traditional healer] and he's done some mental and physical therapy with me. And he's explained to me through crystal gazing what some of my problems are. my wife works on me. I: Massage therapy? P: Yes she's a massage therapist and when the pain gets intense I ask her to work on me. It was a conglomeration of the assistance and the help that I got from all these three facets of health [chiropractor, traditional healer, massage] that was available.
Family Influence re: pain	wife	I myself wouldn't go normally so through the urging of my wife I finally went and saw a chiropractor. my wife works on me... Yes she's a massage therapist

APPENDIX N: QUALITATIVE ANALYSIS – EMIC CODING

Exemplar of the Coding Process for Emic Codes

Emic Code	Subject -Text Pieces
Perceptions of risk, opioids	A. It gets me sick. B. I don't like the pain medications, does have side effects. I don't necessarily feel like I should be taking those for the rest of my life. I don't want to be taking those for the rest of my life because of the side effects. But it helps. C. I'm not a big fan of prescription drugs. D. Prescribe strong medicine to use. E. They scare me. It was like being under the influence and not having control.

APPENDIX O: QUALITATIVE ANALYSIS – SECOND ORDER MATRIX

Codes	Related words/phrases by subject
Pain Assessment	<p>A. x-ray, MRI, blood work</p> <p>B. MRI</p> <p>C. Exam</p> <p>D. (Exam) just look at my left side</p> <p>E. none</p>
Patient/Provider Communication	<p>A. I don't know x 4, [communicates pain and self treatments with provider].</p> <p>B. Tells provider about pain and self treatments, doctors just kind of brushed it off, I wish he [chiropractor] would understand more. Patients are just numbers; eye to eye contact is not there. Getting to know the person could be a helpful tool.</p> <p>C. Tells providers about pain and self treatment, providers understand the pain.</p> <p>D. Tells provider about pain and self treatments, they know about the pain</p> <p>E. Tells provider about pain and self treatments, yes and no [providers understand]. I've been pretty much open.</p>
Beliefs/Attitudes	<p>A. They do things the "white way."</p> <p>B. Chiropractors do not like pain medications. Chiropractors and traditional healers want to work everything out naturally</p> <p>C. The pain entails with my assisting. I need to be more consistent. There are better areas where I could focus more on [besides PT].</p> <p>D. There is nothing else to do, I was born this way, I was born with a short arm.</p> <p>E. It takes a long time [to benefit from chiropractor]. I like chiropractors the best. I am grateful, I am appreciative, I enjoy life more today. Re: wt gain, "I don't like it."</p>
Self-Treatment	<p>A. Excedrin, hot showers</p> <p>B. Ice, heat, exercise, stretching, Motrin</p> <p>C. Exercise. When I'm assisting...I have to put my arm down. Icy Hot, Myoflex, heating pads.</p> <p>D. Ibuprofen, I just buy store bread [instead of making it]</p> <p>E. Go to chiropractors, find something else to do, aspirin, take it easy, contraction of muscles.</p>
Outcomes	<p>A. Not satisfied with treatment. Pain is coming back. Pain limits activities</p> <p>B. Nothing's really become better, It really limited my ability to do basic things, was successful with chiropractor for muscle spasms, pain management and orthopedic doctors were helpful, Hydrocodone helps, I just wish it would be over. Pretty much takes out my career.</p> <p>C. Not sure [if satisfied with pain treatment]. PT is not as good as I was hoping. [Massage] gets me through the day. Seems like it is getting worse</p> <p>D. Breadmaking...is painful, can't wash dishes anymore, it's every day, I can't work. Not really satisfied with pain treatment</p> <p>E. pain started to recede, I'm very much limited, chiropractor worked well, massage helps. Most important outcomes: alleviating the pain, become more physically active again.</p>

Perceptions of risk, opioids	<p>A. It gets me sick. My liver is getting all messed up</p> <p>B. I don't necessarily like the pain medications. I don't feel like I should be taking those for the rest of my life because of the side effects, but it helps.</p> <p>C. I'm not a big fan of prescription drugs</p> <p>D. Prescribe strong medicine to use</p> <p>E. They scare me</p>
Allopathic Interventions	<p>A. Ibuprofen, naproxen, knee surgery</p> <p>B. Pain management doctor, orthopedic surgeon, back surgery, pain medication</p> <p>C. Physical therapy, naproxen.</p> <p>D. Ibuprofen</p> <p>E. Physical therapy, pain killers</p>
Alternative Therapies	<p>A. Acupuncture</p> <p>B. Chiropractor, traditional healer, massage</p> <p>C. Massage.</p> <p>D. I have been many places; I even went to a German doctor.</p> <p>E. Chiropractor, traditional healer, massage</p>
Family Influence re: pain	<p>A. No</p> <p>B. Mother, husband</p> <p>C. I stick to my own reasons. Me and my grandmother talked about going to a medicine man.</p> <p>D. Yes family influences, daughter</p> <p>E. Wife influence</p>

APPENDIX P: QUALITATIVE ANALYSIS - ETIC CODING OF PATIENT INTERVIEWS

Etic Coding of Patient Interviews

Etic codes are in bold letters

Pain Assessment	
Subject	Modality
A	x-ray, MRI, blood work
B	MRI, Consultants
C	Exam
D	Exam
E	None identified

Patient/Provider Communication					
Subject	<i>Pt Education</i>	<i>Pt Communication</i>	<i>Provider communication</i>	<i>Depersonalization</i>	<i>Pt perspective – cultural factors</i>
A	Unsure of diagnosis or treatment	discusses concerns, all treatments, pain level	They don't know what's going on		Denotes differences in "white" vs native tx
B	Aware of diagnoses	Discusses concerns, all treatments, pain level	Providers have limited understanding of pain effects	No eye contact, feels like a number	
C	Aware of diagnoses	Discusses concerns, all treatments, pain level	Verbal explanation and visual demonstration by provider	n/a	
D	Limited understanding of Dx	discusses concerns, all treatments, pain level	Provider understands pain effects		
E	Aware of diagnoses	discusses concerns, all treatments, pain level	Limited understanding of pain effects		

Beliefs/Attitude				
Subject	<i>Pain Source</i>	<i>Treatments</i>	<i>Providers</i>	<i>Co-morbidities due to pain effects</i>
A	Effects of diabetes, obesity, past epidural	Allopathic (white) vs traditional		
B	Muscle spasm, herniated disc	Traditional healer/chiropractor seemed the same, stopped traditional healer visits	Chiropractors/traditional healers want natural treatments only. Referrals well received by pt.	

C	Work contributes to pain	PT is not a good use of time	Accepts personal responsibility for current pain status	
D	Birth defect	Medication is the only available treatment	No further treatment options available	
E	MVA, compressed discs	Chiropractic tx effect takes time;	Likes chiropractors best	Wt Gain

SELF TREATMENT		
Subject	<i>OTC meds</i>	<i>Other</i>
A	Excedrin	Heat
B	Motrin	Ice, heat, exercise, stretching
C	Icy Hot, Myoflex	heating pads, exercise, activity modification
D	Ibuprofen	activity modification
E	Aspirin	Distraction, activity modification, exercise

Outcome					
Subject	<i>Pt Tx Goal</i>	<i>Positive Tx Effects</i>	<i>Adverse Tx Effects</i>	<i>Effect on Lifestyle</i>	<i>Pt Satisfaction</i>
A	Long term relief	Short term relief with tx attempts	Liver effects	Interferes with work ability, ADLs	not satisfied
B	Pain free, QOL, resume career	Short term relief with tx attempts	tx overlap caused worsening (chiropractor/traditional)	Interferes with work ability, ADLs	not satisfied
C	Focus on work, get through the day	Some relief with treatments attempted		Interferes with work, hobbies	not sure
D	Pain free	Partial relief with IBU		Interferes with household duties, ADLs	not satisfied
E	Alleviation of pain, increase physical activity	Gradual improvement with intermittent flares	Chiropractor caused more pain initially	Interferes with leisure activities, ability to exercise	not satisfied

Opioid Risks			
Subject	<i>Effects</i>	<i>Risks</i>	<i>Perceptions</i>
A	Nausea	Liver damage	Intake s/b limited
B	relieves pain	side effects	Intake s/b limited
C	relieves pain		Intake s/b limited
D	relieves pain		s/b prescribed liberally
E	Loss of sense of control	Addiction relapse	Fearful of use, would rather deal with pain

Allopathic Treatments				
Subject	<i>Medications</i>	<i>Therapies/referrals</i>	<i>CAM referrals</i>	<i>Invasive tx</i>
A	opioids, NSAIDs			Knee surgery
B	opioids, NSAIDS	Pain mgmt clinic, ortho surgeon		Considering surgery
C	NSAIDs	PT,	massage	
D	NSAIDs			
E	opioids, NSAIDs	PT,		

Alternative Therapy		
Subject	<i>Therapies</i>	<i>Outcome</i>
A	Acupuncture	Temporary relief
B	Chiropractor, traditional healer, massage	Chiropractor - some relief; traditional healer - "too much" felt like chiropractor; massage; some relief
C	Massage	Very effective
D	German doctor, various provider types	not helpful
E	Chiropractor, traditional healer, massage	Combination therapy helped

Family Influence			
Subject	<i>Yes/No</i>	<i>Who influenced</i>	<i>What was recommended</i>
A	No		
B	Yes	Mother	hospital, clinic
C	No	Grandmother attempted	traditional medicine
D	Yes	Adult children	altered activities
E	Yes	Wife	chiropractor, massage

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