Understanding the Pain Experience of Native Americans: A Qualitative Descriptive Study

Item Type	text; Electronic Dissertation
Authors	Katonak, Rachel Lynn
Publisher	The University of Arizona.
Rights	
Download date	
Link to Item	http://hdl.handle.net/10150/626614

UNDERSTANDING THE PAIN EXPERIENCE OF NATIVE AMERICANS:

A QUALITATIVE DESCRIPTIVE STUDY

by

Rachel L. Katonak

A Dissertation Submitted to the Faculty of the

COLLEGE OF NURSING

In Partial Fulfillment of the Requirements

For the Degree of

DOCTOR OF PHILOSOPHY

In the Graduate College

THE UNIVERSITY OF ARIZONA

2017

THE UNIVERSITY OF ARIZONA
GRADUATE COLLEGE

As members of the Dissertation Committee, we certify that we have read the dissertation prepared by Rachel Katonak entitled "Understanding the Pain Experience of Native Americans: A Qualitative Descriptive Study" and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

Michelle Kahn-John
Michelle Kahn-John, PhD, RN, PMHNP-BC, GNP Date: November 15, 2017

Mary Koithan
Mary Koithan, PhD, CNS-BC, FAAN Date: November 15, 2017

Heather L Carlisle
Heather Carlisle, PhD, DNP, RN-BC, FNP-BC, AGACNP-BC Date: November 15, 2017

Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copies of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

Michelle Kahn-John
Dissertation Co-Chair: Michelle Kahn-John, PhD, RN, PMHNP-BC, GNP Date: November 15, 2017

Mary Koithan
Dissertation Co-Chair: Mary Koithan, PhD, CNS-BC, FAAN Date: November 15, 2017

STATEMENT BY AUTHOR

SIGNED: __Rachel L. Katonak__________________

ACKNOWLEDGMENTS

I am grateful for my committee members’ guidance, help from friends, and support from my family and husband.

I would like to express my deepest gratitude to my dissertation committee co-chairs, Dr. Michelle Kahn-John and Dr. Mary Koithan. They provided critical appraisal, excellent leadership, patience and support. They helped me develop my background in qualitative research and guided my work with a vulnerable population. I was able to achieve high quality analysis and writing with their assistance and encouragement. I would like to thank Dr. Heather Carlyle for lending her expertise in the area of chronic pain and for her inspiring treatment of patients with dignity and respect.

I would like to thank my parents, Aleta and David Katonak, for instilling in me a quest for knowledge and wonder of the world. I miss you Dad and I love you both very much.

Finally, words cannot convey the appreciation I feel for the unending support that my husband, Jeff Wilson, provided during all these years. I would not be where I am today without him.

DEDICATION

This dissertation is dedicated to the Native Americans living with chronic pain, their families and communities.

TABLE OF CONTENTS

LIST OF FIGURES 11
LIST OF TABLES 12
ABSTRACT 13

CHAPTER I: INTRODUCTION 15

Statement of Research Purpose 15
Research Aims 16
    Aim 1: Describe NNM AI's Experiences with Pain 16
    Aim 2: Describe NNM AI's Pain Management Strategies 16
    Aim 3: Describe the Outcomes of Pain Management Strategies and the Pain Experience 17
A Note on Terminology 17
Background and Gaps in Knowledge 17
    Chronic Pain 17
        Opioids and the treatment of pain. 19
Definitions (Adapted from National Institute on Drug Abuse [NIDA], 2014) 20
How do Opioids Work? What are Benefits/Risks? 21
Pain Physiology 21
UCSF Symptom Management Theory (SMT) 22
    Pain Experience 23
The Stigma of Chronic Pain 24
Symptom Management 25
Healthcare Professional Barriers to Treatment of Pain 25
Social Contextual Factors and the Treatment of Pain 26
    Symptom Outcomes 27
    Pain Disparities 27
    Pain Agreements 30
CDC Guidelines 32
Northern New Mexico Pueblo Communities 34
Pueblo Historical Background 35
Historic Trauma and Health Disparities 37
Poverty and Rurality 38
Rural Pain Management 40
Indian Health Service (IHS) 41
Background and Gaps in Knowledge Summary 43
Theoretical Position 43

CHAPTER II: LITERATURE REVIEW 45

Literature Review Method 45
Results 46

TABLE OF CONTENTS – *Continued*

Chronic Pain Management 46
Summary of CDC Guidelines 48
Summary of CDC Guidelines 50
Pain Agreements 50
Summary of Pain Agreements 52
American Indians Pain Experience 53
Summary of American Indians Pain Experience 57

CHAPTER III: METHODOLOGY 59

Research Design 59
Aim 1: Describe NNM AIs Experiences with Pain 59
Aim 2: Describe NNM AIs Pain Management Strategies 59
Aim 3: Describe the Outcomes of Pain Management Strategies and the Pain Experience 60
Qualitative Research 60
Qualitative Description 60
Sampling Strategy 61
Inclusion Criteria 61
Exclusion Criteria 61
Rationale for Sample 61
Change to Sampling Plan 62
Recruitment 62
Data Collection 63
Method 63
Participant Protection 64
Rigor 65
Data Analysis 67
Data Management 67
Coding Process 68
Content Analysis 68
Summary 69

CHAPTER IV: FINDINGS 71

Introduction 71
Characteristics of Participants 71
Results 73
Aim 1: Pain Experience 73
Aim 1a: Describing Experiences 74
Body awareness. 76
Maintaining normality. 77
Unpredictability of pain. 77

TABLE OF CONTENTS – *Continued*

Psychological outcomes. 77
Hope for improvement. 78
Body as confining. 78
Alteration to sense of self. 78
Pain as metaphor. 79
Coping/acceptance. 79
Pain Experience Summary 79
Aim 1b: Environmental Factors 80
Physical environment. 80
Social environment. 82
Workplace support. 83
Material support. 83
Emotional support. 84
Environment and Pain Experience Summary 84
Aim 1c: Demographic Comparisons of Pain Experience 84
Pain experiences by gender. 85
Summary of pain experiences by gender. 86
Pain experiences by employment status. 86
Summary of pain experiences by employment. 87
Pain experiences by place of residence. 87
Summary of pain experiences by residence. 88
Aim 1: Pain Experience Summary 88
Aim 2: Pain Management Strategies 89
Aim 2a: Describing Pain Management Strategies 90
Biomedical strategies. 92
Non-physician professional strategies. 92
Self-care strategies. 92
Summary of Pain Management Strategies 93
Aim 2b: Pain Management and Environmental Context 93
Pain culture environment. 93
Belief in opioids as addictive. 95
Belief in non-biomedical strategies. 95
Belief in opioids causing adverse effects. 95
Social environment. 96
Supportive healthcare provider relationship. 97
Unsupportive healthcare provider relationship. 98
Supportive family/friend relationship. 98
Unsupportive family/friend relationship. 99
Physical environment. 99
Summary of Pain Management and Environment 100
Aim 2c: Demographic Comparisons of Pain Management 100
Demographic comparisons for prescribed medications. 101

TABLE OF CONTENTS – *Continued*

Summary of demographic comparisons for prescribed medications............104
Demographic comparisons for professional pain management strategies. ..104
A note on acupuncture...106
Summary of demographic comparisons for professional strategies. 106
Demographic comparisons for self-care strategies. 107
Summary of demographic comparisons of pain management. 109
Aim 3: Pain Outcomes...110
Aim 3a: Describing Pain Outcomes...110
Functional status. 110
Summary of functional status. 111
Costs 111
Time...113
Financial Costs 114
Health Insurance Status 114
Summary of Costs 114
Quality of Life 115
Loss of Social Role 116
Life Plan Disrupted...117
Emotional Well-Being...117
Summary of Quality of Life 118
Healthcare Utilization...118
Healthcare Provider...118
Health Insurance Status 119
Summary of Healthcare Utilization 120
Aim 3b: Demographic Comparisons of Pain Outcomes............................120
Functional limitations by gender...122
Summary of functional limitations by gender..................................122
Functional limitations by residence...122
Summary of functional limitations by residence............................123
Comparison of healthcare utilization by residence........................123
Summary of healthcare utilization by residence............................124
Comparison of healthcare utilization by gender............................124
Summary comparison of healthcare utilization by gender. 125
Summary Demographic Comparisons of Pain Outcomes..........................125

CHAPTER V: DISCUSSION 127

Discussion of Results..127
Pain Experiences of American Indians 127
Chronic Pain Management 129
Pain Outcomes...133
Implications for Clinical Practice..138

TABLE OF CONTENTS – *Continued*

Implications for Theoretical Model....138
Challenges with Symptom Management Theory (SMT)....139
Study Strengths....141
Study Limitations....141
Future Research....143
Conclusion....143

APPENDIX A: RECRUITMENT FLYER....145
APPENDIX B: FACEBOOK RECRUITMENT....147
APPENDIX C: EMAIL/LETTER SCRIPT....149
APPENDIX D: VERBAL SCRIPT....151
APPENDIX E: INTERVIEW GUIDE....154
APPENDIX F: DEMOGRAPHICS FORM....156
APPENDIX G: THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL....159
APPENDIX H: INFORMED CONSENT....161
APPENDIX I: ETIC CODES AND DEFINITIONS....165

REFERENCES....167

LIST OF FIGURES

FIGURE 1. Diagram of the Symptom Management Theory (SMT) (Dodd et al., 2001) 23

FIGURE 2. Taxonomic Summary of Demographic Comparisons of Pain Experiences........85

FIGURE 3. Pain Experiences of Males and Females..86

FIGURE 4. Pain Experiences, Employed vs. Unemployed 87

FIGURE 5. Pain Experiences, Rural vs. Urban 88

FIGURE 6. Taxonomic Summary of Demographic Comparisons of Pain Management Strategies..101

FIGURE 7. Comparison of Rural vs. Urban, Past and Present, Opioid Prescription...........102

FIGURE 8. Comparison of Men and Women Medications 103

FIGURE 9. Comparison of Medications by Level of Education 104

FIGURE 10. Comparison of Females and Males Professional Pain Management 105

FIGURE 11. Comparison of Professional Strategies by Level of Education 106

FIGURE 12. Comparison of Self-Management, Urban and Rural 107

FIGURE 13. Self-Care Strategies Compared by Education Level 108

FIGURE 14. Comparison of Male and Female Self-Care Strategies.....................................109

FIGURE 15. Taxonomic Summary Demographic Comparisons of Pain Outcomes 121

FIGURE 16. Functional Limitations by Gender 122

FIGURE 17. Functional Limitations by Residence...123

FIGURE 18. Comparison Healthcare Utilization, Urban vs. Rural 124

FIGURE 19. Comparison of Healthcare Utilization by Gender 125

LIST OF TABLES

TABLE 1. *American Indian (AI) Participant Demographics* 72
TABLE 2. *Pain Experiences* 74
TABLE 3. *Physical Environment* 81
TABLE 4. *Social Environment* 82
TABLE 5. *Pain Management Strategies, Past and Present* 91
TABLE 6. *Pain Culture Environmental Factors Influence on Pain Management Strategies* 94
TABLE 7. *Social Environmental Factors Influence on Pain Management Strategies* 96
TABLE 8. *Physical Environmental Factors Influence on Pain Management Strategies* 99
TABLE 9. *Limitations to Functioning/ADLs* 111
TABLE 10. *Cost Outcomes* 112
TABLE 11. *Quality of Life (QOL) Outcomes* 115
TABLE 12. *Healthcare Utilization Outcome* 118

ABSTRACT

Background. Pain is the most commonly reported symptom in primary care and is estimated to affect over 110 million people in the United States. Increased pain severity and occurrence and inadequate treatment of pain is linked to being a minority, healthcare access, socioeconomic status, age and gender. Outcomes of pain include costs, healthcare utilization, functional changes, and quality of life. Gaps in knowledge exist regarding the American Indian (AI) chronic non-malignant pain experience, management and outcomes.

Objective. The purpose of this research is to describe Northern New Mexico (NNM) AIs chronic pain experience, intervention strategies, and outcomes.

Methods. This study utilized a qualitative descriptive (QD) design, with in-depth, one-on-one interviews with semi-structured interview questions. A sample of 14 Native Americans were interviewed for this study. A questionnaire was used to collect demographic data. Domain, taxonomic and content analyses were utilized to gain a highly nuanced description of the research topic.

Results. The participants provided rich qualitative data regarding chronic pain experience, management strategies and outcomes. Frequent pain experiences included the body as a confining entity, body awareness, unpredictability of pain, and psychological outcomes. AIs in the study utilize a variety of biomedical, professional and self-care interventions. Outcomes discussed were functional status, costs, healthcare utilization, and quality of life.

Outcomes. The goal of this research is increased understanding of the chronic pain experience through the perspective of those experiencing it. Findings will be submitted to the University of

Arizona dissertation library, disseminated across relevant peer-reviewed journals focused on pain and pain management, and presented to appropriate groups and organizations.

CHAPTER I: INTRODUCTION

Increased vulnerability to pain is associated with factors, such as race and ethnicity, health care access, income, age, gender, and education (Mossey, 2011). American Indians (AIs) are repeatedly found to have distinctly higher rates of reported pain than non-Hispanic whites (Centers for Disease Control (CDC) & National Center for Health Statistics, 2010; Jiminez, Garroutte, Kundu, Morales, & Buchwald, 2011). Additionally, racial and ethnic minorities tend to be inadequately treated for pain when compared with non-minorities (Mossey, 2011). The seminal Institute of Medicine (IOM) (2011) report on pain recognized gaps in knowledge regarding existing and probable barriers to quality pain care and management for populations that are disproportionately affected by and inadequately treated for pain, including patient, healthcare provider, healthcare system, and sociocultural barriers. Difficulties surrounding the use of opioids, lack of access to resources and pain specialty care, and healthcare provider uncertainties when managing chronic pain contribute to the ineffective treatment of pain. Furthermore, outcomes of chronic pain are related to potential decreased functional status, increased healthcare utilization and costs, and decreased quality of life. Little is known regarding these issues in relation to AIs and chronic pain and will be discussed throughout this dissertation. Effective pain management requires an understanding of the pain experience, the contextual environment in which pain occurs, pain management strategies and outcomes.

Statement of Research Purpose

The goal of this qualitative descriptive (QD) study is to expand understanding of the chronic pain experience of AIs for community members, families, and healthcare providers who serve these communities. This research seeks to build on the narrow knowledge we have about chronic pain and AIs by describing the experience through the perspective of those directly affected. The purpose of this research is to describe Northern New Mexico (NNM) American Indians (AIs) chronic pain experiences, intervention strategies to manage pain, and chronic pain outcomes.

The Symptom Management Theory (SMT) was selected to guide this study's research aims. The elements of the theory are: symptom (pain) experience, symptom management (pain management), and symptom (pain) outcomes. Person, environment, and health state are interrelated and affect the components of the SMT. The theory is comprehensive, with each element relating to one another in various directional ways. The SMT recognizes how adherence to a pain management intervention can affect pain outcomes. All three elements of the theory were addressed. The SMT will be discussed in further detail later in this chapter.

Research Aims

The research aims were to:

Aim 1: Describe NNM AIs Experiences with Pain

a. Describing participants' pain experiences.
b. Describing environmental factors that influence the participants' experiences with pain.
c. Comparing/contrasting participants' similarities and differences of experiences with pain based on demographic characteristics.

Aim 2: Describe NNM AIs Pain Management Strategies

a. Describing participants' biomedical, professional, and self-care strategies to managing their pain.

b. Describing the environmental factors that influence the participants' pain management strategies.
c. Comparing/contrasting participants' similarities and differences in pain management strategies based on demographic characteristics.

Aim 3: Describe the Outcomes of Pain Management Strategies and the Pain Experience

a. Describing the impact of pain and pain management strategies on the participants' functional status, healthcare utilization, costs, and quality of life.
b. Comparing/contrasting participants' similarities and differences in pain outcomes based on demographic characteristics.

A Note on Terminology

Throughout this research study, the terms *American Indian* and *Native American* are used to refer generally to peoples indigenous to North America. A consensus does not exist for the most appropriate terms to use and others are used, such as indigenous peoples. The term Indian is still utilized in the public and private sectors, as in "Indian Health Service." Academic literature most often uses the term American Indian/Alaskan Native.

Background and Gaps in Knowledge

Chronic Pain

The Institute of Medicine (IOM) (2011) released a landmark report, *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research,* calling attention to chronic pain as a public health problem. The report reveals staggering statistics:

- Chronic pain is estimated to affect at least 116 million people in the United States (US) and is the most commonly reported symptom in primary care.

- Pain is a significant public health problem that costs society at least $560-$635 billion annually, an amount equal to about $2,000 for everyone living in the US.
- The total incremental cost of health care due to pain ranging between $261 to $300 billion and $297-$336 billion due to lost productivity (based on days of work missed, hours of work lost, and lower wages).

Pain becomes chronic when it lasts longer than three to six months and low back pain is the most common reported condition associated with chronic pain (Mossey, 2011). The consequences of pain may include decreased mobility, loss of strength, disturbed sleep, immune impairment and increased susceptibility to disease, dependence on pain medicine, and co-dependence on others for activities of daily living (IOM, 2011). Chronic pain is associated with economic and societal costs, such as disability, lost income and higher health care utilization (Meghani et al., 2012).

Data on the incidence, prevalence, and consequences of pain are not reliable or comprehensive, in part because in many cases pain is treated as a symptom of a disease or condition and is often not reported in and of itself (IOM, 2011). Furthermore, there is no standardization of methods, definitions, and survey questions regarding pain used in population-based studies and available data only relate to certain conditions related to pain (IOM, 2011). The Institute of Medicine (IOM) (2011) studied population health data on pain in the U.S. and found higher rates of reported pain increased with age (with age 65+ being the highest) and women reported pain more than men. When controlled for risk factors, less pain was reported as a person's education and income levels rise. Similarly, a large cross-national survey (N=42,249) found a higher prevalence of chronic pain conditions among females and older persons (Tsang et al., 2008). For example, women are seven to nine times more often afflicted by fibromyalgia syndrome than men (Bieber et al., 2008).

Opioids and the treatment of pain. The use of opioids or narcotics for pain management has a long history in the US. Trends have risen and fallen in their use. Most recently, starting in the 1990s, there was recognition of pain not being treated adequately, leading to the treatment of pain being taken more seriously and some advocating for health assessments to include pain as a fifth vital sign (The Joint Commission (TJC), 2016). Coinciding with this trend was the marked increase of healthcare providers prescribing opioids for pain (Dowell, Haegerich, & Chou, 2016). The US is now experiencing an epidemic of prescription opioid overdose deaths, with 165,000 deaths since 1999 (Dowell et al., 2016). The epidemic encompasses all ages, genders, ethnicities, and people of varying socioeconomic status (SES) (Dowell et al., 2016). Factors involved in the increased risk of prescription drug overdose include being male, 35-54 years old, AI, having lower income, mental health conditions, high daily doses, prescriptions from multiple providers/pharmacies, taking opioids with benzodiazepines, and living in rural areas (Haegerich, Paulozzi, Manns & Jones, 2014). As of 2014, NM had the second highest drug overdose death rate in the country. During 2010-2014, 53% of drug overdose deaths were caused by prescription drugs, while 33% were caused by illicit drugs, and 14% involved both types (New Mexico Department of Health (NMDH), 2016). Substance abuse is deemed a top NM Tribal Health Council priority (NMDH, 2016; Kaufman et al., 2010).

The epidemic of drug overdose deaths is inextricably tied to how pain is treated. The opioid overdose epidemic is a significant concern. Balancing this concern with effectively managing chronic pain is a contentious issue and will be discussed in greater detail throughout this dissertation. Opioids have and will continue to have their place in the toolbox for treating chronic pain.

Definitions (Adapted from National Institute on Drug Abuse [NIDA], 2014).

An understanding of terminology used when discussing issues surrounding the use of opioids for the treatment of chronic pain is necessary. Physical dependence is not the same as addiction and occurs because of normal adaptations to chronic exposure to a drug. Someone who is physically dependent on medication will experience withdrawal symptoms when the use of the medicine is suddenly reduced or stopped. These symptoms can be minor or severe and can usually be managed medically or avoided by using a slow drug taper. Dependence is often accompanied by tolerance or a diminished response to a drug with repeated use and often results in the need to take higher doses of a medication to get the same outcome. When tolerance occurs, it can be difficult for healthcare providers to differentiate between a developing drug problem and a real medical need for higher doses to control one’s symptoms. Addiction is a chronic disease characterized by drug seeking and use that is compulsive, or difficult to control, despite the awareness of harmful consequences associated with misuse or abuse of opioid pain medications (NIDA, 2015). Hyperalgesia is a condition where patients have a hypersensitivity to pain caused by pain medications. Healthcare providers should consider opioid induced hyperalgesia (OIH) when an opioid treatment effect dissipates and other explanations for the increase in pain are absent, particularly if found in the setting of increased pain severity coupled with increasing dosages of an analgesic. Treatment for OIH includes decreasing the opioid dose, tapering a patient off the medication, or supplementation with other medications (Lee, Silverman, Hansen, & Patel, 2011).

How do Opioids Work? What are Benefits/Risks?

Opioids work by attaching to particular proteins called opioid receptors, which are found in the brain, spinal cord, gastrointestinal tract, and other organs in the body (NIDA, 2016). When these drugs attach to their receptors, they diminish the perception of pain. Opioid pain medications can decrease pain severity, improve mood and improve functional status (Chou et al., 2015; Deyo, VonKorff, & Duhrkoop, 2015). Some guidelines recommend opioids over NSAIDs for pain in elderly patients over the age of 75 due to gastrointestinal, renal, and cardiovascular risks associated with NSAIDs (American Geriatrics Society Panel, 2009). Opioids can also produce drowsiness, mental confusion, nausea, constipation, and, depending upon the amount of drug taken, can depress respiration (NIDA, 2016). Some people experience an exhilarated reaction to opioid medications, since these drugs also affect the brain regions involved in reward (NIDA, 2016).

Pain Physiology

Numerous variables influence how a person experiences pain, such as physiological and sociocultural factors. Physiologically there are four types of pain, “nociceptive pain (visceral or somatic pain resulting from stimulation of pain receptors), neuropathic pain (pain caused by peripheral or central nervous system stimulation), mixed or unspecified pain (having mixed or unknown pain mechanisms), and pain due to psychological disorders” (Fink, Gates, & Montgomery, 2015, p. 114). Humans generally have similar neurophysiological systems of pain perception (Fink et al., 2015). Often the cause of chronic pain is unknown or does not respond to usual therapy (Huether, 2010). Chronic pain is theorized to occur due to a misinterpretation of nociceptive input, with the following mechanisms believed to initiate and embed chronic pain states:

> '*Changes in sensitivity of neurons – lower threshold with peripheral and central sensitization; spontaneous impulses from regenerating peripheral nerves; alterations in the dorsal root ganglion in response to peripheral nerve injury and neurotransmitters – reorganization of nociceptive neurons (differentiation pain); loss of pain inhibition in the spinal cord; and up-regulation of chemokines and their receptors' (Huether, 2010, p. 492).*

Chronic pain may be persistent or intermittent and is often correlated with a sense of hopelessness and helplessness as relief becomes more intangible and the timeframe more prolonged (Huether, 2010). When pain is chronic and persistent, it allows for physiologic adaptation and the appearance of normal physiologic indicators (e.g,. normal vital signs), which in turn can lead to healthcare providers assuming that patients are not being honest about their pain since they do not appear to be in pain (Huether, 2010).

UCSF Symptom Management Theory (SMT).

The UCSF Symptom Management Theory (SMT) was a useful framework for understanding the various factors underlying chronic pain and guiding this study. The SMT includes three main concepts which are bi-directionally related: symptom experience, symptom management strategies, and outcomes (Figure 1) (Dodd et al., 2001). Self-report and perception of a person's experience is the most important consideration when studying symptoms. Symptom management is a changing process depending on experience and outcomes of the symptom. The nursing domains of person, health/illness, and/or environment are contextual variables that influence the concepts of the SMT. Person variables include demographic, psychological, sociological, physiological and developmental. The health and illness domain consist of variables, such as risk factors, injuries, or disabilities. The environmental domain refers to contextual variables, including physical, social and cultural. The social environment includes one's social support network and interpersonal relationships (Brant, Beck & Miaskowski, 2009). How pain is managed can be largely influenced by the relationship between a healthcare provider and the patient. Cultural variables include beliefs, values and practices and how they influence how one experiences and manages their pain.

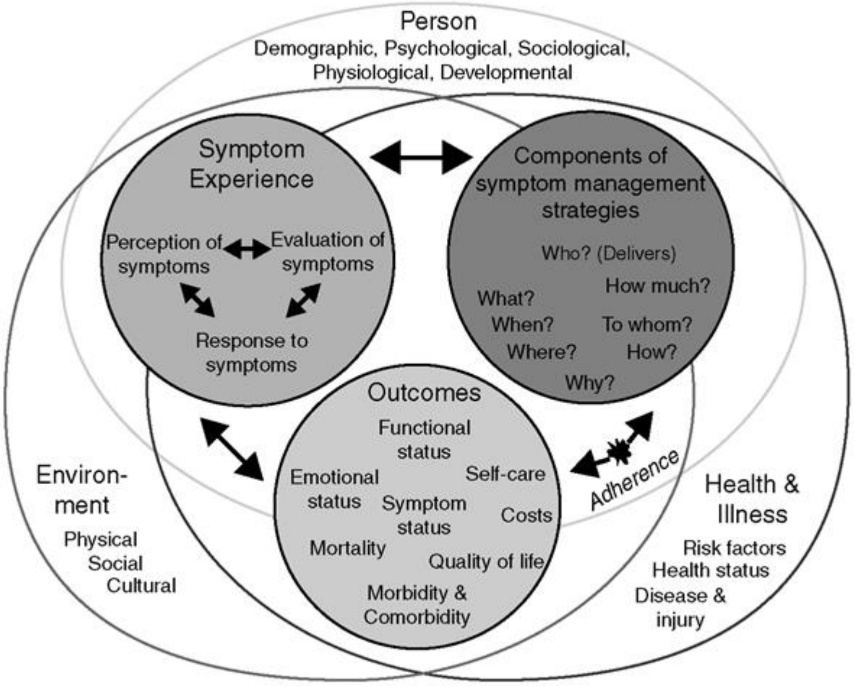

FIGURE 1. Diagram of the Symptom Management Theory (SMT) (Dodd et al., 2001).

Pain Experience

Pain symptoms are a subjective experience. Perception of a symptom leads to an evaluation of what the symptom means to an individual and informs how they respond to the symptom (Larson et al., 1994). As one gains experience with symptoms, they may become better equipped to evaluate the symptom and explain its quality. Pain experience encompasses the personal perception and evaluation of pain, as well as input by others into the evaluation of pain (Brant et al., 2009). Chronic pain sufferers may feel internal aspects of vulnerability, which are emotional, cognitive, and/or behavioral (Glass & Davis, 2004). Emotional responses to pain may include depression, anger, distress, anxiety, and decreased ability to concentrate (Fink et al., 2015). Cognitively pain can influence one's thought processes, how one views themselves in relation to their pain, the knowledge, attitudes, and beliefs one has about pain and its management, and the meaning of the symptom experience (Fink et al., 2015). Pain behaviors describe how one exhibits their pain, such as verbal complaints, moaning, groaning, lying down, or suppression of conveying their pain (Fink et al., 2015).

The Stigma of Chronic Pain

Pain may be defined as an "aversive feeling experienced in the body that cannot be measured directly" (Jackson, 2005, p. 333). As a result, others may doubt one's pain intensity or reality. As pain becomes chronic, it is given less validity than acute conditions by others, including healthcare providers (Jackson, 2005). Some chronic pain conditions, such as non-specific low back pain and fibromyalgia, do not have an identifiable organic pathology that lead to a diagnosis of a psychological rather than a physical problem (Cohen, Quintner, Buchanan, Nielsen, & Guy, 2011). A person or group (chronic pain sufferers) may be categorized as different from a commonly accepted norm (normal physical functioning), with the implication of a negative stereotype (i.e., drug seekers) (Link & Phelan, 2001).

The distinctions between pain experience, pain behavior and the accompanying emotional states are ambiguous and may contribute to the discrimination and stigmatization of pain patients (Cohen et al., 2011; Jackson, 2005). Stigma is a process by which reactions of a community to a specific characteristic reduce a person's identity from a holistic being to a discounted being, causing a person to be discredited, devalued, rejected, and socially excluded from having a voice (Cohen et al., 2011). The experience of stigmatization can lead to feelings of self-blame and unworthiness (Jackson, 2005).

Symptom Management

Pain should be managed, especially when it disrupts the normal routine of life. Intervention components include who delivers, what, when, where, how, to whom, how much, and why (Brant et al., 2009). Symptom management is a dynamic process; where how symptoms are controlled vary over time due to symptom outcomes (Larson et al., 1994). The inclusion of symptom management can aid in the evaluation of interventions (Brant et al., 2009). Various barriers to optimal pain assessment and treatment exist and contribute to increased vulnerability to pain, such as healthcare professional and system barriers and social contextual barriers (Fink et al., 2015). Intervention strategies that are too demanding are related to an increased risk for nonadherence. Such nonadherence may be a reflection of inconsistencies of how the intervention is applied or the characteristics of the individual, family, healthcare provider or the healthcare system (Dodd et al., 2001).

Healthcare Professional Barriers to Treatment of Pain

Healthcare providers face uncertainties when managing chronic pain (Matthias et al., 2010; Bair et al., 2009; Denny, 2009). In the absence of objective evidence for what is causing the pain, it can be difficult to trust the patient's subjective experience (Gulbrandsen, Madsen, Benth, & Laerum, 2010). Additionally, provider perspectives on how to manage pain may be conflicting (Bergman, Matthias, Coffing, & Krebs, 2013; Matthias et al., 2013; Teh et al., 2009).

Primary care providers face numerous challenges in caring for chronic pain patients, such as little or no training in pain management, time constraints, conflicting issues addressed during a patient-provider visit, and relational difficulties (Allegretti, Borkan, Reis, & Griffiths, 2010; Matthias et al., 2010). The problem of managing pain becomes complicated when the underlying cause of pain is less clear or the scientific evidence for treating chronic pain for various conditions is weak and controversial. The patient experiences the pain regardless of the cause. When a provider cannot find the cause, or does not 'believe' the patient should be having the level of pain that they are, then the patient-provider relationship can begin to breakdown. Patients often have difficulties describing their pain and how it affects their everyday lives. Persons are holistic beings and those living with chronic pain are not experiencing pain as something that exists only in their minds.

Social Contextual Factors and the Treatment of Pain

Culture shapes numerous aspects of pain, including how one expresses pain, the use of traditional AI remedies, perceptions of the healthcare system, when/how/where to seek care, illness beliefs and behaviors, and receptivity to allopathic treatments (Campbell & Edwards, 2012). For example, strong beliefs of patients and their families regarding the use of opioid analgesics determine their use or non-use in the treatment of pain. For Native Americans, spirituality is regularly viewed as the basis for wellness, sickness, and healing, and informs all facets of life (BigFoot & Schmidt, 2010; Garrett, Torres Rivera, Dixon, & Myers, 2009; Gone, 2004; Hodge & Limb, 2011). Health is viewed as a process of balance and harmony with the environment (Gray, 2004). Illness is a disruption in this balance that needs to be restored, with the use of traditional healers and ceremonies (Garrett et al., 2009; Yurkovich & Lattergrass, 2008). Each AI communal group has particular ceremonies and other means for diagnosis and remedy (Pijoan, 2010). Healers, often known as medicine people, are considered holy people and have specialized training and draw from dreams, traditional knowledge, and the ability to perceive the problem in the patient (Pijoan, 2010). Disease and biomedical (Western) treatments may be viewed by Native Americans as another intrusion of white culture into AIs' lives (Pijoan, 2010). Outcomes of such beliefs may include refusal to seek biomedical treatments, reluctance to seeking biomedicine, and seeking out indigenous remedies (Campbell & Edwards, 2012). Nonetheless, most AIs utilize a combination of healthcare resources, traditional and non-traditional (Campbell & Edwards, 2012).

Symptom Outcomes

Symptom outcomes are related to the symptom experience, with the status of the symptom as the key influence. Symptom status may affect other variables, such as quality of life, self-care, cost, functional and emotional status (Dodd et al., 2001). Cost includes financial status and healthcare services utilization (Dodd et al., 2001). The chronicity of long-lasting pain may lead to a decrease in resource availability over time. Such factors can add stress to the patient's and family's life and may result in risk-taking behavior, which in turn may lead to a decrease in health status, adverse outcomes and overall decreased quality of life (Meghani et al., 2012).

Pain Disparities

Health disparities are the, "Differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States" (Centers for Medicare & Medicaid Services, 2016). Disparities are noted in pain epidemiology, access to quality pain care, pain assessment and treatments, and pain-related outcomes for racial and ethnic minorities across a wide range of settings and types of illness or injury (Anderson, Green, & Payne, 2009; Crowley-Matoka, 2013; Hausman, Gao, Lee, & Kwoh, 2013; Meltzer et al., 2011; Mossey, 2011; Shavers, Bakos, & Sheppard, 2010). Several studies found that minorities reported higher levels in the severity of pain than non-minorities (Blyth, 2010; Fink et al., 2015; Green & Hart-Johnson, 2012; Meghani & Cho, 2009; Mossey, 2011; Portenoy, Ugarte, Fuller, & Haas, 2004). A review of 12 epidemiological studies reported that eleven of the 12 studies found a higher prevalence of pain overall and for specific sites (low back pain, headache or migraine, neck pain, and joint pain) among American Indians/Alaskan Natives (AI/AN) than in the United States (US) general population (Jiminez et al., 2011). Increased pain severity is related to increased healthcare utilization and work absences, depression and anxiety, catastrophizing (orientation toward negative thinking), poor coping strategies, decreased social activities, and decreased quality of life (Turk, 2002). Population based studies have consistently shown that chronic pain occurrence is inversely related to socio-economic status (Blyth, 2010).

Pain management is related to access to resources, which is linked to social support, SES, access to healthcare, and the patient/provider relationship (Link & Phelen, 2001). Minorities, people with low SES, and uninsured patients are more likely to delay care when sick, encounter interruptions in care, experience poorly coordinated care and avoidable hospitalizations, and exhibit worse health outcomes (Meghani et al., 2012; Sampselle, 2007). American Indians also may be hesitant to access services because of long-standing distrust in United States government services (James et al., 2013). Furthermore, compounding minority vulnerability, persons with chronic pain are often stigmatized or stereotyped as drug seekers by healthcare providers, which contributes to dissatisfaction with the adequacy of pain management (Meghani et al., 2012). For example, studies demonstrate that black patients are less likely than white patients to be prescribed opioids (Hausmann, Gao, Lee, & Kwoh, 2013). Such factors are linked to the inadequate, or as often stated in the literature, undertreatment of pain.

The competing public health concerns of the insufficient treatment of pain for minorities and the abuse of prescription drugs present a major policy dilemma in the US (Payne et al., 2010). Patients who experience pain may be suffering the burden of this dilemma (Inciardi, Surratt, Lugo & Cicero, 2007). Diversion generally occurs when a patient is prescribed an opioid and allocates the medication to family or friends who want to self-medicate for pain (Volkow & McLellan, 2016). Although, the number of diverted opioids that come from patients or physicians in the form of prescribed opioids is unknown and there is evidence that a number of opioids are diverted from somewhere else within the supply chain, including theft, prescription forging, and increasingly illegal internet pharmacies (Centers for Medicare & Medicaid Services, 2014; Payne et al., 2010). In the 2013 and 2014 National Survey on Drug Use and Health, 50.5% of people who misused prescription opioids got them from a friend or relative for free, and 22.1% got them from a doctor (Substance Abuse and Mental Health Services Administration (SAMHSA, 2016). Practices to discourage diversion include educating patients on the hazards of misusing and sharing their medication and the significance of safe storage and disposal. Some advocate the use of pain agreements for patients who use opioids long term to help curb the misuse of such prescriptions, including the American Academy of Pain Medicine, the American Pain Society and the Federation of State Medical Boards (Partnership for Drug Free Kids, 2011).

Pain Agreements

Pain contracts or pain agreements are documents signed by patients as an agreement to meet the providers’ expectations and the conditions under which the provider will prescribe and/or discontinue opioids (Payne et al., 2010). A discussion of what pain agreements are and a literature review of the evidence to support their use will be addressed. The Indian Health Service (IHS) provides healthcare for AIs across the United States and utilizes pain agreements for patients who are receiving chronic opioid therapy (COT).

The documents may be referred to as pain agreement, pain contract, pain management agreement, informed consent, and controlled substance contract. The favorable terminology used today is pain agreement because the document is not a contract that is legally binding. Such agreements usually include an informed consent element. No standardized form exists. Yet, pain agreements often contain (Harris, 2013):

- The number and frequency of opioid prescriptions, including the guidelines for refills;
- Clearly defined treatment goals;
- How outcomes will be measured;
- The risks and benefits of the particular narcotic;
- The patient’s responsibilities for the use of controlled substances, such as keeping the medication in a safe place, receiving the controlled substance from one provider, not using illicit drugs, and only using the medication for oneself;
- An identified pharmacy where the patient will fill the prescription;
- Permission to require the patient to submit random urine drug screenings (UDS);

- Consent to allow the provider to consult with others who have provided care to the patient; and
- The consequences of an agreement violation, including stopping the opioid.

As an informed consent document, pain agreements may empower the patient to make an autonomous decision when educated on the risks and benefits of taking narcotics (Savage, 2010). A provider will be more likely to consciously review the plan of care and reflect on each patient individually when providing informed consent. The documented plan of care provides a shared understanding of treatment goals and continuation or discontinuation of therapy. Pain agreements may help facilitate the alleviation of pain, identify substance abuse, and protect public health by lessening opioid diversion. Such benefits are hopeful, yet the empirical evidence supporting such statements is weak or non-existent (Sehgal, Manchikanti, & Smith, 2012).

Some clinicians and ethicists are concerned that the agreements are authoritarian, harm communication, and can be potentially eroding to the therapeutic relationship and shared decision making (Payne et al., 2010). The language and the content of the document can come across as antagonistic or threatening and works to protect the provider rather than optimizing care for the patient (Savage, 2010). A patient may believe they have to sign in order to receive care. If agreements are only applied to those who are considered high risk for abuse, then issues of judgement and discrimination may arise. Payne et al. (2010) ask relevant questions regarding the utility of pain agreements. When and for whom should pain agreements be used? Should they be used universally or for those who are “at-risk” for abuse/misuse? How do we define who is at risk? Pain agreements may be used to prevent diversion, yet the unintended consequence of such stringent rules about patient care may result in the under treatment of pain. As mentioned earlier, the Symptom Management Theory (SMT) recognizes interventions that are too challenging are related to an increased risk for non-compliance. A pain agreement's stipulations may be too rigid for patients to fulfill.

CDC Guidelines

The Centers for Disease Control and Prevention (CDC) released guidelines to help primary healthcare providers in the prescribing of opioids for chronic non-malignant pain in March 2016 (Dowell et al., 2016). The Surgeon General also began a campaign directed towards primary care providers, called "Turn the Tide," based on the guidelines (Murthy, 2016). To note, the CDC guidelines succinctly recognize that decision making regarding a patient care plan is individualized, based on the relationship and decisions made between a healthcare provider and their patient. Also, the report is quick to point out disparities in the treatment of pain for minorities in the introduction, but does not go further in addressing the issue.

A thorough literature review and expert guidance informed the recommendations. The quality of evidence was considered, but also the balance of harms and benefits, values and preferences of experts, and cost. The recommendations are based on developing evidence, including observational studies or randomized control trials (RCT) with notable limitations. The evidence found regarding the use of opioids for chronic pain treatment was of low quality, but this did not determine the strength of the CDC's recommendations. Since the evidence was found to be weak, contextual evidence was considered. This means that there is no substantial evidence to support the use of opioids, nor is there sufficient evidence not to use such medications for chronic pain. The literature review in Chapter II will delve into this aspect of opioids further. The CDC justified the recommendations, stating they had to look at the harms outweighing the benefits of prescribing opioids. Most controversial was the recommendation that opioids should not be prescribed longer than one week, stating three days should be sufficient and beyond seven days use should be rare. Some doctors and organizations feel the guidelines go too far in emphasizing opioids as addictive drugs. Dr. Richard Payne, a nationally recognized pain specialist, stated:

> ‘*There are populations of people who have chronic pain caused by conditions that are not terminal who use medications appropriately, don't divert them, don't overdose on them and actually improve their function and are able to live better. We have a moral responsibility to address pain and suffering. And we do have a responsibility not to do harm, but you can do harm in either direction’* (Siegel, 2015).

Two of the experts consulted during the development of the guidelines, Starrels and Cunningham (2016), felt the need to respond to the controversy surrounding the release of the report. They recognized that there is a division between various experts about how serious the opioid overdose problem is and ways to address it. They also acknowledged that although the CDC had to rely on expert opinion, that there was significant incongruity between experts. They pointed to the example of how experts disagreed on the proper dose or number of pills to prescribe, or whether and how often urine drug testing should be implemented.

The guidelines are meant to be recommendations and not prescriptive (Dowell et al., 2016). Yet, primary care providers and clinics may see the guidelines as a backup to not have to deal with the complexities of managing chronic pain with opioids. Since the release of the recommendations, I have seen in my own practice providers writing in patients’ electronic health records that they informed the patient that it is our facility policy to not prescribe long term opioids, when in fact this is not the case, or that they will not prescribe opioids period. A national committee is reviewing the CDC report and has not issued any organization-wide policies. As mentioned above, the provider must decide on how they will treat pain with an individualized plan of care and hopefully engage in shared decision making with their patients.

The debate surrounding the CDC guidelines underscores how different people view what is to be done about the overdose epidemic and the issue of inadequate treatment of pain in regards to minorities. Strategies to reduce overdoses are primarily not based on evidence. The public health community, decision makers, and healthcare providers are looking for solutions to a problem with consequences that can unintentionally lead to continuing suffering for persons living with chronic pain and do nothing to address the issue of pain disparities. Critics of the guidelines also point out that people living with chronic pain were not given a voice and were not asked what the medications mean for them (Siegel, 2015).

Northern New Mexico Pueblo Communities

American Indians (AIs) are a relatively small minority in the US and are often left out of research studies. The literature on pain disparities focuses on other minorities, mainly African Americans and Hispanics (Jiminez et al., 2011). The evidence elucidates various factors that predispose minorities to a higher burden of pain related to risk factors such as lower SES, poor health habits, and limited access to healthcare (Campbell & Edwards, 2012; Jiminez et al., 2011). A discussion follows regarding the historical and contemporary background of Northern NM AIs that point to similar risk factors for this minority population.

Native Americans in NM experienced colonization by Spain, Mexico, and the US. They endured forced assimilation, genocide, suppression of religion, culture, and language. Historic trauma theory links the experience of colonization to a range of problems for generations of indigenous people (Braun, Browne, Ka’opua, Kim, & Mokuau, 2014). The social, economic, and spiritual effects of trauma are passed on to younger generations by traumatized parents, creating an established norm for trauma in AI communities (Prussing, 2014; Willmon-Haque & BigFoot, 2008). Historical trauma contributes to increased family violence, loss of cultural and spiritual values, poverty, lack of education, and substance abuse (Braun et al., 2014). Historic trauma is not experienced by all, yet the theory helps support why health disparities exist in numerous areas of health for AIs (Goodkind, Gorman, Hess, Parker, & Hough, 2015).

Pueblo Historical Background

Sando (1998) wrote a comprehensive history of Pueblo Native Americans and illustrates that an important part of Pueblo history are the policies and procedures implemented by the Spanish to encourage colonialization in the late 1500s through the bulk of the 1600s. Grants of Pueblo land were made to Spanish soldiers and other colonists who participated in the Spanish conquest. Land was also taken for cattle grazing, resulting in overgrazing, soil erosion, and drought. The Spanish continually eroded the Pueblo peoples' dignity with actions, such as forbidding ceremonial dances, seizing religious objects, and imposing cruelty and harassment. In the 1670s, three people were hanged publicly after being accused of sorcery. The Pueblos revolted in 1680 and temporarily dispelled the Spanish from their lands for 12 years.

In 1821 Mexico declared independence from Spain and took over the Southwest. Claims to Pueblo lands persisted and continued well after they became a part of the United States. The Spanish land grants assigned to the Pueblos were confirmed as Pueblo lands by the US in 1856 and were used as a means to set the boundaries of the various Pueblos. The Pueblos were not lawfully treated as was other "Indian" tribes in the US until 1913, when they were finally recognized as tribes under federal trusteeship. To this day, AIs cannot sell their land without the consent of the Secretary of the Interior and the fight for land and water rights continues to be a struggle for survival of the Pueblo people.

The Pueblo communities have also endured detrimental United States government policies, such as assimilation and termination. The Allotment Act, otherwise known as the Dawes Severalty Act of 1887, was used as a facade to conform AIs into the non-Indian culture and severely reduced the amount of land held by Natives. The Indian Reorganization Act of 1934 (also known as the Wheeler-Howard Act) stopped the loss of land and encouraged the reorganization of tribal government to follow the format of the United States government. The 1950s brought some of the most harmful policies to AIs at the federal level, namely termination and relocation. The relocation of youth to boarding schools resulted in collective trauma, disrupting families and communities, patterns of emotional response, the loss of indigenous knowledge, languages, traditions and the devaluation of identity (King, Smith, & Gracey, 2009).

Today about 10% of the population in NM, compared to about 2% of the US population, is AI (US Census Bureau, 2016). New Mexico has 22 recognized federal tribes (19 of which are referred to as Pueblos). Each Pueblo has its own traditions, culture, and language. The people of Taos, Picuris, Sandia, and Isleta speak dialects of the Tiwa language; while San Juan, Santa Clara, San Ildefonso, Pojoaque, Nambe and Tesuque peoples speak dialects of the Tewa language; the Zuni speak a Zunian language; Jemez is the only pueblo in which the Towa language is now used; and a Keres dialect is spoken in the other pueblos of New Mexico, which include Cochiti, Santo Domingo, San Felipe, Santa Ana, Zia, Laguna and Acoma (Dutton, 1983).

Historic Trauma and Health Disparities

The Pueblo people suffer historic injustices related to their traumatic colonization and continued experiences with oppression and discrimination. With the loss of land and traditional economies comes decreasing access to indigenous livelihoods (Sotero, 2006). Throughout the generations, feelings of inferiority and shame about their heritage are passed down and families have diminishing access to elders who can uphold their traditional language and culture (Sotero, 2006). Health disparities stem from these historic struggles, racial discrimination, geographic isolation, acculturation stress, years of hopelessness and current conditions, including access to employment, education, decent housing and healthcare, suppression of cultural values and languages, and loss of land, water, and mineral rights (Duran, Duran, Heart & Horse-Davis, 1998; IOM, 2011; Kangovi et al., 2014; King et al., 2009; Sanders, Shaw, Guez, Baur & Rudd, 2009).

The tribes across the US encompass numerous cultural differences, yet a common core of traditional values exists and generally differs from mainstream American values (Garrett et al., 2009). American Indian values include the importance of community, sharing, cooperation, being, harmony with nature, living in the present, respect for elders, and explanations of the world based on nature (Garrett et al., 2009). American mainstream values reflect self-promotion, saving, domination, individualism, the nuclear family, mastery over nature, living for the future, and reverence of youth (Garrett et al., 2009). Cultural value differences and the process of acculturation may contribute to feelings of boredom, anxiety, depression, isolation, stress and self-doubt (Garrett et al., 2009). Thus, acculturative stress may contribute to a decline in the health status of individuals (Duran et al., 1998).

American Indians in NM bear a disparate share of poor health status and disease (Shah et al., 2014). Of the 21 indicators in the 2012 Racial and Ethnic Health Disparities Report Card, AIs in NM have the highest rates on 9 indicators (NMDH, 2012). The largest disparity exists for alcohol related deaths. Other indicators for which they have the largest disparities are homicide, deaths due to diabetes, motor vehicle deaths, pneumonia and influenza deaths, adult obesity, youth obesity, late or no prenatal care, and youth suicide. The indicator for which AIs have the lowest or best rate is drug overdose deaths, compared to whites and other minorities in NM. This finding is puzzling as other sources show that being AI puts one at higher risk for prescription drug overdose (Haegerich et al., 2014).

Poverty and Rurality

The causes of racial/ethnic health disparities are multi-factorial and are mainly related to minority communities tending to have lower SES, lower levels of education, to work in jobs with higher rates of occupational injuries, and live in areas disproportionately affected by environmental exposures (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). Socioeconomic status (SES) is commonly measured by education, poverty, and employment. Poverty limits education and employment opportunities, which in turn leads to weaker social integration, depressive symptoms and a fatalistic outlook (Sanders et al., 2009). In NM, 35% of AIs live below the poverty level (US Census Bureau, 2016). New Mexico Native Americans have an 18% unemployment rate (NM Department of Workforce Solutions, 2015). Nationally, 17% of AI ages 25 and older have a bachelor’s degree, as compared to 33% of whites (Office of Minority Health, 2016).

Living in a rural community in the US is also associated with healthcare disparities (Lutfiyya et al., 2012). In New Mexico, 23% of AIs live in a rural area (US Census Bureau, 2010). Of the Native Americans in NM who are employed and live on or near a reservation, 22% earn below the federal poverty guideline (NMDH, 2012). Native Americans that live on or near reservations experience isolated geography, a lack of resources and economic opportunities, and disinvestment (Housing Assistance Council, 2012). In NM, rural AIs living below the poverty line are two times higher than whites (NMDH, 2012).

People living in rural areas who are seriously ill are vulnerable to a decline in quality of life due to poorly controlled symptoms, psychological and social distress, caregiver burden and financial stress (Coyle, 2015). Rural residents are more likely to not have health insurance, have limited access to healthcare and culturally competent providers, and defer care due to costs (Artnak, McGraw, & Stanley, 2011). They may distinguish between health impairment causing inability to function versus ill health that can be tolerated (Buehler, Malone, & Majerus-Wegerhoff, 2006; Long, 1993). Pain may be tolerated as long as it does not interfere with work. Such behaviors contribute to the risk of premature death, long-term illnesses, and disability (Long, 1993). Additionally, health issues identified in rural populations are associated with occupational risks and by products of the local economy. Occupations in the different Pueblo communities in NM vary, but many AIs work in high risk for occupational fatality and injury industries, including mining, agriculture/forestry, and construction (NMDH, 2012). These high risk for injury professions correlate with higher rates of chronic pain for this population.

Rural Pain Management

Rural residency is linked to higher prevalence of chronic pain and other psychiatric and medical comorbidities, namely depression (Kapoor, Thorn, & Thorn, 2014). Access to chronic pain management resources in rural areas vary widely and rural areas potentially lack the resources that are available to urban areas, such as pain care specialists and interdisciplinary teams (Bakitas, Clifford, Dionne-Odom, & Kvale, 2015; Day & Thorne, 2010; Prunuske et al., 2014). Multi-modal approaches to pain management are often recommended, such as physical therapy, behavioral health interventions, and acupuncture (Prunuske et al., 2014). New Mexico is largely a rural state and 32 of the 33 counties are designated as Mental Health Professional Shortage Areas (Beals et al., 2005). Access to behavioral health is complicated in New Mexico, especially for those living in rural areas. Compounding this issue is many behavioral healthcare providers do not accept public insurance (i.e., Medicaid) or Indian Health Service (IHS) as payment. Those that do accept all insurances are often not taking additional patients, as experienced by this nurse researcher.

Rural residents often have to travel outside their community to receive such care, with logistical and financial considerations being common barriers to access (Pesut, Robinson, Bottorff, Fyles, & Broughton, 2010; Robinson, Pesut & Bottorff, 2010). They may have weather condition considerations and a concern that the poor road conditions may exacerbate their symptoms (Pesut et al., 2010; Robinson et al., 2010). At times, rural residents may not have any choice but to take opioid medications to alleviate their pain and optimize functioning. For AI,s rurality and poverty is compounded with issues regarding eligibility and payment issues that may be available to them through IHS. A discussion follows below explaining the complexities of such challenges.

Primary care providers in rural areas often are the main providers of pain management and many feel inadequately trained to do so. Medical school programs do not include a devoted pain management curriculum (Fishman et al., 2013). Quality continuing education and training for primary care healthcare providers in rural areas is limited. Providers may cover a large geographic area and find it difficult to get coverage while they are receiving education (Katzman et al., 2014). The University of New Mexico has implemented a telehealth program called Project ECHO Pain to help mitigate such issues and offer pain specialist consultation and continuing education to rural providers (Katzman et al., 2014).

Indian Health Service (IHS)

American Indians/Alaskan Natives (AI/AN) have a legal right to healthcare services, which are based on treaties, court decisions, Acts of Congress, Executive Orders, and other legal bases (Grijalva, 2011). The Indian Health Service (IHS) is the federal agency responsible for providing healthcare to AI/ANs and is perpetually underfunded, which limits access to services, including pain care. The IHS is funded by an annual congressional appropriation and is at a considerably lower per capita rate than other federally funded health care systems and is the source of healthcare for many AI/ANs (Warne, Kaur, & Perdue, 2012). A federal prisoner receives twice the amount of funding that the IHS receives per patient per year (US Commission on Civil Rights, 2004). Preventative care is considered of tertiary priority and is available depending on fluctuating budget priorities (Daley et al., 2012). In 2010, less than 10% of the IHS budget was apportioned for mental health programs, including substance abuse treatment, resulting mental health programs available to AI people being severely underfunded (Gone, 2004; Gone & Trimble, 2012; Lucero, 2011).

When an IHS facility does not have services available, the healthcare provider makes a referral, which is then processed through the IHS Purchased Referred Care (PRC) department. The patient must qualify for PRC coverage if they do not have their own insurance to receive funding for services. To be eligible, one must be an Indian from a federally recognized tribe, residing on or near an Indian reservation within a contract health service delivery area (CHSDA). For example, an AI from the Navajo area, but living in Albuquerque can receive services at any IHS facility, but will not qualify for PRC coverage for referrals outside of the IHS facility because they do not live in their tribe's CHSDA. In such cases where there is an emergent need, tribal members may decide to go back to their home in order to receive the service there. The PRC department, especially in the rural clinics, is short staffed and underfunded. These additional factors may further delay care.

The Affordable Care Act (ACA) has allowed for the expansion of Medicaid to childless adults in New Mexico. States are prevented from imposing Medicaid premiums or any other Medicaid cost sharing on Indian enrollees who have used the Indian Health Services system. Indian Health Service facilities are able to bill enrollee's insurance, which in turn expands their budgets and coverage of services through PRC. Funding of referrals is based on a priority rating system, where the priorities fluctuate according to the availability of funds. The ACA also reauthorized the Indian Health Care Improvement Act (IHCIA), which addresses health disparities in Native communities (Grijalva, 2011).

Background and Gaps in Knowledge Summary

Various factors come together to contribute to chronic pain disparities, including the environmental context, race and ethnic discrimination, gender, rural residency, SES and the healthcare system. The Symptom Management Theory (SMT) allows one to take into account these various factors while examining chronic pain experiences, management strategies and outcomes. The inadequate treatment of chronic pain is an important and prevalent concern for AIs. Chronic pain management strategies vary widely and should be multi-modal. Public health solutions for the increased morbidity and mortality related to prescription drug abuse need to be fair and take into consideration the outcomes of recommended solutions. What is known about the chronic pain experience and AIs, pain management strategies and pain outcomes will be discussed in the chapter II literature review.

Theoretical Position

Research reports must acknowledge a researcher's theoretical positioning (meaning their motives, presuppositions, and personal history that shapes a particular inquiry) in order to gain credibility (Caelli, Ray, & Mill, 2003). This study was based on the premises that physical and social entities exist irrespective of human knowledge or understanding; structures exercise power regardless of whether this is known or recognized by individuals, while also recognizing human meaning and experience's influence on behavior, from a critical realist standpoint (Clark, Lissel, & Davis, 2008). The use of pain agreements may contribute to racial discrimination regardless of whether this is known to the patient, organization or individuals who utilize them in their practice of pain management. To explain why disparities in the treatment of pain exist, researchers need to go beyond the surface of observable factors to explore what is happening underneath (Clark et al., 2008). Critical realism recognizes the confluence of individual factors, such as demographic, sociological, and physiological variables, and environmental factors, such as social and cultural context, on outcomes/events (Clark et al., 2008). The treatment of pain presupposes high levels of personal agency to the neglect of structural determinants. For example, a healthcare provider recommends physical therapy for their patient. The patient may have difficulties attending due to structural constraints, such as not being able to take time off from work or transportation issues. This research describes the AI pain experience, management strategies and outcomes of chronic pain, while considering the environmental context within which the pain/pain treatment occurs.

CHAPTER II: LITERATURE REVIEW

Literature Review Method

A search was conducted using PUBMED, CINAHL, the Cochrane Library, and Google Scholar; although, only PUBMED and Goggle yielded results relevant to this literature review. “Chronic pain” AND “management” or “treatment” or “opioids” resulted in eight systematic reviews and treatment guidelines. The literature on chronic pain management is vast and therefore, the analysis focused on reviews and treatment guidelines for chronic pain in general rather than individual studies or specific pain conditions. Furthermore, opioids are commonly prescribed to manage pain and pain agreements are implemented with chronic opioid therapy (COT), so the review of evidence focused mainly on the use of opioids. Other pharmacological and non-pharmacological interventions were briefly addressed.

“Chronic pain contract” or “pain agreement” or “pain contract” or “opioid contract/agreement” yielded 28 results in PubMed, with 24 of these reviewed here. The MESH term “American Indian” AND various combinations of urine drug screen, pain agreements, pain contracts, pain treatment plans/programs, testing, and opioid screening yielded no results. The MESH term “American Indian” AND opioids yielded eight results, yet none were relevant to the topic of interest. The MESH term “American Indian” AND chronic pain yielded 22 results. Only nine of these articles were pertinent. Google Scholar produced abundant articles related to “chronic pain” AND “pain agreements,” “pain contracts” “pain treatment agreements” “opioid screening” “urine drug screen,” yet these articles were not relevant to the aims of this review.

Articles were limited to those published since 2005, printed in English, and concerning human subjects only. Articles were excluded if they focused on pain related to cancer, acute pain

(pain lasting less than three months), and the pediatric population. Little was found regarding the AI pain experience, so studies on cancer patients were included for this population.

Results

Chronic Pain Management

The American Academy of Pain Medicine (AAPM) (2013) reports that no nationally accepted consensus for the treatment of chronic pain (not due to cancer) currently exists. Overall, pain treatment effectiveness remains inconsistent and fairly poor (Turk, Wilson, & Cahana, 2011). Treatment strategies and options vary widely and may include interventional techniques, cognitive and behavioral methods, rehabilitation approaches, and the use of medications, including opioids (AAPM, 2013).

A brief summary of the Turk et al. (2011) review findings relevant to this study are presented here. The empirical evidence regarding the use of opioids for chronic pain is inconsistent and weak. Non-steroidal anti-inflammatory drugs (NSAIDs) are found to be effective for osteoarthritis, rheumatoid arthritis and back pain, but not for fibromyalgia and inconclusive for neuropathic pain. Antidepressants are found to be effective for their analgesic effect, especially for neuropathic pain. Anticonvulsants generally are recommended for neuropathic pain, fibromyalgia and low back pain due to radiculopathy. Muscle relaxants can be used for short-term relief as an adjuvant therapy. Psychological treatment, such as cognitive-behavioral therapy (CBT), results in modest benefits, but further research is needed on long-term efficacy. Massage is supported for use in treating low back and shoulder pain and more research is needed in regards to fibromyalgia and neck pain. Acupuncture evidence is positive for use in the treatment of low back pain, fibromyalgia and neck pain.

A meta-analysis of 70 RCTs found that the use of opioids results in small improvements in pain severity, reduction in pain and functional improvement compared with placebo (Chou, Ballantyne, Fanciullo, Fine, & Miaskowski, 2009; Turk et al., 2011). Only three of the trials followed patients for more than four months.

Other reviews found conflicting evidence and concluded that the use of opioids for chronic pain is controversial because of inadequate evidence on their efficacy for managing chronic pain (Chou et al., 2015; Deyo et al., 2015). Clinical trials on opioids are conducted in a short time frame and there is an insufficient assessment of outcomes and adverse drug events (Arnold, Han, & Seltzer, 2006; Deyo et al., 2015; Noble et al., 2010). Chou et al. (2015) concluded that no studies regarding opioid therapy assessed continuing outcomes (>1 year) related to pain, function, or quality of life. No RCTs of opioids for back pain have lasted for more than four months, although many patients receive treatment for longer (Deyo et al., 2015).

A Cochrane review of 26 studies with a total of 4893 participants found that opioid administration for chronic pain resulted in clinically significant reductions in pain, with the amount of pain relief varying among studies, and signs of opioid addiction were reported in a miniscule number (0.27%) of participants in the studies which reported that outcome (Noble et al., 2010). The review concluded that the evidence is weak due to the lack of randomized control trials (only one) and the rate of attrition for participants was high (Noble et al., 2010).

A recent meta-analysis concluded that there is no evidence to support the sole or preferential use of opioids and the authors recommend an interdisciplinary multimodal combination of approaches to chronic pain management (Reinecke et al., 2015). Although, they recognize that more research is needed to support such statements.

Several organizations and agencies developed guidelines for the prescribing of opioids. Each guideline varies in their specific recommendations concerning issues such as daily dosing thresholds and audience (Dowell et al., 2016). The AAPM advocates the use of COT for those with chronic pain that is not adequately managed with more conservative or interventional methods. Nuckols et al. (2014) appraised 10 guidelines and found that upper dosing thresholds were the only recommendations supported by RCT evidence, although each guideline varied on the specific dosing. All other reviewed recommendations were backed by low quality observational studies. Cheung et al. (2014) conducted a comprehensive review of seven treatment guidelines for chronic non-cancer pain. They all recognized the need for an individualized plan of care, a comprehensive health assessment, an evaluation of risk for abuse/misuse and a trial of therapy to determine the course of treatment. They found that there is a growing body of evidence to support responsible opioid use in chronic pain based on the reviewed guidelines.

Summary of CDC Guidelines

The CDC guidelines are the most recently released recommendations and are briefly outlined here (Dowell et al., 2016). The CDC encourages primary care providers to consider numerous factors before initiating long-term opioid therapy. The provider and patient should have realistic patient-centered goals for the management of pain and maximum functioning. Other therapies should be tried, including non-opioid medications, physical treatments, behavioral treatment, and various procedures. The provider can discuss the benefits and risks of opioid medications with the patient. Some patients may be at a higher risk of harm or misuse. The known risk factors to evaluate for are illegal drug use, prescription drug use for nonmedical reasons, history of substance use disorder or overdose, mental health conditions, sleep-disordered breathing, and concurrent benzodiazepine use. The provider can reduce such risk by discussing the risk factors with the patient, checking the prescription drug monitoring program (PDMP) data, and checking a urine drug screen (UDS). Using the PDMP allows providers to check for opioids or benzodiazepines from other sources and calculate the total amount of opioids prescribed per day in morphine milligram equivalents/day or MME/day. Higher dosages of opioids are associated with greater risk of overdose and death. Dosages at or above 50 MME/day increases the risks for prescription drug overdose. The CDC recommends that the PDMP be checked at least once every three months and perhaps prior to every opioid prescription. The UDS allows one to check for the presence of the prescribed medicines and for other drug abuse. The provider should be clear upfront regarding criteria for stopping or continuing opioids. Providers that dismiss patients based on PDMP or UDS information miss out on an opportunity to provider potentially life-saving information and interventions.

The provider should know the baseline pain and functioning of their patient. A 30% improvement in pain and function is considered clinically significant. Various validated instruments can be used to measure pain and function. Reassessment should occur within 1 – 4 weeks of initiating opioid therapy. Short-acting opioids should be started on the lowest dosage noted on the product labeling and only be prescribed for the length of time needed until the reassessment appointment. Immediate release opioids are recommended over extended release/long acting medications when initiating opioids. If a patient does not experience a 30% improvement in pain and function, the CDC recommends considering a reduced dose or tapering and discontinuing opioids. Opioids may be continued as a deliberate decision by provider and patient when benefits outweigh harms.

When a patient is on a high dose opioid medication, the provider can refer to a pain specialist. Yet, the area where this researcher works has a pain specialty practice that does not manage opioid medications; rather they perform higher cost procedures, such as epidural injections.

Summary of CDC Guidelines

The long-term outcomes of chronic opioid therapy are not known. The lack of reliable evidence should not lead providers to conclude that they should not prescribe COT. Pain is a subjective experience, where the patient should be able to share in the decision-making process of whether opioids are effective for them. Guidelines for the treatment of chronic pain do not exclude the use of opioids, but guide prescribers to try conservative measures before initiating opioid therapy. High quality evidence needs to be generated regarding the benefits and risks associated with long-term opioid use.

Pain Agreements

Little is known about how pain agreements affect pain management experience and outcomes for patients and there is no research on the Native American experience with pain agreements to this researcher's knowledge. The empirical evidence regarding the effectiveness of pain agreements and urine drug screening in reducing drug abuse and diversion is weak; although such strategies are endorsed by various pain and addiction experts, professional societies, and regulatory agencies (Arnold et al., 2006; Chou et al., 2009; Chou et al., 2015; Haegerich et al., 2014; Krebs et al., 2014; Nuckols et al., 2014; Sehgal et al., 2012; Starrels et al., 2014; Starrels et al., 2010). The majority of the existing literature focuses on how pain agreements are written (i.e., is it an informed consent document?), risk assessment (i.e., how the provider can determine who should be on a pain agreement), and whether opioids are effective in treating chronic pain (in which the evidence is controversial and unclear). Evidence supporting the use of risk assessment tools before initiating narcotic therapy for predicting opioid abuse, misuse, overdose or addiction is weak or non-existent (Chou et al., 2015; Dowell et al., 2016). A narrative review reveals that pain agreements have not been proven to improve treatment adherence or patient care, or protect the rights of patients or physicians (Sehgal et al., 2012). Haegerich et al. (2014) note that state policy and systems level interventions are difficult to evaluate since randomization is seldom viable, suitable comparison groups are difficult to recognize, pre-intervention data can be challenging to obtain and changes in the environment that occur at the same time of implementation are hard to measure.

Clinical guidelines recommend that opioid therapy be closely monitored for treatment effectiveness and adherence to a plan of care (Hausmann, Gao, Lee, & Kwoh, 2013). Monitoring practices include the use of opioid agreements, urine drug screenings, requiring follow-up visits and referrals to pain clinics. Two studies demonstrated that these guidelines were differentially applied to minorities (Hausmann et al., 2013; Becker et al., 2011). Such behaviors could lead to feelings of discrimination and mistrust, which could negatively affect patient-provider communication and pain management effectiveness.

Few articles examined the use of pain agreements and the perspectives of the patient and/or the provider (Krebs et al., 2014; Starrels et al., 2014). One qualitative study discussed patients’ positive perception of the use of pain agreements, stating a general sense of feeling protected by them (Krebs et al., 2014). For example, a participant was a drug user who had a positive UDS and this resulted in a more open dialogue with their provider, leading to the patient seeking rehabilitative treatment.

A systematic review found few studies have been conducted on the use of opioid treatment agreements and UDS to reduce opioid misuse (Starrels et al., 2010). The studies that were reviewed were observational studies with various threats to validity, (Burchman & Pagel, 1995; Compton, Wu, Schieffer, Pham, & Naliboff, 2008; Chelminski et al., 2005; Goldberg, Simel, & Oddone, 2005; Hariharan, Lamb, & Neuner, 2007; Ives et al., 2006; Katz et al., 2003; Manchikanti et al., 2006a, Manchikanti et al., 2006b; Wiedemer, Harden, Arndt, & Gallagher, 2007). The studies were not conducted in a primary care setting where most chronic pain is managed. A wide variation in opioid misuse after implementation of treatment agreements and differences in the measures of opioid misuse limit the conclusions that could be drawn from the weak evidence reviewed (Starrels et al., 2010).

One study examined agreement between patient and provider report of the patient signing a pain treatment agreement and found less than 20% of patients who had signed a pain agreement consistently reported having one over the course of a year (Penko, Mattson, Miaskowski, & Kushel, 2012). One-third of patients reported having a pain agreement when their PCP indicated that they had not signed one (Penko et al., 2012).

Summary of Pain Agreements

Opioid medications involve risks and benefits and their use should include making patients aware of these factors. Pain agreements may offer a tool to achieve informed consent. The document should be written at an appropriate literacy level for patients to gain education and understanding. Systematic guidelines for developing and using pain agreements do not exist and resulting practice variation exists (Payne et al., 2010). Individuals, groups, and organizations who decide to use such agreements need to consider serious ethical questions about why they are using them, for whom, and when. Research is also needed to examine clinical outcomes of agreements, such as pain treatment disparities and opioid dependence, overdose, or death (Starrels et al., 2010).

American Indians Pain Experience

Disparities research receives a large amount of attention (primarily focused on African American and Hispanic minorities, not Native Americans), but such research has not contributed greatly to reducing disparities or a clearer understanding of barriers to symptom management (Jiminez et al., 2011). A complete lack of literature exists on the outcomes and consequences of pain treatment agreements for AIs. Questions remain regarding whether pain agreements may be a barrier to effective chronic pain management for AI minorities. Healthcare providers hold a position of authority when it comes to having their patients sign a pain agreement. The healthcare provider holds a great deal of power as the ultimate decision maker in the what, where, and when of patients receiving COT. The provider decides whom the ‘drug seekers’ are and who should and should not receive prescribed opioids.

Much of the research on Native Americans and pain relates to cancer populations. Treating cancer pain is more straightforward in the sense that one knows what is causing the pain and guidelines support the use of opioids for cancer pain. Guidelines for treating pain are differentiated between malignant and non-malignant pain. The problem of managing pain becomes complex when the underlying cause of pain is less clear or the scientific evidence for treating chronic pain for various conditions is controversial.

A critical review found studies focusing on the epidemiology of pain, treatment of pain and healthcare access/utilization in Native American population were rare (Jimenez et al., 2011). Literature is scarce to the point where many of the studies reviewed were >10 years old. A higher prevalence of pain symptoms and painful conditions were found in epidemiological studies of AI/ANs. The reviewed studies demonstrated that Native Americans hold culturally grounded health beliefs and values and forms and patterns of medical communication related to pain are different from their non-Native providers and may contribute to miscommunication (Chae & Walters, 2009; Greensky et al., 2014; Haozous & Knobf, 2013; Haozous, Knobf, & Brant, 2011).

Chae and Walters (2009) conducted a cross-sectional study of 447 AI/ANs to examine the association between racial discrimination and actualization and self-rated health and physical pain and impairment. Actualization is defined as, “the degree of positive integration between self-identity and racial group identity” (Chae & Walters, 2009, p. S144). More than half of the participants (56.8%) reported physical pain and impairment. They found a significant correlation between discrimination and physical pain and disability and that high levels of actualization were associated with significantly lower reports of physical pain and impairment.

Gore et al. (2005) studied pain severity, pain related interference with function, sleep impairment, anxiety, depression, and painful diabetic peripheral neuropathy (DPN). A small proportion of their study population was Native American (0.4%). The study examined symptom experience as evidenced by how the participants perceived, evaluated, and responded to their symptoms. The findings evidenced greater sleep disturbance, anxiety, depressive symptoms, and lower quality of life for those experiencing severe and moderate pain.

Haozous and Knobf (2013) conducted a critical realist ethnography with 13 AI patients and 11 healthcare providers, caregivers, and community members to examine pain experience in AIs. The interviews revealed several dimensions of pain, including physical, emotional, and spiritual pain. Barriers to pain treatment were found due to participants not wanting to describe their pain, numerical scales for pain were not appropriate, especially for elders, and the stigma associated with the use of opioids.

Haozous et al. (2011) used a qualitative descriptive study to explore the experience of cancer pain in Native Americans in Southeastern Montana. The sample was 10 participants, aged 31-75 years. The Brief Pain Inventory-Short Form (BPI-SF) and semi-structured interviews were used as the main outcome measures. The Native Americans in this region were known for their stoic response to pain and the study found that all participants denied pain symptoms at first, but then later described their pain experiences. The participants described their evaluation of their pain, such as the changing intensity of their pain as part of their general pain description. The participants used stories and nature analogies to describe their pain. The discussion concluded with identified differences with this population as compared to non-natives, including social isolation (and geographic), dealing with pain stoically, protection of privacy, reliance on spirituality for pain management, and the distrust of outsiders.

Haozous, Doorenbos, and Stoner (2014) utilized focus groups (n=25) to explore the cultural acceptability of cognitive behavioral strategies for AI/ANs. Cognitive behavioral pain management (CBPM) techniques include diaphragmatic breathing, muscle relaxation, distraction, meditation and guided imagery. They note that access to such techniques for patients and training for providers is limited, especially for rural residents. The focus groups also brought attention to feeling ignored and undertreated for their pain. The use of traditional activities was linked to pain management and prayer. Results supported CBPM strategies as culturally appropriate and at times were related to existing traditional pain management.

The following section will discuss studies focused on traditional AI interventions for chronic pain management with the use of the terms traditional medicine, traditional services, and traditional health practices. The World Health Organization (WHO) defines traditional medicine as:

> ‘*The sum total of the knowledge, skills, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness*’ (WHO, 2016).

Traditional health practices (THPs) comprise a variety of interrelated health behaviors, including individual and group ceremonies, customs with herbal remedies, and use of traditional healers (Greensky et al., 2014). Specific practices differ extensively between AI communities.

Shelley, Sussman, Williams, Segal, and Crabtree (2009) conducted a study in partnership with the Research Involved in Outpatient Settings Network (RIOS Net) in New Mexico with Native American and Hispanic communities. The study found that the participants were willing to reveal their use of *traditional medicine* (TM) to their primary care provider when the provider had an accepting, nonjudgmental response. Many participants spoke about experiences where they were judged or providers responded negatively to the use of TM. Interestingly, participants stated that they would not bring up TM use unless asked about it, yet providers that were interviewed expressed concern about bringing up the topic due to ignorance or disrespect for the practice as not evidence based. The study did not discuss what TM encompasses, only whether the participants revealed their use of it or not.

Greensky et al. (2014) qualitatively explored the traditional health practices (THP) of AIs with chronic pain. The participants were 10 women and 11 men from the Minnesota area. A semi-structured interview was conducted to discuss the chronic pain experience and to identify potential facilitators and barriers to developing an interdisciplinary pain treatment program for this population. The majority of participants (66%) used THP for pain alleviation.

A Detroit area survey of 389 AI/AN participants found that 48% used traditional services, with the majority (63%) of those users being women (Moghaddam, Momper, & Fong, 2013). The study utilized a convenience sample and is not generalizable. These studies point to the likelihood that Pueblo Indians use TM in conjunction with allopathic medicine for the management of their pain, although no such conclusion can be made at this time.

Summary of American Indians Pain Experience

These few studies are non-generalizable, with the samples being small in size and convenience, applying to specific geographic areas. The scarce literature on the chronic pain experience of Native Americans leads one to believe that this population may “embrace culturally grounded health beliefs and values, along with distinctive models of health and illness that distinguish them” from non-minorities (Jiminez et al., 2011, p. 520). Yet, it is important to recognize that cultural understanding or competency does not take the place of recognizing power negotiations that occur in the clinical setting (Rouse, 2009). More research is needed to describe the pain experience of AI/ANs and to explore the power dynamics of healthcare providers and their patients, in order to identify wider societal influences on the problem of pain treatment disparities, while aiming to promote social justice by exposing and questioning the power inequities based on race in our society (Braun et al., 2014).

CHAPTER III: METHODOLOGY

Chapter III discusses the research design selected for this study, based on the research purpose and aims. A *qualitative descriptive* (QD) approach was used to develop a rich description of experiences with chronic pain for American Indians (AIs). Study methods, sample, data collection, and analysis are reviewed here. A discussion of trustworthiness in qualitative studies and human subject protections is also presented.

Research Design

The purpose of this research was to describe Northern New Mexico (NNM) Native Americans' experiences with chronic pain, intervention strategies to manage pain, and chronic pain outcomes. The study addressed the following aims:

Aim 1: Describe NNM AIs Experiences with Pain

a) Describing participants' pain experiences.
b) Describing environmental factors that influence the participants' experiences with pain.
c) Comparing/contrasting participants' similarities and differences of experiences with pain based on demographic characteristics.

Aim 2: Describe NNM AIs Pain Management Strategies

a) Describing participants' biomedical, professional, and self-care strategies to managing their pain.
b) Describing the environmental factors that influence the participants' pain management strategies.
c) Comparing/contrasting participants' similarities and differences in pain management strategies based on demographic characteristics.

Aim 3: Describe the Outcomes of Pain Management Strategies and the Pain Experience

a) Describing the impact of pain and pain management strategies on the participants' functional status, healthcare utilization, costs, and quality of life.

b) Comparing/contrasting participants' similarities and differences in pain outcomes based on demographic characteristics.

Qualitative Research

Qualitative research plays a major role in healthcare research. The method allows examination of human values, culture, and relationships, and clinical questions not easily answered with quantitative methods (Morse & Field, 1995). Research methods are tools for facilitating inquiry. Choosing between qualitative methods depends on what the research questions are, what the anticipated outcomes of the research will be, the limitations of the setting, the participants and the resources available to the researcher (Morse & Field, 1995).

Qualitative Description

The method of choice for this research was a qualitative descriptive (QD) design. The description in QD studies entails the presentation of the facts of the case in everyday language, so that researchers and participants would agree on an accurate accounting of an event and meaning ascribed to an event (Sandelowski, 2000). Such an approach was appropriate for this researcher's interests as the goal was to obtain straightforward answers to questions concerning the chronic pain experience in the context of pain management disparities. The method gave a voice to marginalized peoples and was congruent with my critical realism perspective.

Sampling Strategy

Qualitative research sampling techniques are closely tied to the purpose and objectives of a research study, method and the accessible target population (Campesino & Koithan, 2004). Flexible sampling strategies were needed for this population that is small and potentially difficult to reach. A combination of purposive and convenience sampling met this need. A sample of 14 AIs was obtained to reach consensus among cases that were information-rich (Sandelowski, 2000). The sample was diverse on various characteristics, including gender, socio-economic status and geographic status of where a participant lives. Such a sample led to quality descriptions of each case and important emerging patterns developed across cases and increased their significance from having come out of heterogeneity (Patton, 2000).

Inclusion Criteria

Participants had a chronic pain diagnosis, defined as pain lasting for three months or longer. They self-identified as Native American. They were adults, age 21 or older, and English speakers due to time and resource constraints.

Exclusion Criteria

Patients with a primary cancer diagnosis were excluded from the study. The literature on chronic pain differentiates chronic non-malignant pain from chronic malignant pain. Patients with cognitive impairment, who may not be able to describe their pain/management/outcomes, were excluded from participating.

Rationale for Sample

Northern New Mexico Native Americans were chosen for sampling for several reasons. Two population-based studies using US national databases found that AI/AN patients report a higher prevalence of pain symptoms than the general population and whites (Barnes, Powell-Griner, & Adams, 2010; Deyo, Mirza, & Martin, 2006; Jimenez et al., 2011). Additionally, pain treatment disparity research has primarily focused on minorities other than Native Americans (Jimenez et al., 2011). The study contributes to knowledge regarding AI pain experiences, management strategies and the outcomes of chronic pain.

Change to Sampling Plan

The original intent of the research was to focus on the experience of chronic pain and pain agreements/pain contracts. Yet, participation was not limited to those with a pain agreement, as recruitment with the AI population is historically difficult. As a result, the majority of respondents were never on a pain agreement/contract. Two participants were actively on a pain agreement. Three others were not able to elicit clear memories of the agreements, bringing into question if they were in fact ever on one. As a result, the qualitative data regarding pain agreements was not significant enough to report in the findings of this study.

Recruitment

Participants were identified in several ways. Study flyers were carried at all opportune times for the sake of meeting potential participants (Appendix A). Social media networking, specifically Facebook, was utilized to recruit AIs who have experience with chronic pain. The Santa Fe Indian Center posted the flyer on their group Facebook page, with the permission of their board (Appendix B). All written materials were culturally and linguistically appropriate and were approved by the University of Arizona IRB, including an email/letter script (Appendix C). Colleagues in the healthcare profession and known AI community members assisted in word of mouth recruitment for this study. A non-profit integrative medicine clinic that serves AIs gave clients with known chronic pain the study flyer. Participants received a $30 Visa gift card for the interview. Participants were asked for contact information or they were given the PI’s contact information (email and phone number). The study information was reviewed with potential participants, such as confidentiality and consent, and questions were answered before any data collection took place (Appendix D) (Campesino & Koithan, 2004).

Data Collection

Method

The research aims were addressed with the use of in-depth, one-on-one interviews with semi-structured open-ended interview questions (Sandelowski, 2000). This method helped to describe, compare, and contrast participant experiences with pain, the management of chronic pain and outcomes based on demographic variables. Culturally appropriate interview questions (Appendix E) were developed to cover pertinent areas of chronic pain for participants. The in-depth interviews began with broad, open-ended questions to elicit experiences with chronic pain and moved to focused questions about specific incidents related to experiences with pain management and outcomes. Participants were interviewed in a variety of settings, including private residencies, over the phone, a restaurant and local coffee shops.

In addition, a demographic form (Appendix F) was completed and collected before each interview. All the participants were able to read, but for some participants, the interviewer verbally asked the questions on the forms and recorded the participants’ responses verbatim. The demographic form was de-identified so that it could not be linked to any forms or the recorded interview. Participants were informed that any identifying information emerging during the interview was redacted or changed during transcription. This technique assisted in protecting confidentiality and privacy.

Participant Protection

Participants need to be protected from potential harm. The University of Arizona institutional review board (IRB) reviewed the proposed research study to detect such impact and approved the study (Appendix G). The study was conducted with a diverse tribal/Pueblo sample representation and was conducted off any reservation/Pueblo land, thereby, not requiring any tribal IRB input or review. A consent form for participants to complete included a statement that the person may drop out of the study at any time, the purpose of the study and the format of data collection, the protection of confidentiality for the participant, and potential and known risks and benefits (Creswell, 1998). If the interested participant met all inclusion criteria and wanted to participate, written informed consent was obtained at the start of the interview (Appendix H). The setting for the written consent and interview was at a private location of the participant's choosing. A face-to-face interview was the preferred format for data collection. If an in-person interview was not possible, then the interview was conducted over the phone. The written informed consent and demographic form was sent through the mail, along with a return envelope and correct postage. The written consent was received by the researcher before any data collection took place.

Issues and dilemmas were thought through and anticipated in the early stages of the research design (Miles, Huberman, & Saldana, 2014). Initial agreements and working procedures were revisited and revised when needed throughout the study (Miles et al., 2014). Involvement of others helps to mitigate harm to participants. Dr. Michelle Kahn-John and Dr. Mary Koithan, nurse researchers, with expertise in research among Native American populations, provided additional consultation. Using investigators with various experiences assisted trustworthiness, completeness, and rigor to help realize a greater scope and complexity of understanding of the chronic pain experience for this study (Campesino & Koithan, 2004).

Data was de-identified and original documents, external data, and recordings were stored in a secured locked drawer at the PI's home office and had password protection. Any shared data with the dissertation chair and committee was de-identified and encrypted with password protection.

Interviews were approximately one hour or less and were audio-recorded with a hand held digital voice recorder with the participant's permission. The interviews were conducted at a place chosen by the participant or over the phone.

Rigor

The quality of the work must be equally appraised by the researcher and the reader. Rigor is about "Fidelity to the spirit of qualitative work" (Sandelowski, 1993, p. 2). Strategies to achieve trustworthiness are numerous and must be chosen thoughtfully, with openness and creativity. Reflexivity is necessary throughout the various stages of the research process. Self-awareness can help ensure trustworthiness in the face of multiple realities. Reflexivity helps researchers become mindful of their non-neutrality by encouraging reflection, by being aware of one's own biases and value judgments (Clancy, 2013).

Cultural competence in research includes cultural knowledge, sensitivity, and collaboration. Cultural knowledge encompasses an appreciation of a group's beliefs, values, and practices (Sawyer et al., 1995). Time was taken to gain knowledge and understanding of the historical context and health beliefs of NNM AIs. Cultural sensitivity refers to mindfulness that is based on cultural knowledge and the skill to capture the core of individuals or groups in data collection (Sawyer et al., 1995). Culturally competent research involves issues of trust, credibility, openness, and personal contact (Sawyer et al., 1995). Such competence was aided by the researcher's experience with working with the AI population as a nurse for almost a decade.

Lincoln and Guba's (1985) trustworthiness criteria was implemented for this research study. Truth value refers to the researchers showing that they are representing multiple constructions of reality of their participants. Credibility ensures that findings accurately and faithfully reflect the multiple realities being studied and described by the participants. The use of this investigator and the co-chairs of the dissertation committee to analyze the data improved the credibility of the study findings.

Consistency in qualitative research does not refer to the stability of findings, as human experiences are unique, but it refers to consistency of the researchers who are collecting the data. Dependability adds to consistency and refers to the traceability of the findings linked to the data and that the findings are internally coherent. An audit trail helped enhance these criteria. Field notes provided an audit trail and added reflexive validity (Munhall, 2012). Field notes included remarks on people, behaviors, interactions, affect, discussions, reflexive diary delineating thoughts in the field, thought processes of data analysis, and sequential events (Munhall, 2012). The dissertation co-chairs and the PI coded the first two interviews and refined the codes until 90% inter-coder reliability was achieved. The co-chairs also audited 20% of the remaining interviews' coding to ensure fidelity.

Bias was minimized in order to achieve neutrality, which was achieved by keeping a reflexive journal throughout all the phases of the study and the researcher’s own bias are revealed in the writing of the study report. Debriefing and member checking occurred between the dissertation co-chairs and the PI during meetings and coding discussion sessions that were held about every other week. Trustworthiness of the study was upheld with reflexivity, reflectiveness, and cognizance of strategies.

Data Analysis

Data Management

Data management consisted of documentation and recordkeeping of analyses conducted and plans for retention of data after the completion of the study (Miles, Huberman, & Saldana, 2014). After each individual interview was conducted, the interview was transcribed and read numerous times. The transcript and field notes were read and re-read to check for accuracy. Initial thoughts were jotted in the margins of a copy of the transcript and in a separate notebook. Throughout the data collection process and after each interview, memos were written to take stock of where the study was and where it was going (Glesne, 1999). Such memos included thoughts regarding methodological decisions, theoretical ideas, and notes regarding happenings during interviews that had an impact on the data collected.

Data analysis and data collection were done simultaneously. The interview questions were reviewed throughout the data collection process to ensure they adequately addressed the research questions. Analytic files were created to organize various categories in the early stages of data analysis, including titles and quotations from the literature (Glesne, 1999). A back-up copy of all audio and text files were stored on a flash drive and stored in a locked drawer, along with any raw data. Atlas.ti software was used to manage data. Atlas.ti securely stored a copy of the audio files from interviews and their written transcribed format as well. The software helped visualize code comparisons within and between groups.

Coding Process

Qualitative descriptive studies allow the data to speak for themselves and involve minimal interpretation on the part of the researcher (Sandelowski, 2000). Thematic codes were derived from the Symptom Management Theory (SMT) and research aims (Miles, Huberman, & Saldana, 2014). Such deductive coding was used to fracture the large data set and cluster segments of information relevant to the research aims. Codes were defined and organized into a codebook. The initial codes were further reduced or abstracted into broader categories for data analysis. The codes were clearly linked to the data from the interviews and field notes, as organized by the Atlas.ti software.

Content Analysis

Qualitative content analysis is the favored strategy for data analysis in QD studies (Sandelowski, 2000). Content analysis involves categories derived from the codes, which are generated from the data over the course of a study (Sandelowski, 2000). This process allowed the researcher to identify and analyze patterns, relationships, similarities, and differences within and between the participants studied based on demographic characteristics. The coded data included clusters of information containing meaning and significance in relation to the research questions (Miles, Huberman, & Saldana, 2014). Analysis was aligned with the research aims.

Data displays were utilized as a way of organizing the data that was conducive to “conclusion drawing and action taking” and took the form of matrices, graphs, and other visual representations (Glesne, 1999). Domain analysis was used as an organizing strategy and was one form of visual display of the data. Such analyses were used to look at semantic relationships, identify dominant patterns, and helped organize coding for analysis (Spradley, 1980).

Matrix analysis extended the analysis to comparisons within the study sample based on demographic characteristics. Matrices allowed analysis of similarities, differences, and trends in responses of informants (Averill, 2002). Cross-referenced categories of information were used to establish a range of experiences related to the chronic pain experiences of NNM AIs (Averill, 2002). Following coding of the individual interviews, domain and matrix analyses were utilized. First-order descriptive matrices were developed to examine patterns of chronic pain experiences, management strategies and outcomes within individual subjects using each participant's language. Second-order matrices were constructed for explanatory within group comparisons based on demographic characteristics, including gender, residence, employment and education. Age was not included as a demographic comparison due to the lack of heterogeneity among this sample of 14 interviews. Matrix analyses aided content analyses' task of understanding the knowledge conveyed by human communication and drawing inferences on the basis of this understanding (Krippendorff, 1980).

Summary

The qualitative descriptive (QD) research design provided a rich description of AIs' chronic pain experiences, interventions and outcomes. This approach was appropriate as the lack of literature on the topic warrants a presentation of straightforward answers using the participants' language. Measures were taken to ensure participant protections and the study was reviewed and approved by the University of Arizona IRB before any data collection took place.

Trustworthiness criteria was utilized throughout the study and implementation was aided by closely working with the dissertation co-chairs. The data management and analysis plans were carefully followed, including the use of content analysis and visual displays of the data. Barriers and facilitators to Native Americans' relief from pain were identified. Results and discussion of results are presented in the following chapters.

CHAPTER IV: FINDINGS

Introduction

The purpose of this study was to describe Northern New Mexican (NNM) American Indians (AIs) chronic pain experiences. Three specific aims for this research were identified to address this purpose: Aim 1: Describe NNM AIs experiences with pain. Aim 2: Describe NNM AIs pain management strategies. Aim 3: Describe NNM AIs pain outcomes. This chapter begins with an overview of the participants' demographic characteristics and then describes the results of this study.

Characteristics of Participants

Table 1 displays the sociodemographic variables of the participants in this study. The study included nine females and five males (n=14), with ages ranging from 31-70, with the mean age range of 41-50. Seven participants live in urbanized areas, defined as having a population of 50,000 or more people, and seven participants live in a rural area, including one who lives on a reservation. The education levels of participants ranged from less than a high school diploma (n=3), high school graduate (n=1), and some college (n=6), to postsecondary schooling (n=4). Four interviewees work full-time and three receive disability income, while others were unemployed (n=3), a student (n=1), working part-time (n=1), self-employed (n=1), and other (n=1). Seven participants were married or living with their partner, while the other seven were never married, divorced, or widowed.

The length of time participants experienced chronic pain ranged from 5-30 years, with a mean of 16 years. There are many ways to classify pain and classifications overlap. Some pain disorders are not easily classifiable. The underlying causes of certain pain disorders, such as migraine and fibromyalgia, are not thoroughly understood, although specific treatments for such disorders are well known. For purposes of this paper, the participants' pain diagnoses are classified in the following way. Three participants are classified with a primary diagnosis of immunological type pain (lupus n=2; fibromyalgia n=1), two with neuropathic or neurological pain (migraine n=1; trigeminal neuralgia n=1), and nine with nociceptive or musculoskeletal pain (n=9).

TABLE 1. *American Indian (AI) Participant Demographics*

AI Participant Demographics	**N=14**	**%***
Gender		36
Male	5	64
Female	9	
Race		
American Indian	14	100
Latino	4	29
Caucasian	1	7
Age		
31 – 40	5	36
41 – 50	5	36
51 – 60	3	21
61 – 70	1	7
Marital Status		
Married	4	29
Divorced	3	21
Widowed	1	7
Never married	3	21
Living with partner	3	21
Employment		
Full-time	4	29
Part-time	1	7
Student	1	7
Disability	3	29
Unemployed	3	14
Other	1	7
Self-employed	1	7

TABLE 1 – *Continued*

AI Participant Demographics	**N=14**	**%***
Education		
Graduate	4	29
Some college	6	43
Some HS	2	14
Less than HS	1	7
Trade school	1	7
Type of Pain		
Nociceptive	9	64
Neuropathic/neurological	2	14
Immunological	3	21

**Note. Percentages are rounded up.*

Results

A qualitative descriptive (QD) design was used to address the three research aims. In order to provide an audit trail for this data analysis process, etic coding of the interviews was completed using the Symptom Management Theory (SMT) as a framework. Etic codes and their definitions are seen in Appendix I. Domain and matrix analysis were utilized for further content analysis. Categories and sub-categories were created from content that shared commonalities. Demographics, such as gender, education level and residence (rural vs. urban), provided additional organizational structure for categorizing these data into matrices for qualitative content analysis, which were used to compare various subgroups of the sample and to describe the pain experience, management strategies, and outcomes.

Aim 1: Pain Experience

The first aim of this study was to describe NNM AIs experiences with pain by:

a) Describing participants' pain experiences.

b) Describing environmental factors that influence the participants' experiences with pain.

c) Comparing/contrasting participants' similarities and differences of experiences with pain based on demographic characteristics.

Pain is a multidimensional, subjective, unpleasant sensory and emotional experience associated with actual or potential tissue damage (ISAP, 2012). The pain experience involves the interaction of one's noticing a change in the way one feels, making judgements or attaching meaning to that feeling, and responding to the feeling (Larson et al., 1994).

Aim 1a: Describing Experiences

To describe participants' pain experiences (aim 1a), the interviews were theoretically coded and further distilled into categorical codes. Table 2 identifies and defines these codes, examines frequencies and presents exemplar quotations from the interviews.

TABLE 2. *Pain Experiences*

Pain Experience Codes	Definition	N=14	%*	Exemplar Quotes
Body awareness	Ability to recognize subtle internal cues or embodied self-awareness realized in action and interaction with the environment and world	7	50%	P2: If I walk too much then I know I'll be in so much pain P12: I'm pretty good about reserving my strength, my power P14: I am very cautious on what I do…I am like okay, make sure you bend with your legs, don't, obviously, just bend over with your back
Maintaining normality	To continue conforming to a standard	5	36%	P3: I go about my day. I just don't really… I don't really focus on it as much as I think some people do P5: When I was young, it was like I just had this thing where I needed to buck up and deal with it, and work through it and I minimized it P10: It's pretty chronic pain. It's there but I ignore it

TABLE 2 – *Continued*

Pain Experience Codes	**Definition**	**N=14**	**%***	**Exemplar Quotes**
Unpredictability of pain	Course of pain not able to be known or declared in advance	7	50%	P2: I was good for a while until the Lupus would flare up P4: it's getting more and more frequent. Before, it would be years…not have anything other than the fatigue…But now, it's like every three months or so. P8: Every time I use it the wrong way, it just pops back up. It hurts.
Psychological outcomes	of, affecting, or arising in the mind; related to the mental and emotional state of a person	7	50%	P2: Lupus fog is what they call it and you forget things P5: I was just so tired, and depressed, and sad and angry and all of it was, I think, tied to the pain and the fact that I had professionals telling me that I was crazy. 13: I was pretty sad, embarrassed and crying
Hoping for improvement	a feeling of expectation and desire for quality of being better than before	6	43%	P2: get this knee fixed to see if my chronic pain will go away for a while at least P12: Trying to defeat this pain P14: They did send me to physical therapy, hoping that would help relieve.
Body as confining	the material part or nature of a human being keeping or restricting someone within certain limits	8	57%	P6: I'm a go getter. I'm a mover and you can't do it. It's upsetting. P10: I get so stiff, I'd be trying to move and can't P13: instead of heading out the door…I've got to take a break already because my back hurts

TABLE 2 – *Continued*

Pain Experience Codes	Definition	N=14	%*	Exemplar Quotes
Alteration to sense of self	A change in one's perception of oneself	6	43%	P11: I was very active…I guess I had the mentality that I was invincible to a point where I would just do things physically that probably shouldn't have P14: That's probably been the worst out of this whole issue with my back, the weight gain. I let it go .
Pain as metaphor	Describing pain experience as a figure of speech in which a word or phrase literally denoting one kind of object or idea is used in place of another to suggest a likeness or analogy between them	6	43%	P4: I took a step and it was just like my legs went to jelly and I felt my knees in extreme pain just came on. P6: Like a shock that hits your body like if somebody put electricity and just shocked you P13: the pain just felt like someone was just stabbing me in the back
Coping/ acceptance	Process of contending with life difficulties in an effort to overcome or work through them	4	29%	P2: Now with dealing with everything I think now I'm like I need to live my life. I need to live it to the fullest as I can because I mean I've gone through so many things and it hasn't stopped me. P11: I have to deal with that, and that happens about twice a month

**Percentages rounded up*

Body awareness. Half the respondents (50%) referred to an awareness of their own bodies or their ability to recognize subtle internal cues or embodied self-awareness realized in action and interaction with the environment and world. Living with the chronicity of pain gave the participants the understanding leading to this awareness. As participant 12 stated, "What saves me is the knowledge and the experience that it will come to an end [severe pain]. It may be a few days though." Also, mindfulness of one's own body can have protective effects. "I try to listen to my body…I take into consideration my limitations, and making sure that I'm also not making excuses for my limitations."

Maintaining normality. Several participants (36%) try to live their everyday lives without their pain getting in the way of continuing conforming to a standard of normalcy. Participant one stated, "I'm pretty good at masking my pain or just soldiering through." Living up to this standard often had to do with not letting others perceive the pain the participant is experiencing. "I don't show a lot of pain because I deal with a lot of pain, so I've got a big immunity to it. I still feel it, but I don't cry about it."

Unpredictability of pain. The course of pain is not able to be known or declared in advance for many of the informants (50%). As one remarked, "I can't predict it. It just does whatever it wants to do." Pain may be experienced often, yet sometimes the participants can get unexpected relief. Participant six said, "The pain comes and goes…when I don't have it, I'm like duh, I don't worry about it."

Psychological outcomes. The response to pain is related to the mental and emotional state of a person. Half of the respondents referred to the psychological/cognitive response to pain. Pain is related to cognitive changes, as participant seven pointed out, "Your mind like can't think right sometimes when you're in pain." Others talked about their emotions varying due to their experience with pain. "When your body is hurting and you are unable to do anything and it causes anger for me and then after the anger then I get depressed."

Hope for improvement. Numerous participants alluded to a feeling of expectation or desire for relief in relation to their pain experience (43%). Many experienced such a feeling in the past, as participant one said, “So that was three years right there. They [migraines] just totally went away and it was amazing.” While others talked about a ‘quick fix.’ As participant three responded, “The one thing I do feel that, that maybe people with chronic pain really want is something that’ll, ah, like almost like a quick fix.”

Body as confining. Pain manifested in the body restricted a majority of participants within certain limits (57%). “When you have that limitation…there’s really no way of fixing it, it gets really frustrating, and I was getting really pretty angry with my body and myself, and wondering what it was that I did that made me this way.” Respondents referred to wanting to achieve something, such as a task, and not being able to due to their pain. Participant 13 illustrated this point when she said, “I couldn’t overcome it. Usually with pretty intense pain, you can just grit your teeth and say, I’m going to do it right now. Get it over with. I couldn’t.”

Alteration to sense of self. A number of interviewees perceived a change in how they thought of themselves associated with their pain (43%). For many, this was related to how active they were before experiencing chronic pain. Participant three stated, “I think to start, it was pretty… it was definitely frustrating, because you’re going through your day and you can’t do certain things because you, you just can’t. I mean I like to… I like to be active.” Pain was linked with weight gain, resulting in an altered sense of sense for several of the participants. As a woman related, “It’s about self-image…I just look at it [large t-shirt] and I go, “I wear that?” It’s not like me. It’s not like the real me. I think my self-esteem is down.”

Pain as metaphor. When describing the pain experience, numerous participants referred to their pain as a metaphor or a figure of speech in which a word or phrase literally denoting one kind of object or idea is used in place of another to suggest a likeness or analogy between them (43%). Participant 11 conjured an arresting image when he said, “Our pain develops a personality and a character. I can imagine it’s a beast sitting in the corner, just kind of waiting to mess with me.” Others used metaphors when trying to describe what the pain felt like, such as participant four, “It’s like if somebody could take a nail, those big nails and shove it in your bones, that’s what it feels like.”

Coping/acceptance. Coping is the process of contending with life difficulties, such as living with chronic pain, in an effort to overcome or work through them. Several of those interviewed denoted this concept (29%). Participant one said, “I’ve been living with chronic pain for so long that I, I feel like I’ve developed really good coping mechanisms and so I can put up with it.” While others did not use the term ‘coping,’ they commonly used the phrase ‘deal with.’ As in, “I just deal with the chronic pain of arthritis.”

Pain Experience Summary

The pain experience is subjective and multi-dimensional. Pain experience varied for the study participants. Frequency of the aforementioned pain experience categories ranged from eight participants or 57% (e.g., body as confining) of the sample (n=14) to four participants or 29% (e.g., coping/acceptance). Environmental contextual factors influence the pain experience and will be presented in the following section.

Aim 1b: Environmental Factors

In order to describe the environmental factors that influence the participants' pain experiences (aim 1b), codes derived from the theoretical framework were used to abstract quotes from the participant responses and further analyzed and condensed into categories and sub-categories. The environment refers to the context within which pain occurs, including physical, social and cultural variables, and impacts experiences. According to the SMT, the physical environment includes home, work and play. The social environment entails one's social support network and interpersonal relationships. Cultural variables refer to beliefs, values and practices of a group. The majority of study participants did not address how their cultural environment impacts their chronic pain experience. Although, many discussed how their beliefs and values affected pain management strategies, which will be elaborated upon later in this paper.

Physical environment. Numerous participants referred to how their physical environment aggravated their pain, including their work environment (36%), home environment (21%), and transportation (21%) (Table 3).

TABLE 3. *Physical Environment*

Physical environment definition:	Physical environment Sub-categories	Sub-category definition	N=14	%	Quotes
The physical world in which pain occurs	Workplace environment	Place where job is	5	36%	P14: The desktop job…that didn't help either because I was sitting all day…you can never get comfortable on the chair. P3: I work in a pharmacy, so I stand, I'm standing most of the day P10: I got hired for a job…all I did was got a shovel full of dirt and I went to get up and it just popped…I couldn't even get back straight
	Home environment	Where one lives or physical locale	3	21%	P11: I sleep on the streets. It does not help my back at all. I sleep on concrete sometimes and it's hard to deal with it. P3: it's kind of difficult sometimes to sleep with him
	Transportation	means of moving people from one place to another	3	21%	P5: The thought of driving was horrible. P3: I was driving a lot…the pain had like really aggravated it

The work environment holds its own challenges related to the nature of the job. Participant 13 noted, "It has stopped me from working in a Montessori school, where you have to get on the floor all the time. I can't do that anymore. I have to sit in a chair." The home environment presented difficulties, such as having to climb stairs or do laundry. Driving was a fairly common complaint. As participant six stated, "I have to stop, pull over, stretch …and get back in the car and then drive another two miles and stop because I was having problems and difficulty even sitting down."

Social environment. The social environment category was further condensed into sub-categories. Table 4 describes these sub-categories.

TABLE 4. *Social Environment*

Social environment definition: social support network and interpersonal relationships	Social environment Sub-categories	Sub-category definition	N	%	Quotes
	Workplace support	Degree to which employees perceive that employers care about their global well-being on the job through providing positive social interaction or resources.	5	36%	P1: I know the people will be rolling their eyes and they're like "Ugh, [participant's name] has a migraine that's why she's not here" P4: They've actually accommodated me at my job…'if you need to work at home two days a week…we can do that' P10: I just went through the day [with back injury], didn't want to tell the boss about it or anything
	Material support	various types of tangible help that others may provide, including help with household chores, transportation and accompaniment to healthcare provider appointments	8	57%	P2: He [boyfriend] takes me to my rheumatology appointments. P6: I tell her 'Mama needs help, can you get the laundry?' P10: He [partner at work] did the work. He said just kick back, I got you

TABLE 4 – *Continued*

Social environment definition: social support network and interpersonal relationships	Social environment Sub-categories	Sub-category definition	N	%	Quotes
	Emotional support	expressions of encouragement, active listening, reflection, and reassurance	8	57%	P5: my husband really had a hard time just being present for me…when I'm in a time of need P9: my sister and my auntie…they don't believe me about what I go through. P14: he was so understanding and so sympathetic

Workplace support. Workplace support refers to the degree to which employees perceive that employers care about their well-being while at work through providing positive social interaction or resources. Most interviewees did not perceive positive workplace support (36%). Some felt explicitly not supported. Participant 14 remembered, "I did not feel supported at all…They were always worried about my leave…the way they were giving me the rolling eyes, I'm guessing they didn't care." Others had more subtle experiences where they did not feel comfortable talking about their pain at their workplace or asking to take measures to help alleviate their pain. Participant four was the only person who spoke about their workplace support in a positive manner.

Material support. Living with pain often entails getting tangible help from others, including help with household chores, transportation and accompaniment to healthcare provider appointments (57%). Friends and family help with everyday tasks that are difficult to perform for those with chronic pain. Transportation and accompaniment to healthcare provider appointments are common. As participant seven mentioned, “I’d get a ride or my friend gave me a ride…they’ll send a van for you through the Medicaid.”

Emotional support. Chronic pain experience impacts relationships with family, friends and work colleagues. Emotional support means having others for expressing encouragement, active listening, reflection, and reassurance. Numerous participants (57%) referred to various sources of emotional support, although a few spoke of past experiences with low emotional support from their partners/families. Two participants saw a causal relationship between their chronic pain and divorce. Participant four related,

> “*He [ex-husband] always felt so guilty. And his, his way of coping was he, he started drinking so… I think he became very resentful toward me and then he got abusive. So, it was just like this whole vicious cycle. So finally, I was like, ‘Okay. I had enough. I have to leave,’ so I left.”*

One participant talked about support through social media, “I get on the boards on Facebook, the groups that had trigeminal neuralgia groups.”

Environment and Pain Experience Summary

The social and physical environment were important influences on participants’ pain experiences. Frequency of environmental factors ranged from eight participants or 57% of the sample (n=14) (e.g., material and emotional support) to five participants at 36% (e.g., workplace support). Additional content analysis by subgroups of the sample based on demographic characteristics was conducted to gain a fuller understanding of the pain experience. These findings will be presented next.

Aim 1c: Demographic Comparisons of Pain Experience

The participants’ various genders, employment status, place of residence and classification of pain contributed to a richer variation and understanding of the pain experience.

These demographic variables were used to compare and contrast participants' pain experiences (aim 1c). The groupings for education were not found to be unlike gender and therefore not reported. Figure 2 demonstrates the findings as a taxonomic summary.

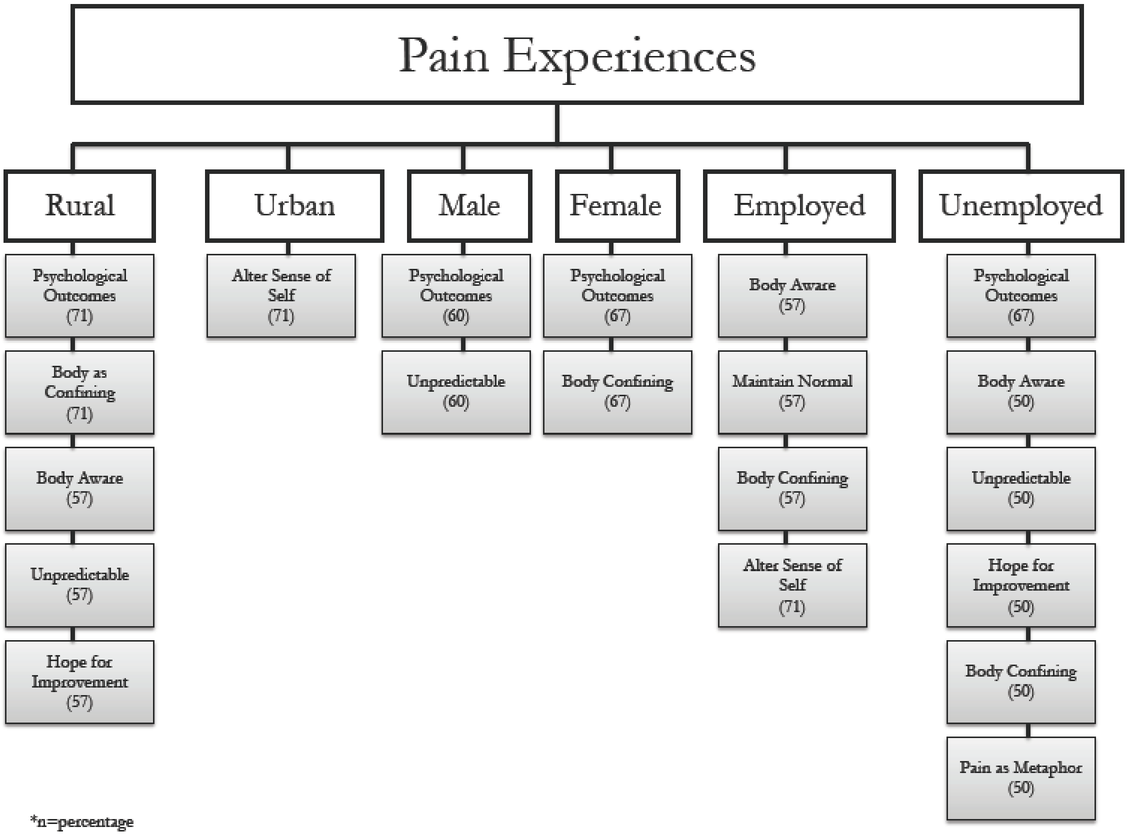

FIGURE 2. Taxonomic Summary of Demographic Comparisons of Pain Experiences (*Level two matrices were constructed to visualize these comparisons.*)

Pain experiences by gender. Figure 3 displays a comparison of pain experiences for males and females. Pain as metaphor and the unpredictability of pain were the most common male experiences (60% each), followed by body awareness, maintaining normality, and body as confining (40% each).

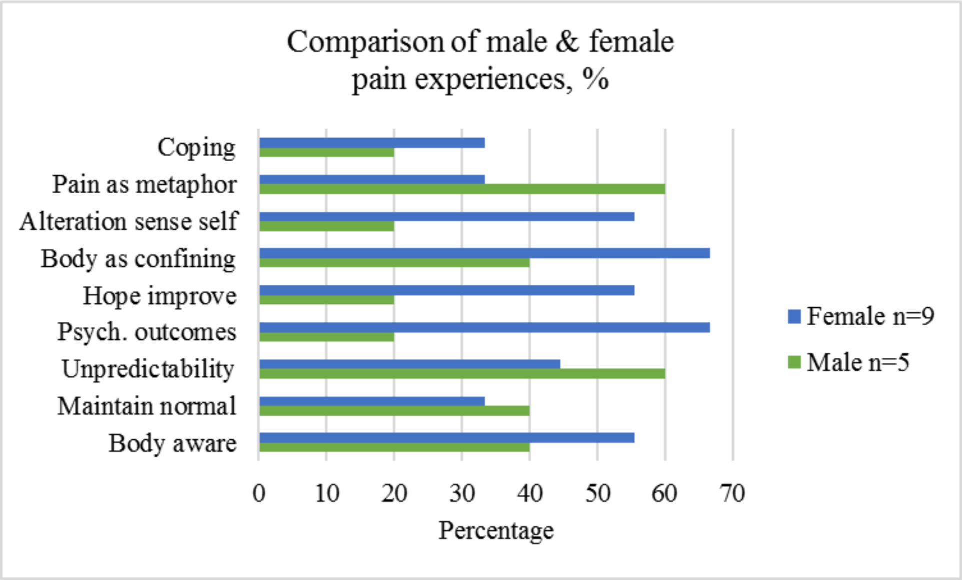

FIGURE 3. Pain Experiences of Males and Females

For females, psychological outcomes and the body as confining were referred to often (67%). Body awareness, hoping for improvement, and alteration to sense of self were pain experiences reported fairly frequently (56%).

Summary of pain experiences by gender. References to pain experiences varied between the males and females of this study. Psychological outcomes, hoping for improvement, and alteration to sense of self were reported frequently by women, but these were not prominent experiences for men. Pain as metaphor was raised as a common category for men (60%), but not for the women (33%).

Pain experiences by employment status. Pain experiences were compared between the employed and unemployed group (Figure 4). One participant answered “other” on the demographic form for employment and as a result his response is not included for either of these groupings. Pain experience categories among the seven in the employed group included: body awareness, maintaining normality, body as confining and altered sense of self (57% each).

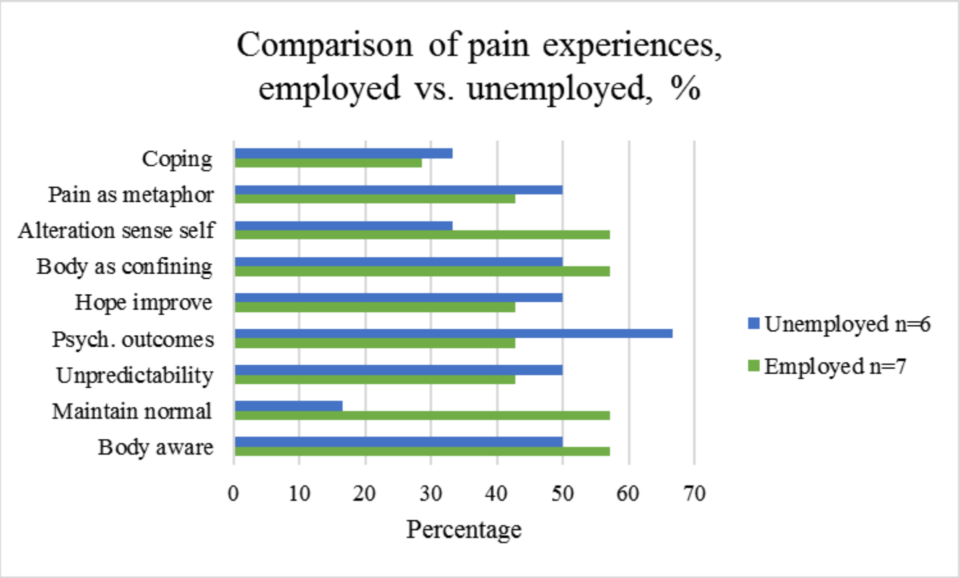

FIGURE 4. Pain Experiences, Employed vs. Unemployed.

In comparison, the unemployed/disabled group (n=6) stated pain experiences included: psychological outcomes (67%) and body awareness, unpredictability of pain, hope for improvement, body as confining and pain as metaphor (50% each).

Summary of pain experiences by employment. Pain experiences differed between the employed and unemployed/disabled participants. Maintaining normality was a main finding for the employed group (57%), yet raised minimally for by the other group (17%). The employed informants talked about an altered sense of self often (57%), while this was less frequently mentioned by the unemployed/disabled group (33%). Psychological outcomes were a common experience for the unemployed/disabled (67%), yet not for those not working (43%).

Pain experiences by place of residence. Pain experiences differed between urban and rural residents, as shown in Figure 5. Those living in rural areas had pain experiences including psychological outcomes and body as confining (71% each), body awareness, unpredictability of pain, and hope for improvement (57% each).

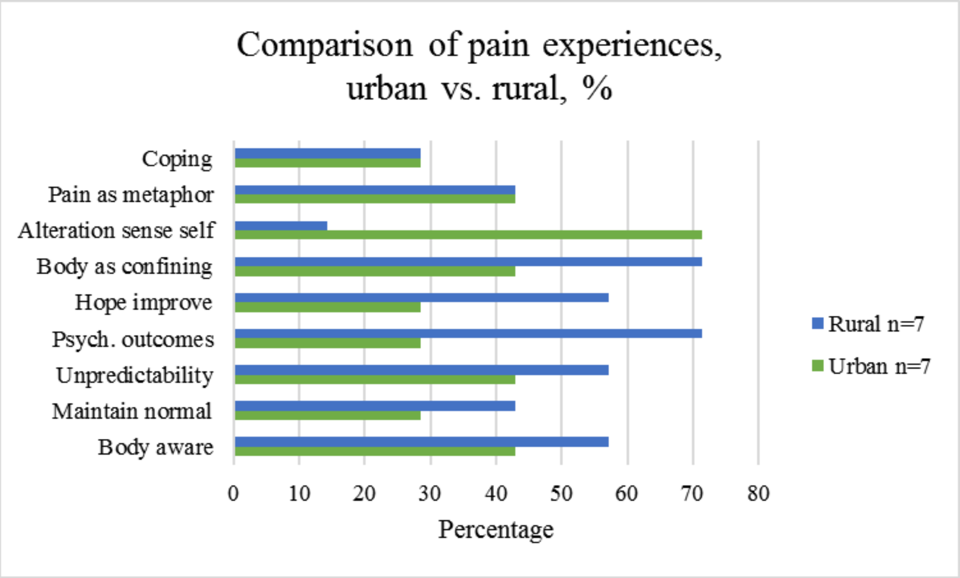

FIGURE 5. Pain Experiences, Rural vs. Urban.

The urban residents in this sample discussed pain experiences including alteration to sense of self (71%) and body awareness, unpredictability of pain, body as confining, and pain as metaphor (43% each).

Summary of pain experiences by residence. Both urban and rural residents referred to body as confining, body awareness, and the unpredictability of pain as the most frequent pain experience categories. Alteration to sense of self was frequently mentioned by urban participants (71%), while minimally by the rural group (14%). Another noted difference between these groupings was psychological outcomes were commonly spoken about for the rural residents (71%) and marginally by the urban (29%).

Aim 1: Pain Experience Summary

Pain experiences of this sample were multi-factorial and diverse. Body as confining, body awareness, unpredictability of pain and psychological outcomes were the most common pain experiences overall. The physical and social environment have a profound influence on the chronic pain experience. Comparison by demographic subgroups also exhibited a wide range of pain experiences. The males in this sample reported the pain experience sub-categories pain as metaphor and the unpredictability of pain most frequently, while the females referred to psychological outcomes and the body as confining most often. The most common pain experiences for employed participants were alteration to sense of self, body as confining, maintain normality, and body awareness. Psychological outcomes were the main finding for the unemployed group. The rural participants reported the body as confining and psychological outcomes as compared to alteration to sense of self as the top consideration for the urban group. The pain experience is inextricably related to how one treats their pain and will be discussed in the following section.

Aim 2: Pain Management Strategies

The second aim of this study was to describe NNM AIs pain management strategies by:

a. Describing participants' biomedical, professional, and self-care strategies to managing their pain.
b. Describing the environmental factors that influence the participants' pain management strategies.
c. Comparing/contrasting participants' similarities and differences in pain management strategies based on demographic characteristics.

All the participants have a long history of experience with chronic pain (mean = 16 years) and as a result most have tried various approaches to treating their pain over time. The literature review in chapter 2 revealed that multi-modal approaches to treating chronic pain are generally recommended. Opioids are not strongly recommended due to the lack of evidence on effectiveness for chronic pain.

Aim 2a: Describing Pain Management Strategies

To describe approaches to pain management (aim 2a), individual participant responses were first coded and then categorized into biomedical, professional, and self-care strategies (Table 5). Strategies described included those used in the past and present. Reasons for continuing or discontinuing certain strategies will be further elucidated later in this chapter. For purposes of this paper, biomedical pain management strategies are defined as physician services related to the maintenance of health, prevention of illness, and treatment of illness or injury. Professional strategies are those provided by a non-physician licensed professional of services related to the maintenance of health, prevention of illness, and treatment of illness or injury, such as physical therapy and acupuncture. Self-care refers to personal healthcare performed by a layperson for their families, their communities, and/or themselves.

TABLE 5. *Pain Management Strategies, Past and Present*

Category	**Definition**	**Strategy**	**N=14**	**%***
Biomedical	Provision by a physician of services related to the maintenance of health, prevention of illness, and treatment of illness or injury	Medication		
		Opioids	10	71
		Analgesics	6	43
		NSAIDs	5	36
		Anticonvulsants	4	29
		Salicylates	4	29
		Muscle relaxants	3	21
		Antidepressants	2	14
		Ergot alkaloids	2	14
		Corticosteroids	2	14
		Triptans	1	7
		Anxiolytics	1	7
		Neurotoxin (BOTOX)	1	7
		Antipsychotic	1	7
		Surgery	3	21
		Injections/shots	2	14
		Knee brace	1	7
		Ace wrap/bandage	1	7
		TENS	1	7
Non-physician professional provided services	Provision by a non-physician licensed professional of services related to the maintenance of health, prevention of illness, and treatment of illness or injury	Physical therapy	8	57
		Massage	5	36
		Chiropractor	2	14
		Counseling	2	14
		Acupuncture	1	7
Self-care	Personal healthcare performed by a layperson for their families, their communities, and/or themselves	Stretching	6	43
		Changing positions/movement	4	29
		Biologic medicine	4	29
		Yoga	3	21
		Cannabis	3	21
		Traditional healing/medicine	2	14
		ETOH	2	14
		Heating pad	2	14
		Managing diet	2	14
		Coping mechanisms	2	14
		Home exercise	1	7
		Lifestyle change	1	7
		Hot tub	1	7
		Touch feel therapy/tapping	1	7
		Music	1	7
		Merrell brand shoes	1	7

**Note: Percentages rounded up*

Biomedical strategies. Due to the diversity of pain conditions, pharmaceutical treatments varied widely. Past and present use of opioids (71%), analgesics (43%), and NSAIDs (36%) were reported most frequently. Although 71% of the participants have tried opioids in the past, only two participants (14%) currently use opioid analgesics daily, while four (29%) use them sparingly.

Three participants (21%) had surgical procedures related to their pain diagnoses, including spinal surgery for a bulging disc, bilateral hip replacements due to osteonecrosis, and craniotomy vascular decompression for trigeminal neuralgia. Other biomedical strategies included injections/shots (14%), a knee brace (7%), an Ace bandage (7%), and a TENS unit (7%).

Non-physician professional strategies. Eight participants (57%) tried physical therapy (PT) in the past, yet no one was currently attending. Massage was the second most commonly reported professional intervention to treating pain (36%). Other strategies included seeing a counselor (14%), chiropractor (14%) and an acupuncturist (7%).

Self-care strategies. Many participants relied on self-care pain management strategies. Stretching was the most commonly used intervention (43%). Biologic or herbal medications (29%) included Fire Fighter, Naturally Calm, tree sap, and Epsom salt. Several mentioned the need to position their bodies in various ways or simply lying down on the floor or a bed (29%). Yoga was mentioned by three participants (21%), yet only one currently practices yoga. One informant uses a technique she called touch feel therapy, which may be known as tapping, that she learned during a mental health session that also helps relieve her pain. Three male informants

(21%) use cannabis for their pain. Two males (14%) openly spoke about their use of alcohol (ETOH) to assuage their pain, but did not elaborate further beyond this.

Summary of Pain Management Strategies

Past and present pain management strategies were wide-ranging for this sample. Biomedical interventions were most frequently used, with opioid pain medications being the most common. Although, opioids were utilized in the past mostly, with currently only 14% taking them daily and 29% sparingly. A majority reported physical therapy in the past (57%), but no one was currently attending. Self-care strategies varied and ranged from stretching (43%) to buying a certain brand of shoe (7%) to alleviate pain. The environment in which pain occurs is related to how pain is treated and will be presented in the next section.

Aim 2b: Pain Management and Environmental Context

In order to describe the environmental factors that influence the participants' pain management strategies (aim 2b), quotes were abstracted from the participant responses and further distilled into categorical and sub-categorical codes. The environment refers to the context within which pain occurs, including cultural, social and physical variables, and impacts treatment decisions.

Pain culture environment. Pain culture environment was defined as a set of shared beliefs held by the sample participants. Analysis of responses revealed sub-categories of the pain culture environment and included belief in opioids as addictive (36%), belief in non-biomedical strategies (36%) and belief in adverse effects of opioids (57%) (Table 6).

TABLE 6. *Pain Culture Environmental Factors Influence on Pain Management Strategies*

Pain culture environment definition: A set of shared beliefs of this group of NM AIs.	Sub-category	Sub-section definition	N	%*	Quotes
	Belief in opioids as addictive	True or false assumption that taking opioids for pain leads to compulsive physiological need for and use of opioids	5	36	P4: I'm afraid to take them because they are addictive P5: I think because addiction is so prevalent in my family, that it's just there was always this kind of fear or anxiety that I had around using opioids in particular to manage the pain P14: Being in the medical field…I actually have some relatives that have been [addicted]
	Belief in non-biomedical strategies	a firmly held opinion or conviction in regards to superiority of non-biomedical strategies to relieve pain as compared to biomedical strategies	5	36	P5: I try to really manage the pain in other ways versus taking pharmaceuticals P9: I don't want to get surgery done on me. I don't believe in it. In my tradition that's what it is. For this [swelling in knee], I just use tree sap to cover it…It healed up itself, sucked out the blood and stuff, pus, just covered it. Healed itself
	Belief in opioids causing adverse effects	True or false assumption that opioids cause undesired harmful effects	8	57	P2: Like one day you'll be fine…then there's other days when you're just so constipated you can't go, other days where you can't hold nothing in and everything just ends up coming out P4: It takes away the pain for sure [opioid], but the side effects aren't worth it to me P10: It makes me feel sick in the stomach and groggy, just don't have energy…I don't care for pills

Belief in opioids as addictive. Many participants (36%) spoke about their belief in opioids as addictive in regards to not taking opioid pain medications. For some, this had to do with a family history of substance abuse or seeing others in their community who were addicted to opioids. As participant six said, “I’ve seen too many, including elderly people, addicted and young kids addicted. I just, I can’t stand it.” Others held a personal belief that opioids are addictive, “I would end up getting addicted to the opioid. Like everybody else.”

Belief in non-biomedical strategies. Several (36%) referred to a belief in not taking prescribed medications when possible. As one woman stated, “I gear more towards like changing the mind instead of taking any kind of medications or look more into a natural type of medicine.” A few referred to AI traditional healing, including using a sweat lodge and medicine men in the past. Participant 12 talked about his indigenous perspective in regards to using cannabis for his pain, stating, “We’re given different things in this life from the natural world to help us. This is one of those things. My elders, my grandparents, go to way back having to use…plants in all kinds of ways. This was a plant that they used for lots of things.”

Belief in opioids causing adverse effects. The majority of participants (57%) spoke about their preference for non-opioid medications, mostly related to the adverse effects of opioids. The adverse effects mentioned included gastrointestinal, allergic and cognitive/psychological effects. Gastrointestinal problems included nausea, constipation, diarrhea, stomach pain, and emesis. One participant had a severe allergic reaction to morphine. Cognitive effects were the most common concern, including feeling sleepy or groggy, hung over, and psychological issues. One participant noted taking, “Tylenol with codeine and I ended up crawling around on the floor because it was making me so weird." Or as another respondent stated, "I don't feel sharp intellectually or mentally or emotionally sharp."

Social environment. The social environment was an important contextual factor influencing how pain was managed by the participants. Social environment entails one's social support network and interpersonal relationships. This category was divided into sub-categories as shown in Table 7.

TABLE 7. *Social Environmental Factors Influence on Pain Management Strategies*

Social Environment Definition:	Social Environment Sub-categories	Sub-category definition	N	%	Quotes
Social support network and interpersonal relationships	Supportive Healthcare Provider relationship	good rapport with healthcare provider for medical management	5	36	P1: I go to a specific pharmacy where I've worked hard to kind get develop relationships…who I think trust me. P5: He was literally the first one who was like, 'Oh, you have pain?'…we developed a plan P13: They believed me…we have a very good relationship
	Unsupportive Healthcare Provider relationship	Feeling judged, unfairly treated, isolated and/or invalidated by healthcare providers	8	57	P1: It is hard to an advocate for myself, especially when I'm met with so much suspicion when I go to the doctor… expectation that all pain patients are drug-seeking. P3: I never tell my provider that this is what's going on and that I want something done, because for the most part, I know that they're probably just gonna end up sending me to physical therapy that I can't go to P11: I was going to get an MRI done because it gets to the point where you have to prove it because they just don't believe you anymore.

TABLE 7 – *Continued*

Social Environment Definition: Social support network and interpersonal relationships	Social Environment Sub-categories	Sub-category definition	N	%	Quotes
	Supportive family/friend relationship	Network providing various resources needed to manage pain	6	43%	P2: He's [boyfriend] very supportive and he knows my limits and he knows everything that I've gone through so he's very patient with me P4: He says, 'I think you need to go lay down.' P12: I get on the boards on Facebook, the groups that had trigeminal neuralgia groups
	Unsupportive family/friend relationship	Feeling judged, unfairly treated, isolated and/or invalidated by family/friends	6	43%	P3: I don't wanna seem whiny P5: We're driven in a society where there are these high expectations of performance and it's like you're tired and all you want to do is sleep and rest P14: [family] kind of roll their eyes, like you're being silly…there's no complaining

Supportive healthcare provider relationship. Numerous informants (36%) spoke about their positive relationship with their healthcare provider and the protective factors of having a doctor-patient relationship history. As participant two stated,

> "*I've always had the same doctors since I got diagnosed…I heard that they [urgent care] were trying to put mine as a drug seeker flag but my doctor was like 'no she knows what she's doing. She knows what she's talking about, so there's no way you're gonna do that."*

Also, a supportive relationship ensures that patients get the care they need to effectively treat their pain. Participant four noted, "He's a very good doctor. He'll work with you and he'll make sure that you'll see the right specialist."

Unsupportive healthcare provider relationship. Commonly, participants relayed experiences of being or feeling judged, unfairly treated, isolated and/or invalidated by healthcare providers due to being a patient with chronic pain (57%). When one participant went to a specialist via a referral, "The gal at the desk was treating me like I was just there to get drugs…and I said I'm not. I am in pain. I have a chronic pain problem." Participant six said, "I have a good doctor, but sometimes I have to go to other doctors or something, I don't tell them everything, the whole truth because I feel like I'm going to get labeled." Participant 5 went through several doctors over several years with her pain not being believed. This prevented her from implementing a plan of care, guided by a biomedical professional. A couple of informants felt they were treated a certain way due to being AI. Participant 11 noted,

> "*I'm sure if I was white they'd be okay with it…I guess the stigma is in a lot of people's minds is that Mexicans or Indians are just druggies or drunks. It's more of a subtle thing. They have ways of deterring people, not giving them the medication that they need, or making them feel in a lot of ways like when they ask for it, it makes them feel kind of bad because it almost makes you feel like a druggie asking for drugs. 'I need this medication,' it makes you feel kind of like a druggie."*

Supportive family/friend relationship. Participants recognized that having a network of resources is instrumental to managing pain (43%). When asked about carrying out recommended pain management strategies, one participant said, "I'd get a ride or my friend gave me a ride. My appointments, you have to call it maybe two to three days in advance, then they'll send a van for you through Medicaid." Supportive relationships allow participants to feel comfortable to take measures to treat their pain, such as being able to rest. A participant stated,

> "*When I told him [boyfriend] I like I just want to go home and lay down and rest, he was so understanding and so sympathetic with me, which was so nice to hear because I didn't get it from my boss, I didn't get it from my coworkers, my family…not that they're not sympathetic towards it, but I think they're kind of sick of hearing me about it.*"

Unsupportive family/friend relationship. The participants spoke to various instances where they did not feel comfortable or open to communicating their pain experiences to their family/friends (43%). They did not want to seem 'whiny' or 'to complain' with the feeling that, "There's really nothing…anybody can do about it." As participant 12 stated,

> "*It's one of those things where because it is invisible [pain], it's hard for people to see just how brutal it can be to a person. But for us, there's no way to really tell unless we complain about it. 'Oh, geez, there he goes again, complaining about it.*"

Some explicitly stated that they never share the full extent of their pain with their family. "I don't really tell them everything, but they see."

Physical environment. For interviewees, the physical environment encompasses their place of work (Table 8).

TABLE 8. *Physical Environmental Factors Influence on Pain Management Strategies*

Physical Environment Definition: Work place	Physical Environment Sub-categories	Sub-section definition	N	%	Quotes
	Function in workplace	social role altered at place of employment	3	21	P14: I could do it [lying under desk at work] in front of one of my other coworkers …because she deals with pain. She has pain issues too, so she knew what I was dealing with.

The informants' physical space at work impacted how they were able to manage their pain (21%). The type of movement, stretching and/or exercises needed to relieve pain were difficult to accomplish at work. This mostly had to do with social unacceptability of strategies. As one informant noted, "Laying on the floor and putting my knees up to my chest really helped, but I mean I can't do that…at work." The staffing at work also impacts one's ability to treat their pain by going to healthcare appointments, such as physical therapy. “It’s kind of a difficult time for me to kinda do anything, we’re kinda shorthanded right now, so, it’s not ideal at the moment.”

Summary of Pain Management and Environment

Cultural, social and physical environmental variables affected the selection of pain management strategies and varied among this sample. Unsupportive healthcare provider relationship (57%), belief in opioids having adverse effects (57%), supportive and unsupportive family/friend relationships (43% each) were the most frequent environmental factors influencing pain management decisions for the participants. Additional analysis was conducted to relate demographic sub-groups’ pain treatment interventions for richer understanding of the data and will be discussed in the following section.

Aim 2c: Demographic Comparisons of Pain Management

As noted in chapter 2, very little is specifically written about non-malignant chronic pain management and Native Americans. More is known about other minorities and the general population. The literature reveals that living in rural areas limits access to care needed to manage chronic pain. Half of the informants were living in rural residencies and half were in urban areas. Other variables related to the inadequate treatment of pain include being a minority, gender and socioeconomic status (SES) (income and education). Comparing and contrasting participants’ responses by demographic variables contributed to a fuller description and understanding of pain management strategies (aim 2c). The groupings for employment were not found to be unlike gender and therefore not reported. Figure 6 illustrates a taxonomic summary of findings.

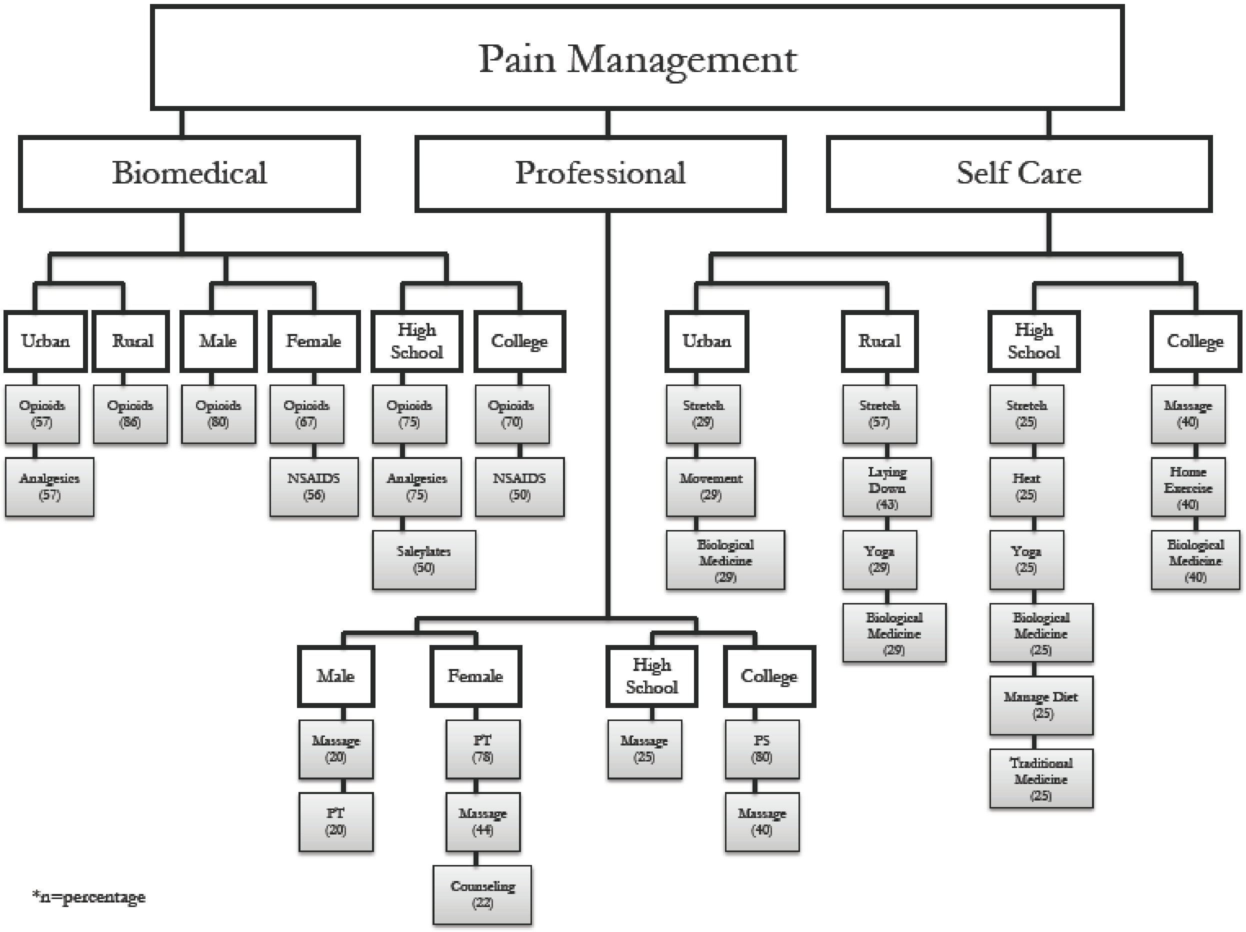

FIGURE 6. Taxonomic Summary of Demographic Comparisons of Pain Management Strategies.

Demographic variables included in this analysis were place of residence (rural or urban), gender, and education level. Level 2 matrices were constructed to visualize these comparisons.

Demographic comparisons for prescribed medications. Figure 7 illustrates that rural respondents most frequently used medications were opioids (86%), NSAIDs (43%) and muscle relaxers (43%). Opioids (57%) and analgesics (57%) were for the urban dwellers. Opioids were more likely to be prescribed for rural than urban dwellers. Muscle relaxers were not utilized for the urban group.

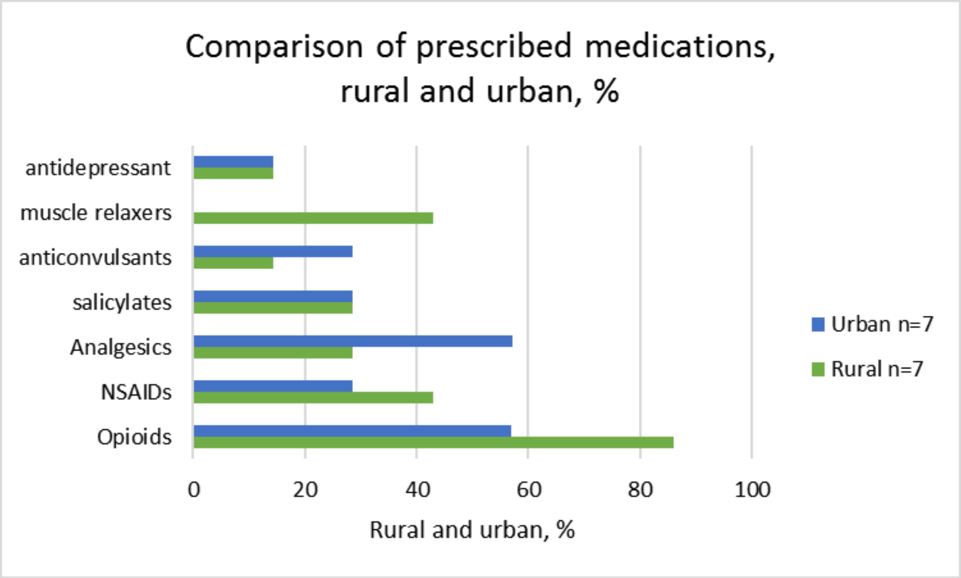

FIGURE 7. Comparison of Rural vs Urban, Past and Present, Opioid Prescription

Figure 8 compares women and men's use of medications (past and current) to relieve pain, respectively. The most frequently used medications for men were opioids (80%) and analgesics (40%). Opioids (67%), NSAIDs (56%) and analgesics (40%) were the women's. The men were more likely to be prescribed an opioid medication than women. Over half (56%) of the women have used NSAIDs and zero men mentioned utilizing them. Two women (22%) were given antidepressants, while no men ever had them prescribed.

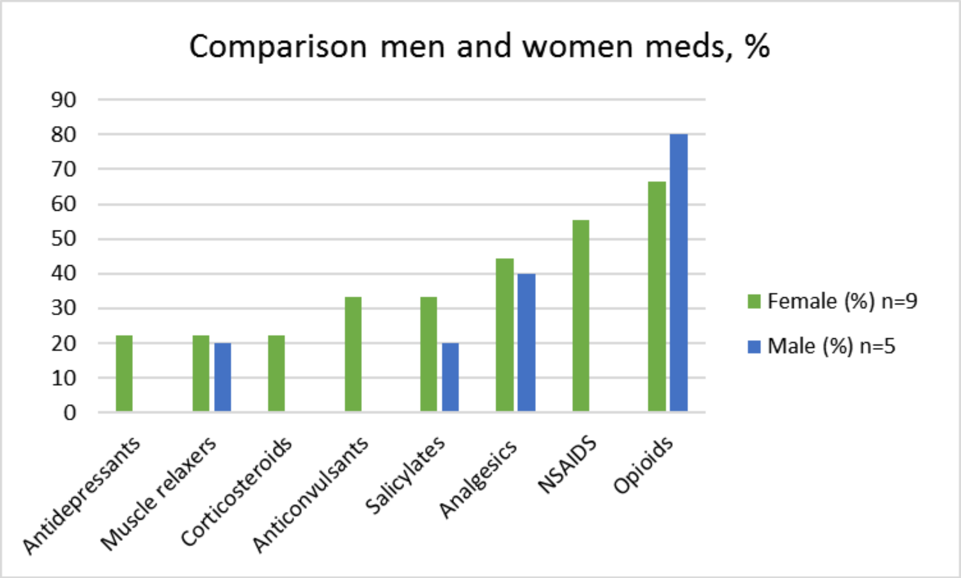

FIGURE 8. Comparison of Men and Women Medications

The high school or less group were all male and to note, 80% of all the males in the study (4 out 5). Figure 9 compares medications by level of education. The most frequently used medications for the college or more group were opioids (70%), NSAIDs (50%), and analgesics and anticonvulsants (30% each). Analgesics (75%) and salicylates (50%) were commonly mentioned by the high school or less group. Opioids were fairly equivalent between the two groups, those with a high school education or less (75%) vs. a college education or more (70%).

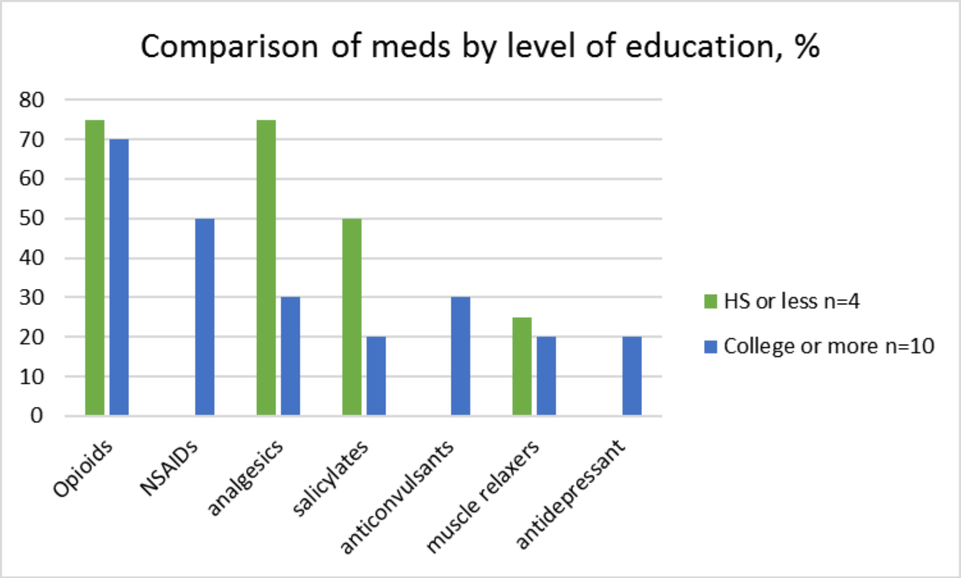

FIGURE 9. Comparison of Medications by Level of Education.

Summary of demographic comparisons for prescribed medications. Prescription medication use varied among the demographic subgroups. Opioids were more likely to be prescribed for rural residents, males, and those with a high school education or less. Overall, women in the sample used more medications than the men. The women were given various medications, such as NSAIDs and antidepressants, that men did not take at all.

Demographic comparisons for professional pain management strategies. Figure 10 presents professional approaches to treating pain for males and females. Women tried more professional interventions than men, including physical therapy (78%), massage (44%), and chiropractor (20%). Two female participants actively attend counseling (22%), although one is required to go in order to obtain valium for neck muscle spasms. She used to get the medication from her primary care provider, yet suddenly the provider decided she no longer felt comfortable prescribing it with little explanation.

Four of the male participants (80%), never participated in PT. All were recommended to get PT, yet some never went due to drinking or as two spoke about their pain making them incapable of doing therapy. As one stated, “I should, but I mean, how am I going to get physical therapy if my knees are worn out and I can't even do squats anymore…I refuse.”

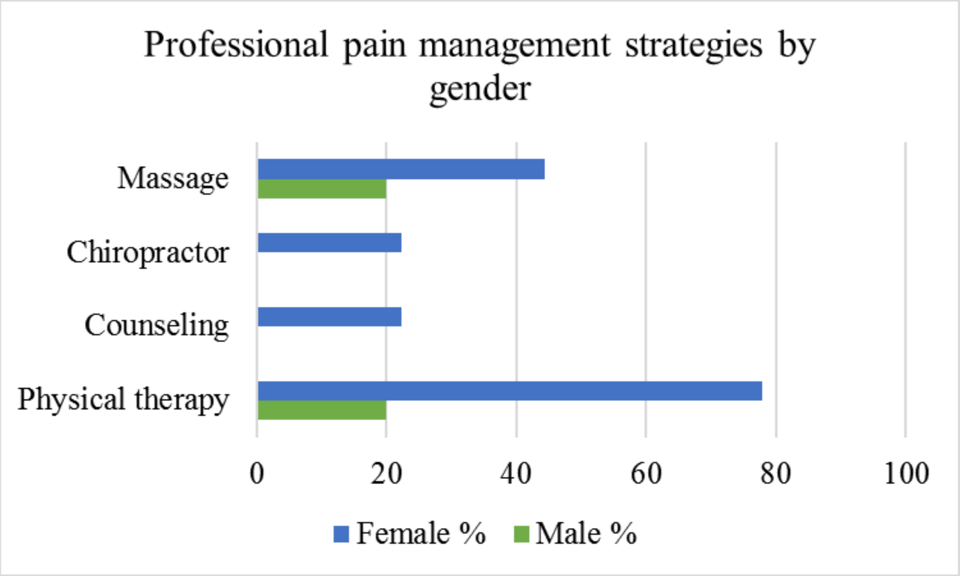

FIGURE 10. Comparison of Females and Males Professional Pain Management

The high school or less education group did not use any professional interventions, except participant 10 mentioned massage (25%) (Figure 11). Those with a college education or more tried PT (80%), massage (40%), chiropractor (20%), counseling (20%), and acupuncture (10%).

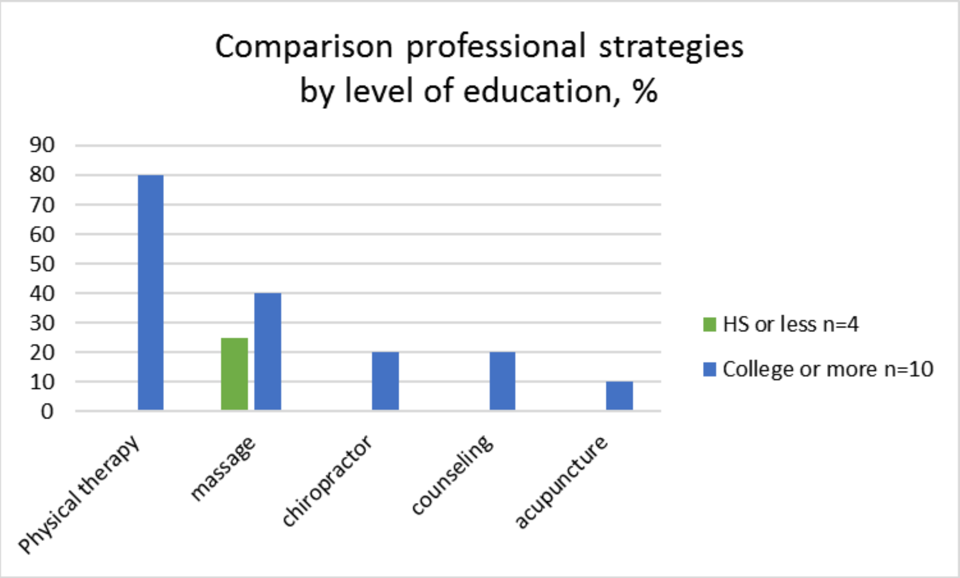

FIGURE 11. Comparison of Professional Strategies by Level of Education

A note on acupuncture. One urban participant (14%) used acupuncture covered by her health insurance plan and stated that it really helped her sciatica. Another informant was offered acupuncture, but refused it because after researching the topic, she decided that it was only temporary relief not worth pursuing. One other participant would like to try acupuncture, but she felt that she did not have access to it due to living in a rural area, stating, “we’re kind of small and we don’t offer very much.”

No differences were found between urban and rural residents for physical therapy, counseling, and chiropractor. Only massage was utilized more with the rural residents (43%) than the urban dwellers (14%).

Summary of demographic comparisons for professional strategies. Physical therapy was the most common professional intervention for all comparison groups, except the high school or less participants. Females tried more professional strategies overall than the males in this study. The high school or less group utilized almost no professional strategies, including none ever trying physical therapy.

Demographic comparisons for self-care strategies. Figure 12 illustrates self-care strategies for urban and rural residents. The most frequently used self-care strategies for the urban group included: stretching, movement and biological medicine (29% each); and the rural group: stretching (57%), lying down (43%), yoga (29%), and biological medicine (29%). The rural participants generally implemented more self-care strategies than the urban. Traditional medicine was utilized by one urban and one rural participant (14% each).

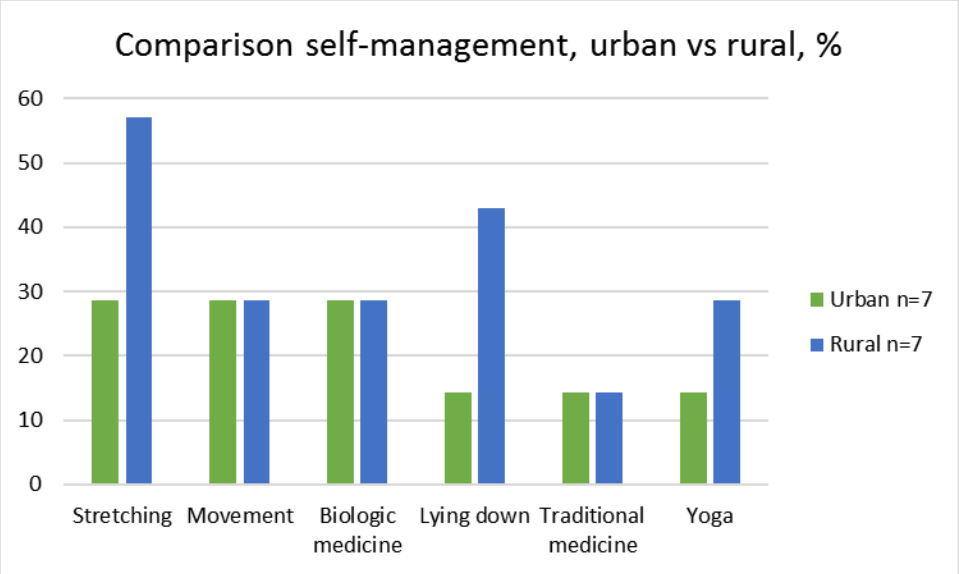

FIGURE 12. Comparison of Self-Management, Urban and Rural

Figure 13 illustrates self-care strategies, comparing those with a high school education or less with participants with some college or more. Those with a high school education or less (n=4) implemented the least number of tactics, with only 25% of the group trying stretching, biological medicine, traditional medicine, managing diet, heat and yoga. The strategies for the college or more group included stretching (50%), and massage, home exercise, and biological medicine (40% each).

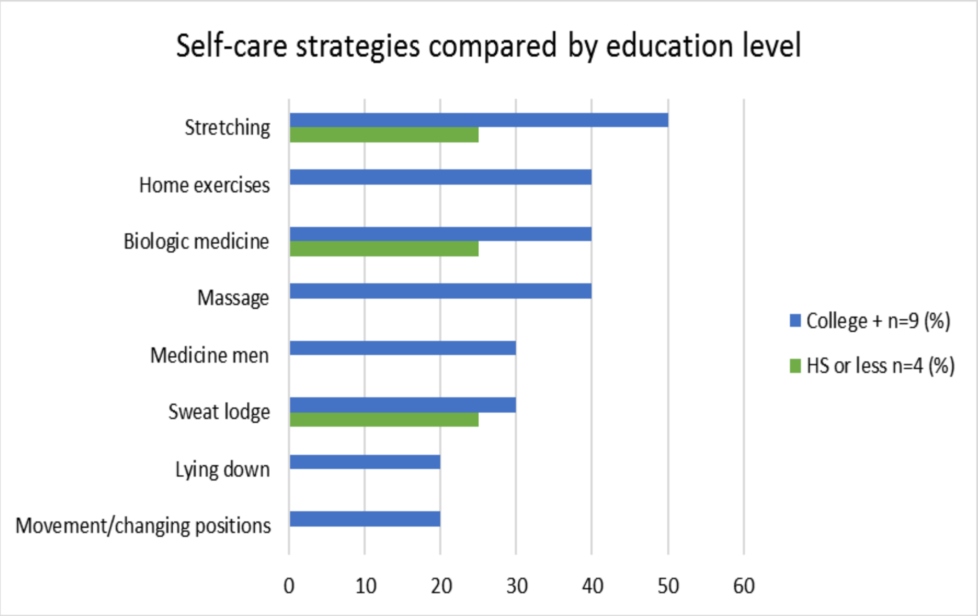

FIGURE 13. Self-Care Strategies Compared by Education Level

Figure 14 compares male and female self-care strategies. The female participants implemented self-care strategies more frequently than the males. Stretching was popular for men (40%) and women (44%). Biologic medications, home exercise, and traditional medicine were utilized by 25% of the males. Whereas, movement (40%), lying down (40%) and yoga (30%) were tried by some of the women and none of the men.

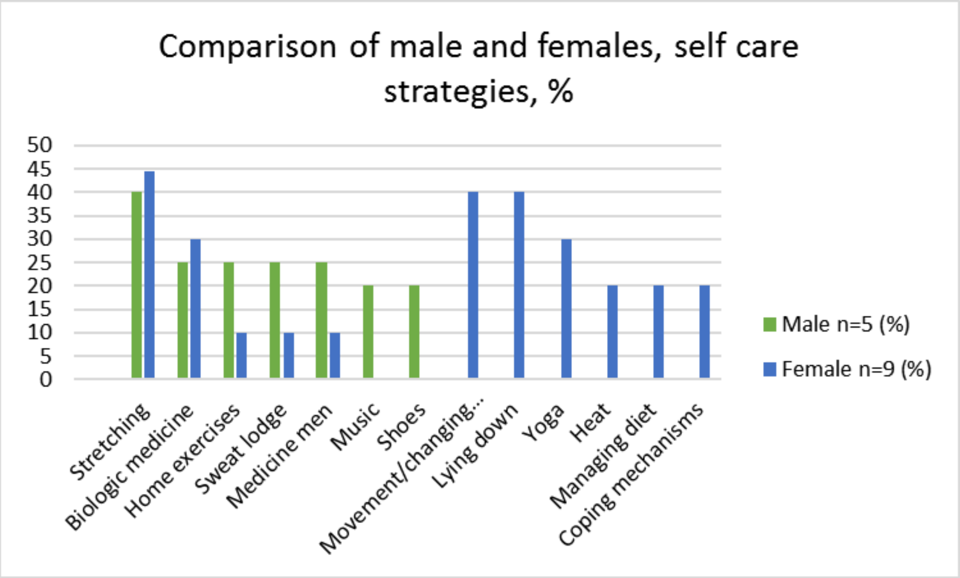

FIGURE 14. Comparison of Male and Female Self-Care Strategies

Summary of demographic comparisons of pain management. Between sample analysis showed reports of pain management were diverse among this sample of Native Americans and included biomedical, professional and self-care strategies. Pain management patterns were found when demographic groupings of the sample were compared and contrasted. Participants who were rural residents, men, and those with a high school education or less tended to be prescribed opioid medications more often. Women implemented various pain management strategies more frequently than men. Those with a high school education or less never tried physical therapy and no one in the sample was currently attending PT. Rural residents used a variety of self-care strategies most frequently as compared to the urban group. No discernable pattern could be found in relation to the utilization of AI traditional medicine as only two participants referred to their traditional beliefs, of which one was a rural woman, the other an urban man.

Aim 3: Pain Outcomes

The third aim of this study describes the outcomes stemming from pain management strategies and the pain experience by:

a. Describing the impact of pain and pain management strategies on the participants' functional status, healthcare utilization, costs, and quality of life.
b. Comparing/contrasting participants' similarities and differences in pain outcomes based on demographic characteristics.

The Symptom Management Theory (SMT) illustrates how various symptom outcomes may be related to each other. While the theory focuses on eight factors of the outcome dimension, this qualitative study honed in on four of these factors, which are functional status, healthcare utilization, costs and quality of life (aim 3a). Individual responses were theoretically coded and further abstracted into categories and sub-categories.

Aim 3a: Describing Pain Outcomes

Functional status. Functional status is defined as an individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being. All the participants (n=14) expressed one or more limitations to their activities of daily living (ADLs), including walking (71%), sleeping (21%), employment (29%), social activities (43%), sports/exercise (50%), driving (21%) and sitting (21%) (Table 9).

TABLE 9. *Limitations to Functioning/ADLs*

Pain Outcome	**Definition**	**Functioning/Activities of daily living (ADLs) limitations**	**N=14**	**%***
Functional status	Individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being.	Walking	10	71
		Sleeping	3	21
		Employment	4	29
		Social activities	6	43
		Sports/exercise	7	50
		Driving	3	21
		Sitting	3	21

Functional limitations were not always constant and fluctuated with the status of their pain. Participant two noted, "For about a year I couldn't do anything because of the pain," which was related to her steroid treatment for lupus and resulting osteonecrosis in her hips. At times, social activities were limited and related to pain severity. Participant three said, "And then, some days, I'd been in so much pain, I couldn't even just go to like family functions cause I don't wanna sit in the car." Numerous participants lamented over their inability to participate in sports or exercise that they enjoyed in the past. As one stated, "I can't walk like I used to walk and I miss that very much." Four of the informants were unable to work directly due to their chronic pain.

Summary of functional status. Walking, sports/exercise, social activities, and employment were the most common activities limited by pain. All participants experienced one or more functional limitations. Such limitations were dependent on pain status.

Costs

The outcome of costs is defined as the expenditure of something, such as time or labor, necessary for the attainment of a goal. The SMT defined cost to include financial status and health services utilization. For the purposes of this study, health services utilization will be addressed separately due to the special circumstances of AIs and access to healthcare via the Indian Health Service (IHS). Although, these factors certainly do cross over each other. The category of costs was distilled into the sub-categories time, financial status, and health insurance status (Table 10).

TABLE 10. *Cost Outcomes*

Costs sub-categories	**Definition**	**Exemplar Quotes**	**N=14**	**%***
Time	measurable period during which an action, process, or condition exists or continues	P1: There's also the time that goes into it, the time that of like going to all these appointments. It cuts into my work time, it cuts into my family time. P5: It was a process. I mean, like every six months I would go to a new doctor and go through the whole process and then have them tell me I was depressed P14: Even if I ask for one at home [massage] it's like we don't have time. We've got two kids and just chores around the house and working all day.	7	50
Financial Status	mainly affected by *person's* income, including assets, savings, property	P6: So my money, any extra money I have, I have to pay people to come and help me because I can't do it. P11: Financially, I have to look forward to working a minimum paying job for back breaking work P13: I can't work anymore. I'm on SSI and I had to do that because I tried to get several jobs and each time it was my back P14: [massages] they're expensive	12	86

TABLE 10 – *Continued*

Costs sub-categories	**Definition**	**Exemplar Quotes**	**N=14**	**%***
Health insurance status	Having insurance to cover all or part of medical expenses	P3: I've thought about going to a spine center, but then…it's difficult to get in…the co-pays for it are really expensive and they're out of my network, so the decision not to go was kind of based on that P5: Prior to that I didn't have health insurance. It was I think what hindered me from seeking help was health coverage P6: I think it was my insurance, they won't pay for them [baclofen] anymore, so we let that go	12	86

Note. Percentages rounded up.

Time

Half of the participants (50%) spoke about how not having enough time affects their pain experience and management options. Travel time, time off from work and time away from everyday life were major concerns. As participant three stated when referring to physical therapy, "I don't really have time…I mean unless you're like able to do an hour every week and I live like 30 miles away, I can't do that." A few recalled the long period of time trying to gain disability insurance/income, while physically not being able to work. "I had to fight for disability. Three or four times I got denied."

The challenges of managing pain while experiencing homelessness with fewer resources available were especially apparent with one male participant. He was prescribed an opioid, but did not have valid identification to obtain the prescription. He would need to travel to his Pueblo, get his baptismal card, and "[Certificate of Indian Blood] CIB, my original and then come back down here and get my Social Security card. So, I've got to go through a big process."

Financial Costs

The financial costs of pain management had a substantial impact on the majority of participants (86%). Participant 12 is working to get a medical marijuana card, but, “It can be costly because to get a recent diagnosis by this new doctor…he could have ordered an MRI to make sure it’s not something else…it’s totally unnecessary because I’ve been dealing with it for 26 years.” Services available or not available at IHS played a role in how some treated their pain. “IHS is there and I use it cause, I mean, if I don’t have to pay.” One participant lamented that IHS did not give her an injection treatment for her knee because, “it’s a thousand bucks a shot.”

Health Insurance Status

Closely related to financial costs is health insurance status. Although many of the interviewees had health insurance, some still had high deductibles and co-pays that prevented them from getting the care they needed. Participant 4 mentioned, “I was going to physical therapy, but…it was really expensive. It was $35 co-pay each time.” The bureaucracy of health insurance also impacts pain treatment decisions. “I was going to get a MRI done, but then Medicaid wouldn’t pay…I had to do rehabilitation first before I did my MRI.” Participant one also noted, “I just pay out of pocket because trying to fight with insurance just isn’t worth it to me cause that would be even more time.”

Summary of Costs

Costs were a frequently mentioned concern for the sample. Time and financial worry limits participants’ ability to follow through on recommended interventions. Health insurance did not guarantee participants’ ability to manage their pain, as costs are not always fully covered and the health insurance system can act as a roadblock as well.

Quality of Life

Quality of life (QOL) is defined as a broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life. The QOL code was further abstracted into the sub-categories loss of social role, life plan disrupted and emotional wellbeing (Table 11).

TABLE 11. *Quality of Life (QOL) Outcomes*

QOL sub-categories	**Definition**	**Exemplar Quotes**	**N=14**	**%***
Loss of social role	Unable to perform social role, which encompasses the acting out of socially defined categories	P1: [stopped drinking alcohol due to medications] I noticed how boring people are…really affected my life…and I think people think I’m a little standoffish too because of it P13: She [friend] said, “Do you want to come along?” “I can't walk, especially in that heat. I just can't walk very far, maybe half a block, then I've got to rest my back. It’s not like I'm out of breath or anything, it’s that my back is hurting so bad. P14: mother-son thing… obstacle courses and stuff like that…The first thing that popped in my head was my back was going to hurt and I’m not going to be able to do it…I didn’t even go. I didn’t even take him.	8	57

TABLE 11 – *Continued*

QOL sub-categories	Definition	Exemplar Quotes	N=14	%*
Life plan disrupted	Personal goals interrupted	P2: I put in my two weeks' notice and so I moved home at the end of February. And then and then that's when I moved home is when I really got sick. P6: it prevents me from working. I had a real good career going P12: I had to quit my masters' program…I moved back to…where my parents lived…so I could get some support	4	29
Emotional wellbeing	Positive sense of wellbeing which enables an individual to be able to function in society and meet the demands of everyday life	P2: I've gone through depression…asking yourself, 'why me? Why do I have to deal with this?' P3: I'm not mad at myself anymore for it P10: my emotions, the pain, you just don't feel good some days…just wishing it wasn't there P11: I'm hopeless about it…it puts a big damper on my life	10	71

Loss of Social Role

Loss of social role is defined as an individual being unable to perform their social role, which encompasses the acting out of socially defined categories, such as mother, husband and friend. The majority of participants (57%) felt a loss of various social roles due to their chronic pain. For some this involved a disruption in their roles within their own families and others referred to relationships with friends and co-workers. As participant 4 noted, "I don't do much of anything anymore. I don't really have much of a social life cuz I'm tired all the time. When I get off work, I just go home."

Life Plan Disrupted

Life plan disrupted refers to personal goals that are interrupted by the pain experience and management. Several participants (29%) altered their life plan, involving higher education, employment and decisions regarding starting a family. Interviewee 12 stated that his chronic pain, "Impacted our decision to have children… That basically had to do with the uncertainty of it all. What we were really uncertain is to whether or not how long I was going to be able to keep even playing music."

Emotional Well-Being

Emotional well-being may be defined as a positive sense of wellbeing, which enables an individual to be able to function in society and meet the demands of everyday life. Such wellbeing can encompass personal satisfaction, affect/mood, self-esteem, and status/respect. A large majority of those interviewed frequently referred to how their chronic pain compromised their emotional well-being, especially at points in their lives when pain was unrelieved (71%). A few participants spoke about how their reduced activities lead to weight gain and lower self-esteem or self-image. "Emotionally…just not being happy with myself and my body…insecure now about my body." Others referred to intermittent outcomes in their affect or mood. As participant five stated, "I remember that time being really, really challenging for me emotionally…it [pain] impacted my life in a lot of ways."

Summary of Quality of Life

Quality of life was profoundly affected by chronic pain for the participants. Emotional wellbeing was most frequently raised by interviewees. The chronicity of pain impacted normal social roles and disrupted life plants.

Healthcare Utilization

The outcome healthcare utilization is defined as the use of healthcare services or resources available. For this sample, healthcare utilization includes: Indian Health Service (IHS) present use (21%), IHS past use (36%), private PCP (29%), integrative medicine clinic (43%), traditional medicine (14%), Medicaid and/or Medicare (50%), private health insurance (50%) and seeing more than one biomedical provider (21%) (Table 12).

TABLE 12. *Healthcare Utilization Outcome*

Pain Outcome Code	Definition	Healthcare utilization strategy	N=14	%
Healthcare utilization	Use of healthcare services or resources available	Indian Health Service (IHS)		
		Present use	3	21
		Past use	5	36
		Private primary care provider (PCP)	4	29
		Integrative medicine clinic	6	43
		Traditional medicine	2	14
		Medicaid and/or Medicare*	6	50
		Private health insurance*	6	50
		Seeing >1 biomedical provider	3	21

**Note: unknown insurance status for 2; n=12*

Healthcare Provider

As noted earlier, Native Americans can access healthcare services at an Indian Health Services (IHS) facility. Three participants currently use IHS (21%). One spoke about how the care at IHS has improved since the patients at her clinic got assigned to a PCP. “I’ve only had a primary care for about four years now. So, before that, it was kind of just walk-in, so seeing whoever was there and they refused to do any kind of x-rays, any MRIs.” Participant 2 has had the same doctor at IHS since she was diagnosed with lupus. Others no longer use IHS due to accessibility or negative past experiences (36%). As participant 1 stated, “Having grown up in

IHS where I’ve had such shitty treatment my whole life and I have all these stories that, you know, of being misdiagnosed or being left in hospital room for hours or being treated poorly by these young doctors.” Another participant would like to be closer to her family, but will not move back to her home reservation due to the lack of specialty services provided by IHS for her condition.

Several participants (43%) see a primary care provider (PCP) at a facility that offers integrative services, such as massage, acupuncture, and traditional AI medicine. Although, only one participant seems to use any of these services, when he stated that he attends their sweat lodge. The other interviewee that prefers traditional medicine and herbal medications over biomedical interventions does not live close to this clinic. As mentioned earlier, she used to live on a Pueblo where she had access to medicine men and a sweat lodge.

A few (21%) interviewees had to regularly utilize more than one biomedical provider. This requires time and tenacity to see numerous providers and coordination of care in order to get what is needed. “So, then they referred me to the pain clinic and it takes for me to get in to the pain clinic because there’s only one doctor and she takes forever coz she’s only there like two days or half a day like out of the whole week…finally I could get in to see her and get the Botox, you know of course the insurance has to approve it. It took me three years.”

Health Insurance Status

Health insurance status often dictates the care that a patient receives, whether it is the costs involved (e.g., copays and deductibles), which treatments insurance will cover, and which providers are accessible or in-network. Six of the participants had Medicare and/or Medicaid, six had private insurance and two were unknown. Participant five experienced trying to find an in-network provider that would believe her pain for almost two years, “The very first thing they would say to me is like, ‘Oh, you’re depressed. You should see the counselor.’ As soon as they would say that I just would be like I’m going to find another person.” Although participant seven had Medicaid, she was getting care with IHS in the past and she stated, “The Indian Hospital can’t afford to give me protein shots because it’s a thousand bucks a shot so they were giving me ibuprofens for that which didn’t work.”

Summary of Healthcare Utilization

Indian Health Service was currently used by 21% of the sample at the time of data collection. Others no longer utilized IHS (36%) and instead attended a private practice (29%) or a non-profit integrative medicine clinic (43%) for their primary care. The majority of participants had some form of health insurance, although the data was missing for two in the sample. Twenty one percent were presently seeing more than one biomedical provider.

Aim 3b: Demographic Comparisons of Pain Outcomes

Studies addressing chronic non-malignant pain and AIs were sparse. As discussed previously, living in a rural area, education level and one’s gender may impact the utilization of healthcare. Comparison of pain outcomes by demographic subgroups relates a richer understanding of the data collected from this sample. Cost and QOL outcomes were not significantly different between the demographic subgroups of this sample. The groupings for education and employment were not found to be unlike gender and therefore not reported. Figure 15 displays a taxonomic summary of pain outcome findings compared by demographic variables.

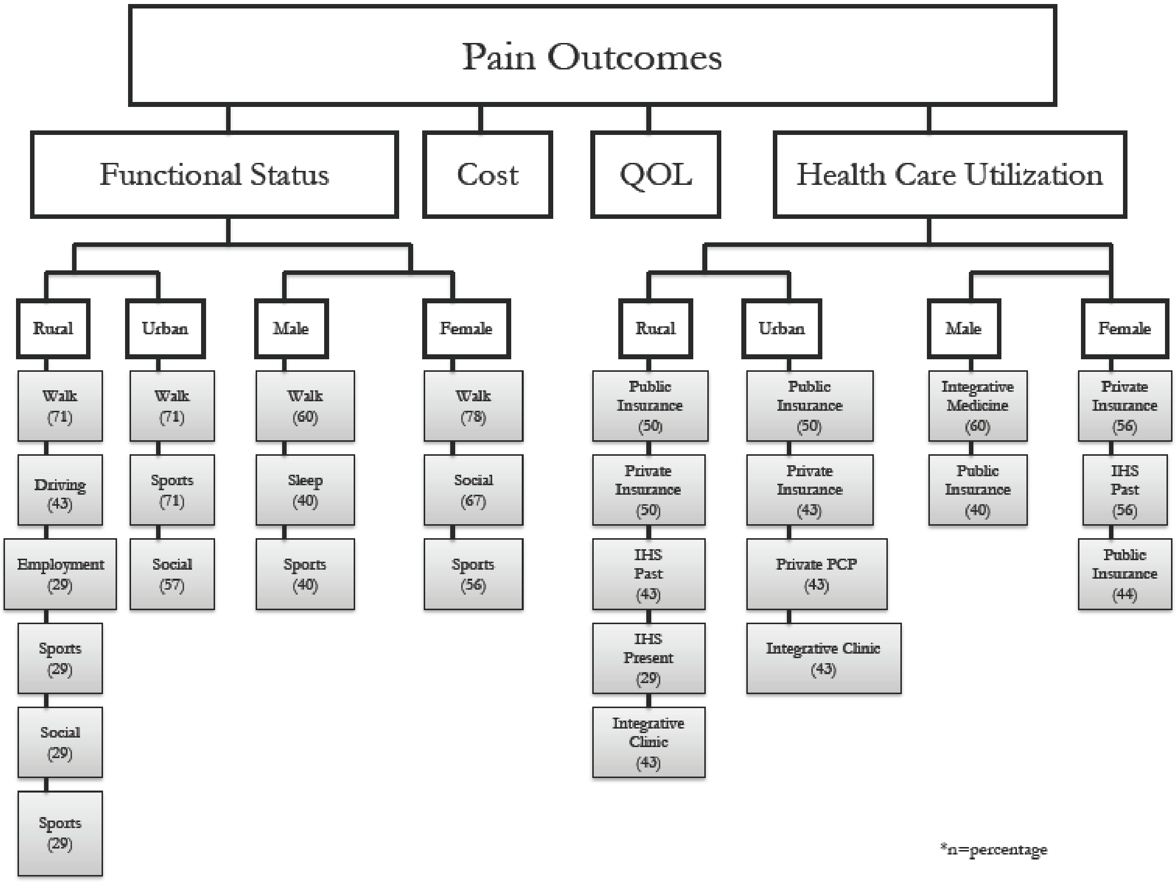

FIGURE 15. Taxonomic Summary Demographic Comparisons of Pain Outcomes

The most common functional status limitations and healthcare utilization outcomes were compared by gender and place of residence demographic variables (aim 3b). Comparative level two matrices were constructed to describe these outcomes.

Functional limitations by gender. Figure 16 displays functional limitations compared by gender. Functional limitations for the males (n=5) included: sports/exercise (40%), sleeping (40%), and walking (60%). The functional limitations for females (n=9) were walking (78%), social activities (67%), and sports/exercise (56%).

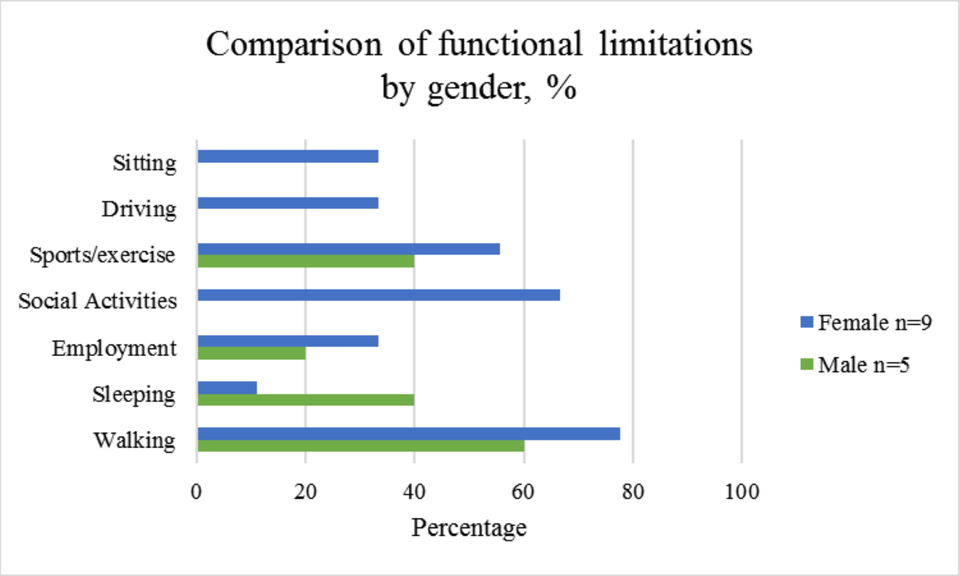

FIGURE 16. Functional Limitations by Gender

Summary of functional limitations by gender. The most frequent functional limitations varied for females and males of this sample. Walking was the most frequently mentioned limitation for both groups. While social activities affected 67% of the women, but none of the men. Sleep was frequently referred to by the men (40%), but only 11% of the women. Sports or exercise limitations were a concern for both groups.

Functional limitations by residence. Figure 17 compares the most common functional limitations of rural and urban residents in this study. The urban limitations were walking (71%), sports/exercise (71%), and social activities (57%). Comparatively, for the rural respondents:

walking (71%), driving (43%), and employment, social activities, sports/exercise, and sitting (29% each).

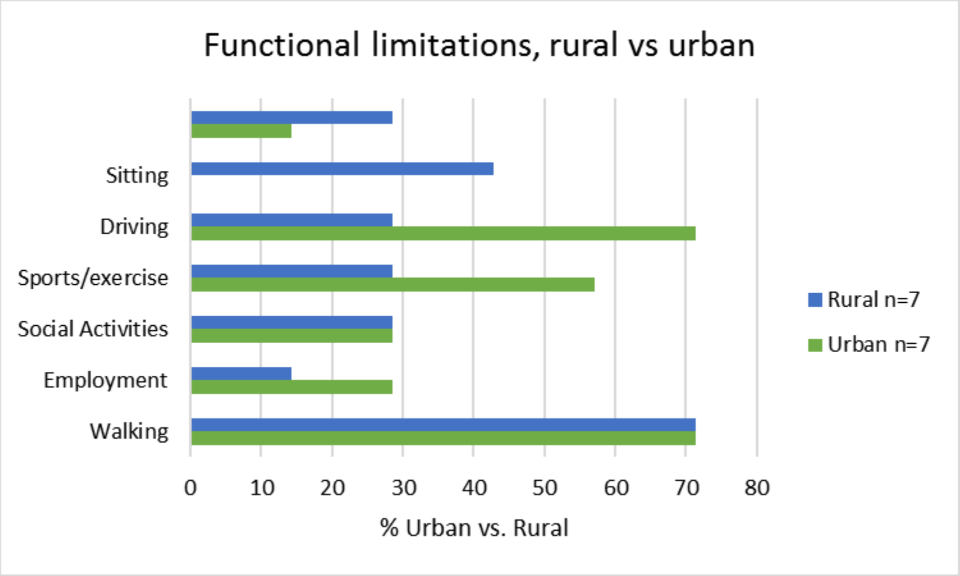

FIGURE 17. Functional Limitations by Residence

Summary of functional limitations by residence. The most common functional limitation for both urban and rural residents was walking. Other responses varied for these groups. Driving was a top concern for the rural group (43%), while not for any of the urban group. Sports/exercise was frequently mentioned by urban respondents (71%), but not as frequent for the rural (29%). Social activities differed also, with 57% of the urban versus 29% of the rural group.

Comparison of healthcare utilization by residence. Healthcare utilization categories were compared by place of residency (Figure 18). The urban and rural residents had an equal number of participants with private and public health insurance (50% each). The urban group utilized a private PCP or the integrative medicine clinic most frequently (43% each). The rural participants went to IHS in the past (43%), the integrative medicine clinic (43%) and IHS presently (29%).

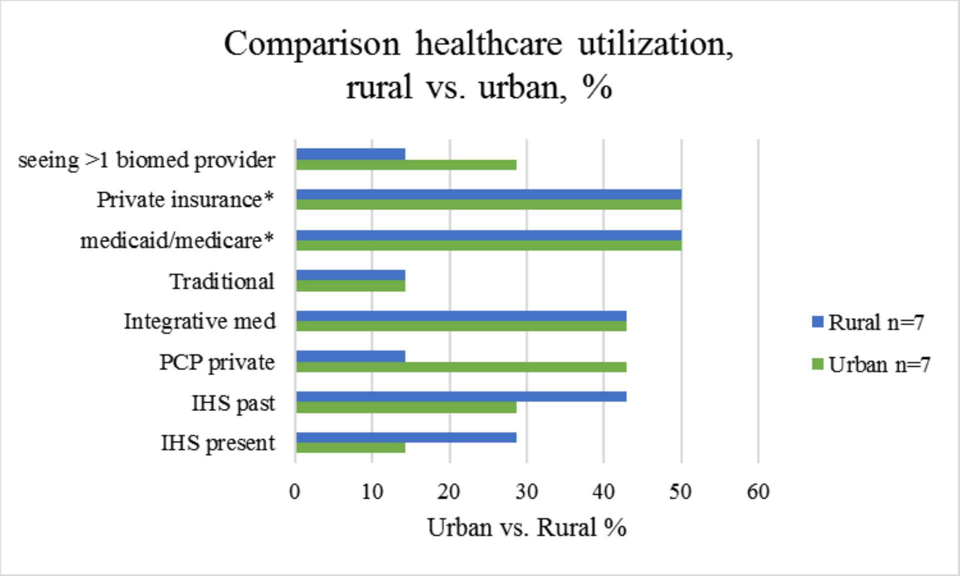

FIGURE 18. Comparison Healthcare Utilization, Urban vs. Rural

Summary of healthcare utilization by residence. The majority of participants had private or public (Medicare and/or Medicaid) health insurance, although the health insurance status for two of the participants is unknown. Both urban and rural residents fairly frequently receive their healthcare from an integrative medicine clinic (43% each). Rural residents currently utilize IHS (29%) more than their urban counterparts (14%). The urban group was more likely to have a private PCP (43%) than the rural group (14%).

Comparison of healthcare utilization by gender. Figure 19 illustrates healthcare utilization categories compared by gender. Females accessed private health insurance and IHS in the past frequently (56% each). They had a fairly high number of participants on Medicare and/or Medicaid (44%). Of the females used IHS currently, the integrative medicine clinic, 33% saw a private PCP, and more than one biomedical healthcare provider. The male group most frequently accessed care via the integrative medicine clinic (60%). A fairly large number were on Medicare and/or Medicaid health insurance. Of the males, 20% saw a private PCP, utilized traditional medicine and private health insurance.

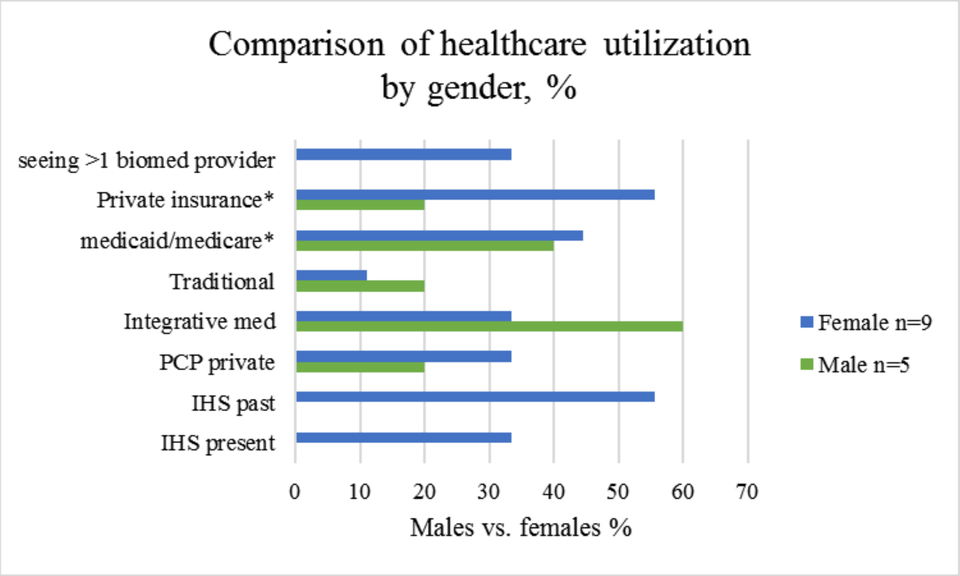

FIGURE 19. Comparison of Healthcare Utilization by Gender.

Summary comparison of healthcare utilization by gender. Healthcare utilization varied by gender. Females attended IHS clinics in the past (56%) and presently (33%), while no male referred to going to IHS at any time. Females more frequently had private health insurance (56%) than the males (20%). Both groups fairly frequently had Medicare and/or Medicaid (44% females; 40% males). The males were more likely to utilize the integrative medicine clinic (60%) than the females (33%). The female group reported seeing more than one biomedical provider (33%), as compared to none of the males.

Summary Demographic Comparisons of Pain Outcomes

Functional limitations and healthcare utilization outcomes varied between groups based on gender and residency demographic variables. Quality of life and cost outcomes were not significantly different when compared between demographic groups. Walking was a common functional limitation for all groups. Females and urban residents frequently mentioned social activity and sports/exercise limitations, while the males and rural residents did not. Females and rural residents were more apt to utilizing IHS in the past, while a large number of the males utilized an integrative medicine clinic. Private health insurance was more prevalent with the females than the males. Both urban and rural participants utilized public and private health insurance equally. A discussion of research findings, implications for clinical practice and the SMT, and future research follows.

CHAPTER V: DISCUSSION

The purpose of this qualitative descriptive (QD) research was to describe Northern New Mexico (NNM) American Indians (AIs) chronic pain experiences, intervention strategies and outcomes. Research regarding AIs and chronic non-malignant pain is very limited. More broadly, the literature describes risk factors that incline minorities to a higher burden of pain, including lower income and education and limited access to healthcare. Results from this study reveals new information regarding the chronic pain experience, management strategies and outcomes of AIs. The goal of this study was to increase understanding of the chronic pain experience of AIs for community members, families, and healthcare providers who serve these communities.

The study addressed three research aims by:

Aim 1: Describing NNM AIs experiences with pain.

Aim 2: Describing NNM AIs pain management strategies.

Aim 3: Describing NNM AIs pain outcomes.

Discussion of Results

Pain Experiences of American Indians

The literature review found that AIs may not want to describe their pain, use different forms and patterns of communication related to pain and this may contribute to miscommunication of their level of pain (Haozous & Knobf, 2013; Jimenez et al., 2011; Palit et al., 2013). Findings from this study differed as the participants easily and readily described their chronic non-malignant pain experiences. Pain experiences were diverse, yet a pattern of similar themes emerged from these experiences. The most frequent pain experiences across the sample (n=14) included body awareness (50%), unpredictability of pain (50%), psychological outcomes (50%) and body as confining (57%). The nature of living with pain over time allows an awareness and knowledge of one's body, which helps to act in ways as to prevent exacerbating or initiating pain. Yet, many of the participants felt restricted by the limitations of their own bodies when experiencing pain and its ensuing unpredictability. Such experiences are linked to psychological outcomes. Numerous qualitative studies support these pain experiences findings (Miles, Curran, Pearce, & Allan, 2005; Bailly, Foltz, Rozenberg, Fautrel, & Gossec, 2015; Bunzli et al., 2013; Bunzli et al., 2016; Snelgrove & Liossi, 2013; Hui Lin et al., 2014). A qualitative meta-synthesis of chronic pain experience across conditions found there were more similarities than differences in pain experiences, despite the location of the pain or the organic cause (Crowe et al., 2017).

Physical and social environmental variables provide the context within which the pain experience occurs. Various physical environments exacerbated pain for many of the participants. Material support (e.g., getting a ride from a friend to a doctor's appointment) and emotional support (e.g., having an active listener) were frequently mentioned by participants (57% each). Family members and friends were the most important source of emotional support, whether it was positive or negative. This may reflect the importance of family and community for AIs (Boyd & Thin Elk, 2008).

Demographic variables were used to compare and contrast pain experiences. Pain experiences differed for the males and females in this study. The literature shows that chronic pain is more prevalent in women and women tend to report greater pain severity and disability and are more often psychologically affected by their pain (Racine et al., 2014). For this sample, psychological outcomes and body as confining were referred to often by the females (67%), whereas pain as metaphor and the unpredictability of pain were the main experiences for the males (60%).

Employment status resulted in differences in pain experience. The employed groups' most common experiences were body awareness, maintaining normality, body as confining and altered sense of self (57% each). While the unemployed leading experience was psychological outcomes (67%). Studies demonstrate that chronic pain sufferers with low socioeconomic status may adapt poor coping strategies and have higher levels of distress linked to their pain (Day & Thorn, 2010).

Both urban and rural participants' most frequent experiences were body as confining, body awareness and the unpredictability of pain. Alteration to sense of self was the most common experience for the urban group, but rarely for the rural group. Psychological outcomes were recurrently mentioned for the rural residents, but not the urban. Rural residency is found to be related to higher prevalence of chronic pain and other psychiatric and medical comorbidities, namely depression (Kapoor, Thorn, & Thorn, 2014).

Chronic Pain Management

This research seeks to build on the narrow knowledge we have about chronic non-malignant pain management for AIs. The participants had a long history of experience with chronic pain (mean = 16 years) and numerous interventions for the treatment of pain were tried over the years. Use of a wide variety of pain management strategies was found in another study of AIs in the Pacific Northwest and Southwest (Haozous, Doorenbos, & Stoner, 2014). Chronic pain is difficult to manage, with no cure for many conditions related to pain. Patient-centered stepwise treatment approaches are the cornerstone of treatment recommendations. The literature on chronic non-malignant pain management shows little to no evidence supporting the sole or preferential use of opioids and includes interdisciplinary multi-modal approaches (Prunuske et al., 2014; Reinecke et al., 2015). The opioid overdose epidemic is changing the landscape of prescribing patterns in family medicine and recommendations for use with chronic pain are weak (Finnerup et al., 2015). Intervention recommendations are largely similar across chronic pain conditions and the evidence supporting various treatments varies (Babatunde et al., 2017). Physical therapy is the most frequently recommended strategy, although the supporting evidence for various chronic pain conditions varies (Chaibi, Tuchin, & Russell, 2011; Semmons, 2016). Mind/body interventions (e.g., guided imagery, biofeedback, relaxation) and exercise-based techniques (e.g., yoga, qigong and tai chi) are strongly recommended (Ablin et al., 2013; Lauche, Cramer, Hauser, Dobos & Langhorst, 2015). Acupuncture and massage evidence varies, yet chronic pain sufferers praise their short-term benefits (Ablin et al., 2013; Lauche et al., 2015).

Biomedical medications were the most frequently implemented strategy for this sample. Opioids were the leading medication tried (71%), followed by analgesics, NSAIDs, anticonvulsants, and salicylates. To note, opioids were tried in the past, but only two participants reported daily use and four use them sparingly. Physical therapy was the leading professional strategy, although no one was currently attending. Self-care strategies varied widely across the sample. Stretching was the most common self-care intervention (43%). Cross and Day (2015) found a lack of compliance for following healthcare provider recommendations for more than half of participants in a study of AIs across the nation. They attributed this finding to possible cultural differences between the provider and the patient.

The environmental factors that influence pain management refers to the context within which pain occurs and included physical, social and cultural variables. Some evidence addressing cultural beliefs of AIs and pain management reveal a fear of addiction to opioids and a general disbelief in biomedical medications (Jiminez et al., 2011). This study fairly supports these findings as 36% discussed their fear of addiction and beliefs in their traditional health practices (21%) (e.g., herbal medication preferred over a prescribed medication). A majority of the participants preferred to not take opioids due to their adverse effects (57%). Adverse effects of opioids were found to be a common aversion to taking such medications in a study examining cancer pain experiences of AIs (Haozous & Knobf, 2013). A few of the participants talked about their preference for traditional healing and ways, including sweat lodges, medicine men and cannabis as a plant provided by the earth. Evidence shows that most AIs use a combination of traditional and biomedical interventions for their chronic pain (Campbell & Edwards, 2012).

Social environment plays a large role in how pain is treated and refers to one’s social support network and interpersonal relationships. Unsupportive healthcare provider relationship was the most frequent response for this social environment category (57%). Other studies show that people with chronic pain are often stigmatized or stereotyped as drug seekers by healthcare providers and a barrier to treatment for AIs is stigma associated with the use of opioids (Haozous et al., 2011; Meghani et al., 2012; Vallerand & Nowak, 2010). The respondents referred to the importance of supportive family/friend relationships (43%) to provide a network of various resources needed to manage pain. Social support, whether coming from family, friends or healthcare providers, is found to be related to improved health outcomes (Brooks, Andrade, Middleton & Wallen, 2014).

Living in a rural area, being a minority, gender and socioeconomic status contribute to the risk for inadequate pain treatment (Mossey, 2011). Demographic variables were used to compare and contrast participants' responses, including place of residence, gender, and education level. Opioids were more frequently prescribed for rural residents, males, and those with a high school education or less. Rural residents and their providers may feel that opioid prescription is the only plausible option for pain management due to financial and time constraints.

Women utilized medications more than men. Of note, two women were taking an antidepressant related to their pain. Population-based studies report that women are more likely to be prescribed muscle relaxers, anticonvulsants and antidepressants (Racine et al., 2014). Other studies report that women are more likely to have their pain characterized as emotional and psychogenic (Bartley & Fillingim, 2013).

No differences were found between urban and rural residents for physical therapy, counseling and chiropractor in this sample. This differs from the literature on this topic, which demonstrates that rural areas are more likely to lack chronic pain management resources that are available in urban areas (Bakitas, Clifford, Dionne-Odom, & Kvale, 2015; Day & Thorne, 2010; Prunuske et al., 2014). Multi-modal approaches to pain management are often recommended, such as physical therapy, behavioral health interventions, and acupuncture (Prunuske et al., 2014). One participant referred to living in a remote area where access to acupuncture did not seem plausible and driving to attend physical therapy was too much of a time burden. In addition, as previously noted, the largely rural state of New Mexico has a behavioral health shortage (Beals et al., 2005).

Women implemented professional interventions more frequently than men, including physical therapy, massage, counseling and chiropractor. A majority (80%) of the males never went to physical therapy. Findings were similar for the education groupings as the high school or less group were all male and those with a college education included only one male.

The number of different self-care strategies implemented by the rural group was greater than the urban group. This makes sense as rural residents are more apt to delay seeking healthcare and tolerate ill health longer due to accessibility and cost issues (Buehler, Malone & Majerus-Wegerhoff, 2006; Long, 1993). The literature shows that traditional healing may be important for both rural and urban populations (Jimenez et al., 2011). One rural and one urban participant utilized sweat lodges and medicine men in the past for their pain.

Women tried more self-care strategies than the men. Although, ETOH and cannabis use was only prevalent with the male group. A large population based study found that men more frequently used alcohol and cannabis to manage their chronic pain compared to their female counterparts (Racine et al., 2014). The same study reported that women utilized natural products more often than the men. The same findings were reflected in this sample. The participants with a high school education or less implemented the least number of self-care strategies as compared to the college or more group.

Pain Outcomes

Research shows that chronic pain may lead to a decrease in resource availability over time, which can compound stress and lead to a cascade of increased risk-taking behavior, a decrease in health status, adverse outcomes and overall decreased quality of life (Meghani et al., 2012). This study describes outcomes stemming from the pain experience and management, including functional status, healthcare utilization, costs and quality of life. The Symptom Management Theory was used as a theoretical framework and recognizes that the concepts pain experience, management and outcomes influence each other in a bi-directional manner.

All the participants (n=14) expressed one or more functional limitations due to their pain, with walking, sports/exercise, social activities and employment being the most common. Native Americans have some of the highest rates of disability when compared to other race or ethnic groups (Goins et al., 2010; Ni et al., 2011). Cross and Day (2015) conducted a study, which found a high prevalence of functional disabilities regardless of age, gender or reservation status with a sample of 75 AIs.

Costs are defined as the expenditure of something necessary for the attainment of a goal and included time, financial and health insurance status for this sample. The time taken to coordinate pain care was significant for participants. Financial worries impacted pain experience and management choices. Several participants were unable to work due to their pain. The literature reflects these findings where chronic pain is linked with various costs, such as disability, lost income and higher health care utilization (Meghani et al., 2012). The large majority of this sample had health insurance, yet co-pays, deductibles and specific coverage for various treatments were frequently mentioned concerns.

Quality of life (QOL) is defined numerous ways in the literature and was condensed into sub-categories for this study. Emotional well-being was the most frequent factor for the QOL category (71%). Participants referred to positive and negative aspects, which have changed over time in relation to their chronic pain. Many described how difficult their experiences were when they were first experiencing their pain, including depression and suicidal thoughts, and how they learned to cope. Self-image and self-esteem were linked to weight gain resulting from decreased activity level and the chronicity of pain. Loss of social role was frequently mentioned, ranging from decreased ability to socialize and inability to perform parental roles due to chronic pain. Similar findings regarding loss of self-esteem, depression, and loss of normative roles were reported in another qualitative study on chronic pain and QOL outcomes (Vallerand & Nowak, 2009).

Healthcare utilization refers to the use of healthcare services or resources available. Very few (21%) participants were currently accessing their healthcare through the Indian Health Service (IHS). Reasons for not going to IHS ranged from past negative experiences, not having access (geographic location), and needing specialty services not available at most IHS hospitals/clinics. Indian Health Services does not offer pain specialty care, such as pain specialists. Other services offered are highly variable between sites and if a specialty is offered it usually comes in the form of a contracted provider coming to an IHS facility at certain intervals (e.g., rheumatologist that comes once per month), not as a full-time employee. The underfunding of IHS as discussed earlier in this paper contributes to the limited services available for chronic pain care. The woman interviewee who did not receive an injection, as she perceived was due to costs, illustrates this point. The IHS has a drug formulary and when they do not carry a drug, the healthcare provider may attempt to attain the drug and entails researching the costs and supporting evidence to use the drug. The IHS has to carefully consider cost decisions due to their limited budget.

Others were seeing a primary care provider (PCP) through a private practice (29%) or a non-profit integrative medicine clinic (43%). The integrative clinic offers family medicine, behavioral health, massage, traditional healing, and acupuncture. Although, only one person spoke about using their sweat lodge and one other was receiving counseling at this clinic. Others saw their PCP and/or accessed the clinic's services for the homeless (i.e., food and bus passes). Some participants (21%) had to utilize more than one healthcare provider, with resulting coordination of care frustrating and time consuming.

As discussed earlier, the majority of participants had health insurance, with about half using Medicare and/or Medicaid and about half private. Health insurance dictates the care one can receive. For example, public insurance does not cover acupuncture, massage or chiropractors, but a private health insurance plan might. The one participant that had acupuncture did state that her insurance covered it and she only paid her co-pay. Medicare and private insurance involves cost sharing as coverage is not 100% of billings, whereas in NM, Medicaid for AIs has no cost sharing involved. Such costs prevented some from receiving the care they needed.

Social acceptability is closely related to costs and healthcare utilization. A discussion regarding cannabis illustrates this point. Cannabis use for chronic pain is increasingly a viable option. With legalization in numerous states for medical and recreational use, it becomes more acceptable to the general public. The Food and Drug Administration (FDA), classified medical marijuana as a Schedule I drug, does not approve the drug and therefore, health insurance does not cover those costs. Those with chronic pain may benefit with relief from pain, yet unable to afford procurement. Cannabis was a favored treatment for a few males in this study and they referred to costs and trying to obtain the medication in a legal fashion. A female mentioned that she heard that marijuana may help her condition, but does not use it because her fear of losing her job precludes its use.

There were gender and residence related differences found in functional status and healthcare utilization outcomes. Cost and QOL outcomes were not significantly different between the demographic subgroups of this sample. The groupings for education were not found to be unlike gender. Walking was a frequent limitation for both males and females. Social activity limitations were common for the women (67%), but not at all for the men. Disrupted sleep was often revealed by males, but seldom for the female group. A large study comparing gender outcomes found no significant difference between males and females for functional status, pain related sleep problems, and psychological outcomes (Racine et al., 2014).

Rural and urban residents in this sample frequently discussed walking difficulties related to their pain. Sports/exercise and social activities were raised by the majority of urban participants. Yet, fewer rural residents mentioned other limitations, including driving (43%), employment, social activities, sports/exercise and sitting (29% each). Living in a rural area may relate to social isolation regardless of pain experience.

An equal number of urban and rural residents received their healthcare from the integrative medicine clinic. The urban group had more participants with a private PCP than the rural group. Although not a majority, the rural residents were more likely to utilize IHS than the urban group. Two of the rural participants of this sample used IHS to avoid paying co-pays to see a private provider or they felt IHS was their only choice.

Healthcare utilization differed by gender. Females accessed IHS in the past and presently, while no males referred to ever going to IHS. The female group had private health insurance more frequently (56%) than the males (20%). A large number of the males utilized the integrative medicine clinic. Population-based studies report that women tend to utilize healthcare resources at a higher rate than men (Racine et al., 2014).

Implications for Clinical Practice

The understanding of the pain experience can lead to more appropriate, whole person/holistic interventions. Variability in symptoms, pain intensity, psychological responses, coping abilities and responses to treatment need to be taken into consideration when caring for chronic pain patients. Although the diagnoses related to participants' pain varied, an interdisciplinary multi-modal approach to pain management may be appropriate across conditions (IOM, 2011). The Symptom Management Theory (SMT) recognizes that adherence to a pain management strategy is related to a number of factors that go beyond clinicians' usual understanding of 'non-compliance.' This study reflects the importance of understanding a patient's reasoning for non-compliance. The patient may lack knowledge of what the recommended intervention entails and may misunderstand their ability to follow through on the recommendation, as reflected in several of the participants' reasoning for not trying physical therapy. Patient-centered care and shared decision making relies on healthcare providers to discuss what their patients' expectations, misperceptions and fears are to enhance intervention adherence (Spitaels et al., 2017).

Implications for Theoretical Model

The Symptom Management Theory (SMT) provides a comprehensive approach to understanding the various dimensions of chronic pain. The chronicity of pain is dynamic and is reflected in the bi-directional arrows of the theory illustrating the interrelatedness of the pain experience, management and outcomes. The SMT was chosen to guide this study for the above reasons and particularly due to the recognition of the influence of the contextual environment on the elements of the theory.

The SMT defines the symptom experience to encompass an individual’s perception of a symptom, evaluation of the meaning of a symptom and response to a symptom (Dodd et al., 2001). Perception of pain entails when a person notices a variation from the way one usually feels or behaves. Evaluation of pain refers to making judgements about the pain, such as the severity, location, temporal nature and effect of pain on their lives. This also includes evaluating the threat of pain, is it ‘dangerous’ or disabling? Is the pain bad enough to disrupt everyday life? When one has long experience with pain, then accounts of the quality of pain are better described. Responses to pain include physiological, psychological, sociocultural and behavioral components.

Challenges with Symptom Management Theory (SMT)

The authors of the SMT recognize that an issue arises with distinguishing perception from evaluation of a symptom and that there is little data to distinguish between these two concepts. They try to distinguish them by stating perception is simply recognizing the sensation, whereas evaluation involves a higher cognitive process of attaching meaning to symptom. Yet, when conducting qualitative interviews, it becomes difficult to separate whether a description of a pain experience would be categorized as a perception or an evaluation of pain. For example, when a participant states that their pain is sharp, one may think that they are perceiving a change within their body, yet they are making a judgement of what the pain feels like. During an interview, a participant is describing and thinking about what an experience means to them.

Therefore, when analyzing the data for this study, I found it very difficult to separate experiences into categories of perception, evaluation and response. The few times that I was able to do this were times when the participants' experiences were extreme. For example, participant four suddenly lost her ability to walk. She is obviously recounting a perceived change in her body. She then describes how she handled this situation, which entails an evaluation and response to her not being able to walk. Perhaps another remaining issue with the SMT factors into this problem, which is that the theory does not differentiate between acute and chronic symptoms. If one were conducting a study about an acute symptom process, then differentiating between perceptions and evaluations would be more logical.

The social environment is commonly related to the 'social determinants of health.' Social determinants of health include healthcare access, social and community context, education, economic stability and neighborhood and built environment (US Department of Health & Human Services, 2017). The SMT's definition of social environment was different and defined as interpersonal relationships. Variables of the social determinants of health were scattered throughout the theory. For example, factors such as financial costs and healthcare utilization were categorized as symptom outcomes, rather than as the social environment context. In addition, analysis revealed overlapping of many of the elements of the theory and it was sometimes difficult to determine how a quote should be coded or categorized. Yet, one may recognize that it is not always possible to create mutually exclusive categories when dealing with the complexity of human experiences (Graneheim & Lundman, 2004).

Study Strengths

The common themes found in this study are consistent with other studies regarding chronic non-malignant pain and minorities and provides new information about AIs. To this researcher's knowledge, this is the first qualitative descriptive (QD) study to describe AI chronic non-malignant pain experiences, strategies and outcomes. This dissertation provides important information regarding AI patient, healthcare provider and healthcare system related facilitators and barriers to adequate treatment of chronic non-malignant pain. The use of QD design provided a description of a poorly understood topic and offers valuable insights into a hard to reach population. The diversity of this study's demographic characteristics enhanced the findings and contributed to an intricate analysis and understanding of the AI chronic pain experience. The content analysis and matrices methods contributed to a highly nuanced description of the categories and sub-categories extracted from the interviews of this study. Frequencies summarizing the data supplemented the content analysis and contributed to descriptions and staying close to the data.

Study Limitations

The use of QD design is limited. The purpose of this study was a straightforward description of chronic pain experiences, but misses analysis allowing for thick-description, theory development, or meaning of the experience that can be explored with other qualitative designs. The low-inference approach lacks the in-depth complexities of experiences of participants.

The shortage of literature on chronic non-malignant pain in the AI population and the small sample size of this study limits any conclusions that can be made and impedes the generalizability of the data. Generalizability of findings is not a goal of qualitative research and furthermore, the US comprises over 560 diverse AI/AN tribes. The study participants lived in New Mexico, except one participant who now lives in rural Oregon. Although the sample was evenly divided between rural and urban participants, only one lived on a tribal reservation. The chronic pain experience may vary for those living within an AI community as compared to those who do not. Furthermore, the semi-structured interview questions did not ask participants specifically about how living in a rural area affects how they experience and manage their pain and would have been meaningful information to collect. Rurality is intricately related to the social determinants of health. Living in a rural area may compound problems with managing pain, such as limited transportation, healthcare access and culturally competent healthcare providers. Additionally, the study included only one person over the age of 60. Chronic pain is known to increase with the age of 65 and older. Access to the AI population is limited and therefore, sampling was targeted toward AIs with chronic pain generally, rather than targeting participants who took opioids and/or were on a pain contract/agreement.

Knowing the risk factors for undertreated pain, it would have been useful to collect demographic information on income. Low socioeconomic status encompasses education and income levels. One must not conflate income with employment status. An employed person may still live below the poverty line as is the case for a proportion of AIs living in New Mexico.

In addition, a large number of qualitative studies on chronic pain include data collection using a tool, such as the Brief Pain Inventory-Short Form (BPI-SF), to assess pain severity. Pain severity relates to many factors that were examined in this study, such as functional status and

QOL. Although participants were able to describe their pain, a severity comparison was not possible and therefore, using the BPI-SF or similar tool would enrich the data collected.

Future Research

More research is needed to advance understanding of AI chronic pain experiences. Other methodologies are important to gaining this knowledge and giving a voice to those AIs living with chronic pain, such as community based participatory research, which allows community members to be guides of their own inquiry, and critical ethnographies.

Some patients are unable or unwilling to follow through on biomedical and professional recommendations, due to cost (financial and time) and personal belief barriers. A number of self-management strategies can be taught. Future research should investigate the development of training programs for healthcare providers, including nurses, in cognitive behavioral pain management techniques, such as those described by the Haozous et al. (2014) study. Such interventions are mainly taught by behavioral health professionals, but growing evidence shows that it can be implemented by other providers and maybe lay people; more research is needed to support positive outcomes (Nicholas, 2015).

Further research on pain agreements and opioid monitoring practices remains important. Numerous pain experts, professional societies, regulatory agencies, and IHS recommend their use. Little is known in regards to outcomes of these practices, such as pain treatment disparities and opioid dependence, overdose, or death.

Conclusion

The aim of this qualitative descriptive study was to describe AIs chronic pain experiences, management strategies and outcomes. Findings from this study differ from the dominant narratives that AIs have different forms and patterns of communicating their chronic pain experiences from their non-Native healthcare providers. The participant pain experiences were reflective of other qualitative study findings and suggest experiences are more similar than different across pain conditions.

Although the US has seen a marked increase in the prescribing of opioids for pain, the participants of this study largely did not use opioids due to their adverse effects. For some, the aversion to medication was shaped by cultural beliefs in the preferential use of traditional healing or tied to fear of becoming addicted to the medication.

Material and positive emotional support was integral to effective pain management. Pain management is related to access to resources. Rurality precluded some pain management strategies, coupled with cost (financial and time) concerns. Indian Health Services was not utilized by the majority of participants and may reflect geographic availability, distrust in US government services, and/or inability to receive services that were needed for pain care.

High rates of functional limitations were found in this sample and this coincides with epidemiological studies' findings that AIs experience a higher prevalence of pain and pain severity. This study described AI patient, healthcare system and sociocultural related barriers to quality pain care and management through the perspective of those directly affected and contributed to increased understanding of the chronic pain experience for community members, families and healthcare providers who serve the AI population.

APPENDIX A:

RECRUITMENT FLYER

Recruiting Native American Study Participants who have Chronic Pain

DO YOU HAVE CHRONIC PAIN?
DO YOU KNOW SOMEONE THAT DOES?
ARE YOU NATIVE AMERICAN?

If so, we want to talk with you!

You are eligible to participate in the study if:

You are 21 years of age or older.

You have experienced pain for three months or longer

You speak English

What would happen if I took part in the study?

If you decide to take part in the study, you would:

- Participate in a 60 – 90 minute face-to-face, phone, or internet initial interview
- May be asked to participate in another 30-minute interview.

To take part in this research study or for more information, please contact the Principal Researcher, Rachel Katonak (call, text, or email):

Phone 718-309-3942 (cell) or rkatonak@email.arizona.edu (email)

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.
Or leave your contact info. on this form and we will contact you.
If you agree to participate, **you will be compensated.**
Name and Contact Info: ____

APPENDIX B:

FACEBOOK RECRUITMENT

THE UNIVERSITY OF ARIZONA

Recruiting Native American Study Participants who have Chronic Pain

DO YOU HAVE CHRONIC PAIN?
DO YOU KNOW SOMEONE THAT DOES?
ARE YOU NATIVE AMERICAN?

If so, we want to talk with you!
You are eligible to participate in the study if:

You are 21 years of age or older.

You have experienced pain for three months or longer

You speak English

What would happen if I took part in the study?

If you decide to take part in the study, you would:

- Participate in a 60 – 90 minute face-to-face, phone, or internet initial interview
- May be asked to participate in another 30-minute interview.
- If you agree to participate, **you will be compensated.**

To take part in this research study or for more information, please contact the Principal Researcher, Rachel Katonak (call, text, or email):

Phone 718-309-3942 (cell) or rkatonak@email.arizona.edu **(email)**

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX C:

EMAIL/LETTER SCRIPT

Email/letter script

Dear (insert name):

I am conducting a research study that is designed to examine experiences with pain and pain agreements, pain management and outcomes (you do not need to know what a pain agreement is in order to participate in the study). Participants eligible to participate in the study will be interviewed for a period of approximately 60- 90 minutes. The interviews will be audio recorded and later transcribed into a document that will be used to analyze responses of all participants. It may be necessary to conduct a second follow up interview that will last approximately 30 minutes for the purpose of clarifying information.

Participation in the study is voluntary. To determine if you're eligible to participate in this study, please contact the Principal Investigator:

Rachel Katonak at 718-309-3942 (cell) or rkatonak@email.arizona.edu (email)

Thank you

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX D:

VERBAL SCRIPT

Verbal Script

Verbal Script for Principle Investigator to Determine Study Eligibility and Continued Interest in Participation:

"Hello, my name is Rachel Katonak and I'm a graduate student in the College of Nursing at the University of Arizona. Is this a good time to talk?

I'm returning your [telephone call/email] about my project researching the chronic pain experience of American Indian [Native American] in Northern New Mexico. Thank you for contacting me.

Are you still interested in hearing more about the study?

[If No]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [day/night]. Goodbye.

[If Yes]: Ok, great. The goal of this study is to increase understanding of the chronic pain experience of Native Americans for community members, families, and healthcare providers who serve these communities. This research aims to describe the chronic pain experience through the perspective of those directly affected. I will be interviewing Native Americans over several months to hear about their experiences.

Is this something you are interested in participating in?

[If No]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [day/night]. Goodbye.

[If Yes]: Ok, great. I need to make sure that you qualify to participate in this study. With your permission, I need to ask you a couple of questions. <u>I will not be recording any of your answers</u>.

1. Do you have or did you have pain that lasted at least three months or longer?
2. Is your pain due to cancer? [Must be no]
3. Do you read and speak English fluently? [Must be yes]
4. Are you over the age of 21? [Must be yes]
5. Will you continue to have access to a telephone or the internet over the next 6 months? [Must be yes]

[Does not qualify to participate]: Unfortunately, you do not qualify to participate in this study. However, I'm extremely grateful for your time [today/tonight] and wish you all the best. Thank you for your time. Goodbye.

[Qualifies to participate]: You meet the criteria to participate in this study. Your participation would be completely voluntary.

Are you still interested in participating?

[If No]: Ok, thank you very much for your time. Thank you again for contacting me, and have a great [day/night]. Goodbye.

[If Yes]: Ok, I'm going to provide you with some more information and schedule your interview. Once again, participation in this study entails being interviewed at least once for up to 90 minutes. A small number of people will be asked for a second interview, lasting about 30 minutes. This process will take up to three months if you continue to be interviewed. <u>You can stop participating at any time</u>. The interviews will take place wherever you feel the most comfortable. The first interview is preferred to be in-person with me, but later interviews may be either in-person or on the telephone, or by using the internet, such as through Skype or FaceTime. The interviews will be audio recorded by me. It’s important that you know that any personal details or information about yourself will be kept confidential.

Do you have any questions about this process?

If you are still interested in participating, let’s schedule your first interview now.

An Institutional Review Board responsible for human subjects’ research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX E:

INTERVIEW GUIDE

Interview Guide

Time of interview:
Date:
Place:
Interviewer:
Interviewee:
(Briefly describe purpose/background of research and interview)

Semi-structured interview questions for Northern New Mexican Native American patients:

Tell me about the steps you take to get relief from your pain?

What prevents you from getting pain relief?

What do you think about taking opioids or narcotics (such as: Oxycodone, OxyContin, morphine, hydrocodone, etc.) for your pain?

Describe how chronic pain has affected your life.

Describe an experience where a family member or healthcare provider did not believe your pain

Tell me about any experience where how you felt your pain should be managed conflicted with the way your doctor (healthcare provider) wanted to treat your pain.

(For those on pain agreement):

How do you feel about being on a pain agreement?

What was your reaction when your provider first asked you to sign a pain agreement?

How have pain agreements affected you getting relief from your pain?

Are there any difficulties with following the rules of your pain agreement?

How has the pain agreement affected your relationship with your healthcare provider?

APPENDIX F:

DEMOGRAPHICS FORM

Project Title: Understanding the pain management and pain agreement experience among Native Americans: A qualitative descriptive proposal

Primary Investigator/Interviewer: Rachel Katonak
Participant Number: _________ **Date (mm/dd/yy):** _________________________
PI/Interviewer to administer to all enrolled participants after Informed Consent is complete.
INTERVIEWER READS: The following are some basic questions regarding your background to help us know what type of people participated in this study. All the information you provide will be kept confidential and will not be shared with anyone else besides the research study staff. You may refuse to answer any of the questions.

What is your age range?	○ **21-30** ○ **31-40** ○ **41-50** ○ **51-60** ○ **61-70** ○ **71 and above** ○ **Prefer not to answer**
What is your self-described gender?	○ **Male** ○ **Female** ○ **Prefer not to answer**
What is your self-described ethnicity and/or race? (Select all that apply)	○ **White (Non-Hispanic)** ○ **African-American/Black** ○ **Hispanic or Latino/Latina** ○ **Asian** ○ **Native Hawaiian or other Pacific Islander** ○ **American Indian or Alaska Native** **Tribal affiliation: ______________** ○ **Prefer not to answer**
What is your current marital status?	○ **Never married** ○ **Married** ○ **Living with a partner** ○ **Separated or divorced** ○ **Widowed** ○ **Prefer not to answer**
What is your current employment status?	○ **Full-time** ○ **Part-time** ○ **Retired** ○ **Student** ○ **Homemaker** ○ **Unemployed** ○ **Unemployed due to disability or**

	illness ○ **Other** ○ **Prefer not to answer**
What is your highest level of education?	○ **Less than high school** ○ **Some high school** ○ **High school graduate** ○ **Trade school** ○ **Some college** ○ **College graduate** ○ **Graduate/professional** ○ **Prefer not to answer**
What community do you live in? (i.e. Santa Fe)	○ **_________________ (fill in blank)** ○ **Prefer not to answer**
If you have a diagnosis associated with your chronic pain, what is your diagnosis? (may be more than one)	○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **Prefer not to answer**
About how long have you lived with chronic pain? (months, years?)	○ **_________________ (fill in blank)**
What medication(s) do you take for your pain, i.e. hydromorphone, Percocet, tylenol	○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** ○ **_________________ (fill in blank)** **Prefer not to answer**
What languages do you speak?	○ **_________________ (fill in blank)** **Prefer not to answer**
Of those languages, which is the one you use most in your home?	○ **_________________ (fill in blank)** **Prefer not to answer**

Notes:

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX G:

THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD APPROVAL LETTER

Date: February 20, 2017
Principal Investigator: Rachel Katonak
Protocol Number: 1702224435
Protocol Title:
Understanding the pain management and pain agreement experience among Native Americans: A qualitative descriptive proposal
Level of Review: Expedited
Determination: Approved
Expiration Date: February 19, 2018
Documents Reviewed Concurrently: Data Collection Tools: DEMOGRAPHICS FORM1.24.17.docx Data Collection Tools: Interview Guide.docx HSPP Forms/Correspondence: f107_v2016-07 Katonak1.24.17.docx HSPP Forms/Correspondence: f200_v2016-07 Katonak draft final.docx HSPP Forms/Correspondence: Signature page.pdf Informed Consent/PHI Forms: INFORMED CONSENT.1.24.17.docx Informed Consent/PHI Forms: INFORMED CONSENT.1.24.17.pdf Recruitment Material: Email.letter script1.24.17.docx Recruitment Material: Final recruitment flyer.facebook1.24.17.docx Recruitment Material: Verbal Script1.24.17.docx
This submission meets the criteria for approval under 45 CFR 46.110, 45 CFR 46.111 and/or 21 CFR 50 and 21 CFR 56. This project has been reviewed and approved by an IRB Chair or designee.
• No changes to a project may be made prior to IRB approval except to eliminate apparent immediate hazard to subjects. • The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218). • All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB. • The current consent with the IRB approval stamp must be used to consent subjects. • The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or others. Please refer to Guidance Investigators Responsibility after IRB Approval and Reporting Local Information. • For projects that wish to continue after the expiration date listed above please submit an F212: Renewal Progress Report, forty-five (45) days before the expiration date to ensure timely review of the project. • All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented the approved consent(s) are attached to the approval notification from the HSPP Office

APPENDIX H:

INFORMED CONSENT

The University of Arizona Consent to Participate in Research

Study Title: Understanding the pain management and pain agreement experience among Native Americans: A qualitative descriptive proposal

Principal Investigator: Rachel Katonak, BSN, RN, PhD Candidate

This is a consent form for research participation. It contains important information about this study and what to expect if you decide to participate. Please consider the information carefully. Feel free to discuss the study with your friends and family and to ask questions before making your decision on whether or not to participate.

Why is this study being done?

The purpose of this study is to describe Northern New Mexico Native Americans' experience with managing their chronic pain and pain agreements or contracts, if they have signed one in the past. This study will explore how American Indians manage their pain in order to improve understanding for the community, the family, and healthcare providers.

What will happen if I take part in this study?

If you choose to take part in this study you will be interviewed in-person, by phone, or over an internet service, such as Skype, by a researcher at least once concerning your experiences with managing your chronic pain. This interview will take place in a private setting of your choosing and last about an hour. A 30 minute follow up interview may be necessary. This additional interview may be conducted either in-person in a private setting of your choice or via telephone or the internet (i.e. Skype, FaceTime, etc.), depending upon your preference and location. All of the interviews will be audio recorded.

How long will I be in the study?

The interviewing process for this study is expected to take a total time of approximately 90 minutes over a period of up to 3 months between the first and the second interview (if a second interview is required).

How many people will take part in this study?

Twenty people with chronic pain will participate in this study.

Can I stop being in the study?

Your participation is voluntary. You may refuse to participate in this study. If you decide to take part in the study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you.

What are the costs of taking part in this study?

There are no costs to you for participating in this study other than your time. The interview will take 60 – 90 minutes. A second interview may be requested of a small number of study participants. The second interview will take up to 30 minutes. If you are unable to meet in person, you will need to have access to a working telephone or the internet.

Will I be paid for taking part in this study?
You will be compensated if you choose to participate in this study. Compensation is in the form of a $30 gift card that will be issued at the completion of each interview. If the interview was conducted on the telephone or internet, the gift card will be mailed to you upon completion of the interview.

By law, payments to subjects may be considered taxable income.
What risks, side effects or discomforts can I expect from being in the study?
This study is anticipated to have minimal risks. There are no physical, social, or legal risks. The economic risk is also considered minimal in the form of the time you spend being interviewed.

What benefits can I expect from being in the study?
A potential benefit to participants is expanded understanding of the chronic pain experience of American Indians (AI) for community members, families, and healthcare providers who serve these communities. This research seeks to build on the narrow knowledge we have about chronic pain management and pain agreements for AIs by describing the experience through the perspective of those directly affected.

What other choices do I have if I do not take part in the study?
You may choose not to participate in this study without penalty or loss of benefits to which you are otherwise entitled.

Will my study-related information be kept confidential?
All efforts will be made to keep your study-related information confidential. However, there may be circumstances where this information must be released. For example, personal information regarding your participation in this study may be disclosed if required by state law.

Also, your records may be reviewed by the following groups:

- Office for Human Research Protections at the University of Arizona
- The University of Arizona Institutional Review Board

Your name, location, and any other identifying details will be removed from all of the recorded interviews or significantly altered by the researcher to ensure confidentiality; this will also occur for any patient identifiers (i.e. diagnosis, tribal affiliation, etc.) that are discussed during interviewing. Again, all identifying details will be either removed from the study or altered so as to be unrecognizable.

Who can answer my questions about the study?

For questions, concerns, or complaints about the study you may contact the researcher, Rachel Katonak, at rkatonak@email.arizona.edu or (718) 390-3942.

If you do not feel comfortable contacting the researcher you may contact Dr. Michelle Kahn-John at mkahnjohn@email.arizona.edu or 520-626-4736.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at the University of Arizona at 520-626-6721 or online at VPR-IRB@email.arizona.edu

An Institutional Review Board (IRB) responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research. The UA IRB may be reached at VPR-IRB@email.arizona.edu

Signing the consent form

I have read (or someone has read to me) this form and I am aware that I am being asked to participate in a research study. I have had the opportunity to ask questions and have had them answered to my satisfaction. I voluntarily agree to participate in this study.

I am not giving up any legal rights by signing this form. I will be given a copy of this form.

______________________________	______________________________
Printed name of subject	**Signature of subject**
	______________________________
	Date and time

APPENDIX I:

ETIC CODES AND DEFINITIONS

Etic code	**Definition**
Environment	physical, social and cultural context within which a symptom occurs
healthcare utilization	Planning and directing the course of one's healthcare, which includes the utilization of hospital/facility resources, medications, and healthcare providers
Outcomes: cost	Expenditure of something, such as time or labor, necessary for the attainment of a goal. Cost includes financial status and health services utilization
Outcomes: functional status	Functional status is an individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being
Outcomes: quality of life	Broad multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life, including life satisfaction, physical and mental health, leisure time and social belonging. Aspects of culture, values, and spirituality are also key domains of overall quality of life.
Pain agreement or contract	healthcare providers use to monitor patients' adherence, or to help check that patients are compliant with the medications ordered. Such agreements are most commonly used when narcotic pain relievers are prescribed.
symptom experience	Symptom experience is dynamic, involving the interaction of the patient's perception of a symptom, evaluation of the meaning of a symptom and response to a symptom.
symptom management: what	Symptom management includes the nature of the intervention, which depends on the state of the science for the particular symptom. Goal of symptom management is to avert or delay a negative outcome through biomedical, professional, and self-care strategies.
Symptom management: adverse effects	undesired harmful effect resulting from a medication

REFERENCES

Ablin, J., Fitzcharles, M. A., Buskila, D., Shir, Y., Sommer, C., & Häuser, W. (2013). Treatment of fibromyalgia syndrome: recommendations of recent evidence-based interdisciplinary guidelines with special emphasis on complementary and alternative therapies. *Evidence-Based Complementary and Alternative Medicine, 2013*.

Allegretti, A., Borkan, J., Reis, S., & Griffiths, F. (2010). Paired interviews of shared experiences around chronic low back pain: Classic mismatch between patients and their doctors. *Family Practice, 2*7(6), 676-683.

American Academy of Pain Medicine (AAPM) (2013). Use of opioids for the treatment of chronic pain: a statement from the American Academy of Pain Medicine. Retrieved from http://www.painmed.org/files/use-of-opioids-for-the-treatment-of-chronic-pain.pdf

American Geriatrics Society Panel (2009). Pharmacological management of persistent pain in older persons. *Journal of American Geriatrics Society, 57*, 1331-1346.

Anderson, K. O., Green, C. R., & Payne, R. (2009). Racial and ethnic disparities in pain: causes and consequences of unequal care. *The Journal of Pain, 10*(12), 1187-1204.

Arnold, R. M., Han, P. K., & Seltzer, D. (2006). Opioid contracts in chronic nonmalignant pain management: objectives and uncertainties. *The American Journal of Medicine, 119*(4), 292-296.

Artnak, K. E., McGraw, R. M., & Stanley, V. F. (2011). Health care accessibility for chronic illness management and end-of-life care: a view from rural America. *The Journal of Law, Medicine & Ethics*, *39*(2), 140-155.

Averill, J. (2002). Matrix analysis as a complementary analytic strategy in qualitative inquiry. *Qualitative Health Research*, *12*(6), 855-866.

Babatunde, O. O., Jordan, J. L., Van der Windt, D. A., Hill, J. C., Foster, N. E., & Protheroe, J. (2017). Effective treatment options for musculoskeletal pain in primary care: a systematic overview of current evidence. *PloS one*, *12*(6), e0178621.

Bailly, F., Foltz, V., Rozenberg, S., Fautrel, B., & Gossec, L. (2015). The impact of chronic low back pain is partly related to loss of social role: a qualitative study. *Joint Bone Spine*, *82*(6), 437-441.

Bair, M. J., Matthias, M. S., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Kroenke, K., & Damush, T. M. (2009). Barriers and facilitators to chronic pain self-management: a qualitative study of primary care patients with comorbid musculoskeletal pain and depression. *Pain Medicine, 10*(7), 1280-1290.

Bakitas, M. A., Clifford, K. N., Dionne-Odom, J. N., & Kvale, E. (2015). Rural palliative care. In Ferrell, B.R., Coyle, N. & Paice, J.A. (Eds.), *Oxford textbook of palliative nursing* (4th Ed) (pp. 812-822). Oxford: Oxford University Press.

Barnes, P. M., Powell-Griner, E., & Adams, P. F. (2010). Health characteristics of the American Indian and Alaska Native adult population, United States, 2004-2008. Retrieved from http://www.cdc.gov/nchs/data/nhsr/nhsr020.pdf

Beals, J., Novins, D. K., Whitesell, N. R., Spicer, P., Mitchell, C. M., & Manson, S. M. (2005). Prevalence of mental disorders and utilization of mental health services in two American Indian reservation populations: mental health disparities in a national context. *American Journal of Psychiatry, 162*(9), 1723-1732.

Becker, W. C., Starrels, J. L., Heo, M., Li, X., Weiner, M. G., & Turner, B. J. (2011). Racial differences in primary care opioid risk reduction strategies. *The Annals of Family Medicine, 9*(3), 219-225.

Bergman, A. A., Matthias, M. S., Coffing, J. M., & Krebs, E. E. (2013). Contrasting tensions between patients and PCPs in chronic pain management: a qualitative study. *Pain Medicine*. Advance online publication. doi:10.1111/pme.12172

Betancourt, J. R., Green, A. R., Carrillo, J. E., & Ananeh-Firempong 2nd, O. (2003). Defining cultural competence: a practical framework for addressing racial/ethnic disparities in health and health care. *Public Health Reports, 118*(4), 293.

Bigfoot, D. S. & Schmidt, S. R. (2010). Honoring children, mending the circle: cultural adaptation of trauma-focused cognitive-behavioral therapy for American Indian and Alaska Native children. *Journal of Clinical Psychology*, *66*(8), 847-856.

Blyth, F. M. (2010). The demography of chronic pain: an overview. *Chronic Pain Epidemiology From Aetiology to Public Health*, 19-29.

Braun, K. L., Browne, C. V., Ka‘opua, L. S., Kim, B. J., & Mokuau, N. (2014). Research on indigenous elders: from positivistic to decolonizing methodologies. *The Gerontologist, 54*(1), 117-126.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*, 77-101.

Brooks, A. T., Andrade, R. E., Middleton, K. R., & Wallen, G. R. (2014). Social support: a key variable for health promotion and chronic disease management in Hispanic patients with rheumatic diseases. *Clinical Medicine Insights. Arthritis and Musculoskeletal Disorders, 7*, 21.

Buehler, J. A., Malone, M., & Majerus-Wegerhoff, J. M. (2006). Patterns of responses to symptoms in rural residents: the symptom-action-time-line process. *Rural Nursing: Concepts, Theory, and Practice, 2*, 129-137.

Bunzli, S., McEvoy, S., Dankaerts, W., O'Sullivan, P., & O'Sullivan, K. (2016). Patient perspectives on participation in cognitive functional therapy for chronic low back pain. *Physical Therapy*, *96*(9), 1397-1407.

Burchman, S. L. & Pagel, P. S. (1995). Implementation of a formal treatment agreement for outpatient management of chronic nonmalignant pain with opioid analgesics. *Journal of Pain and Symptom Management, 10*(7), 556-563.

Caelli, K., Ray, L., & Mill, J. (2003). "Clear as mud": toward greater clarity in generic qualitative research. *International Journal of Qualitative Methods, 2*(2), 1-13.

Campbell, C. M. & Edwards, R. R. (2012). Ethnic differences in pain and pain management. *Pain, 2*(3), 219-230.

Campesino, M. & Koithan, M. (2004). An exploration of perceived racial/ethnic discrimination in cancer care delivery. Retrieved from https://d2l.arizona.edu/d2l/le/content/392596/viewContent/3078078/View

Centers for Disease Control (CDC) and National Center for Health Statistics (NCHS) (2010). Health, United States, 2010. *Chartbook, special feature on death and dying*. Hyattsville, MD: CDC and NCHS.

Centers for Medicare & Medicaid Services (CMS) (2014). Partners in integrity: what is a prescriber’s role in preventing the diversion of prescription drugs? Retrieved from https://www.cms.gov/medicare-medicaid-coordination/fraud-prevention/medicaid-integrity-education/provider-education-toolkits/downloads/prescriber-role-drugdiversion.pdf

Centers for Medicare & Medicaid Services (2016). *Health disparities*. Retrieved from https://www.medicaid.gov/medicaid-chip-program-information/by-topics/data-and-systems/health-disparities.html

Chae, D. H. & Walters, K. L. (2009). Racial discrimination and racial identity attitudes in relation to self-rated health and physical pain and impairment among two-spirit American Indians/Alaska Natives. *American Journal of Public Health, 99*(1), S144.

Chelminski, P. R., Ives, T. J., Felix, K. M., Prakken, S. D., Miller, T. M., Perhac, J. S., ... & Pignone, M. P. (2005). A primary care, multi-disciplinary disease management program for opioid-treated patients with chronic non-cancer pain and a high burden of psychiatric comorbidity. *BMC Health Services Research, 5*(1), 3.

Cheung, C. W., Qiu, Q., Choi, S. W., Moore, B., Goucke, R., & Irwin, M. (2014). Chronic opioid therapy for chronic non-cancer pain: a review and comparison of treatment guidelines. *Pain Physician, 1*7(5), 401-414.

Chou, R., Fanciullo, G. J., Fine, P. G., Adler, J. A., Ballantyne, J. C., Davies, P., ... & Miaskowski, C. (2009). Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain. *The Journal of Pain, 1*0(2), 113-130.

Chou, R., Turner, J. A., Devine, E. B., Hansen, R. N., Sullivan, S. D., Blazina, I., ... & Deyo, R. A. (2015). The effectiveness and risks of long-term opioid therapy for chronic pain: a systematic review for a National Institutes of Health Pathways to Prevention Workshop. *Annals of Internal Medicine*, *162*(4), 276-286.

Clark, A. M., Lissel, S. L., & Davis, C. (2008). Complex critical realism: tenets and application in nursing research. *Advances in Nursing Science, 31*(4), E67-E79.

Clancy, M. (2013). Is reflexivity the key to minimizing problems of interpretation in phenomenological research? *Nurse Researcher, 20*(6), 12-16.

Cohen, M., Quintner, J., Buchanan, D., Nielsen, M., & Guy, L. (2011). Stigmatization of patients with chronic pain: the extinction of empathy. *Pain Medicine, 12*(11), 1637-1643.

Compton, P. A., Wu, S. M., Schieffer, B., Pham, Q., & Naliboff, B. D. (2008). Introduction of a self-report version of the prescription drug use questionnaire and relationship to medication agreement noncompliance. *Journal of Pain and Symptom Management, 36*(4), 383-395.

Coyle, N. (2015). *Introduction to palliative nursing ca*re. In Ferrell, B.R., Coyle, N. & Paice, J.A. (Eds.), Oxford Textbook of Palliative Nursing (4th Ed) (pp. 3-10). Oxford: Oxford University Press.

Creswell, J. W. (2013). *Qualitative inquiry and research design: choosing among five approaches*. London: Sage Publications.

Creswell, J.W. (1998). *Qualitative inquiry and research design: choosing among five traditions.* Thousand Oaks, CA: Sage Publications.

Cross, S. L. & Day, A. G. (2015). American Indians' response to physical pain: functional limitations and help-seeking behaviors. *Journal of Social Work in Disability & Rehabilitation*, *14*(3-4), 176-191.

Crowe, M., Whitehead, L., Seaton, P., Jordan, J., Mccall, C., Maskill, V., & Trip, H. (2017). Qualitative meta-synthesis: the experience of chronic pain across conditions. *Journal of Advanced Nursing*, *73*(5), 1004-1016.

Crowley-Matoka, M. (2013). How to parse the protective, the punitive and the prejudicial in chronic opioid therapy? *Pain, 154*(1), 5-6.

Daley, C. M., Filippi, M., James, A. S., Weir, M., Braiuca, S., Kaur, B., Choi, W. S., & Greiner, A. (2012). American Indian community leader and provider views of needs and barriers to mammography. *Journal of Community Health, 37*, 307-315.

Day, M. A. & Thorn, B. E. (2010). The relationship of demographic and psychosocial variables to pain-related outcomes in a rural chronic pain population. *PAIN®, 151*(2), 467-474.

Denny, E. (2009). I never know from one day to another how I will feel: pain and uncertainty in women with endometriosis. *Qualitative Health Research, 19*(7), 985-995.

Department of Veterans Affairs (2014). Informed consent for long-term opioid therapy for pain. Retrieved from http://www1.va.gov/vhapublications/ViewPublication.asp?pub_ID=3005

Deyo, R. A., Mirza, S. K., & Martin, B. I. (2006). Back pain prevalence and visit rates: estimates from US national surveys, 2002. *Spine, 31*(23), 2724-2727.

Deyo, R. A., Von Korff, M., & Duhrkoop, D. (2015). Opioids for low back pain. *BMJ, 350*, g6380.

Dilworth-Anderson, P., Pierre, G., & Hilliard, T. S. (2012). Social justice, health disparities, and culture in the care of the elderly. *Journal of Law, Medicine & Ethics, 40*(1), 26-32.

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., ... & Taylor, D. (2001). Advancing the science of symptom management. *Journal of Advanced Nursing, 33*(5), 668-676.

Dowell, Haegerich, & Chou (2016). Morbidity and Mortality Weekly Report (MMWR): CDC guideline for prescribing opioids for chronic pain. — United States, 2016. Retrieved from https://www.cdc.gov/mmwr/volumes/65/rr/rr6501e1.htm

Duran, E., Duran, B., Heart, M. Y. H. B., & Horse-Davis, S. Y. (1998). Healing the American Indian soul wound. In *International handbook of multigenerational legacies of trauma* (pp. 341-354). Springer US.

Dutton, B. P. (1983). *American Indians of the Southwe*st. Albuquerque: UNM Press.

Fink, R. M., Gates, R. A., & Montgomery, R. K. (2015). *Pain assessment*. In Ferrell, B.R., Coyle, N. & Paice, J.A. (Eds.), Oxford Textbook of Palliative Nursing (4th Ed) (pp. 3-10). Oxford: Oxford University Press.

Finnerup, N. B., Attal, N., Haroutounian, S., McNicol, E., Baron, R., Dworkin, R. H., ... & Kamerman, P. R. (2015). Pharmacotherapy for neuropathic pain in adults: a systematic review and meta-analysis. *The Lancet Neurology*, *14*(2), 162-173.

Fishman, S. M., Young, H. M., Lucas Arwood, E., Chou, R., Herr, K., Murinson, B. B., ... & Bakerjian, D. (2013). Core competencies for pain management: results of an interprofessional consensus summit. *Pain Medicine*, *14*(7), 971-981.

Garrett, M. T., Torres Rivera, E., Dixon, A. L., & Myers, J. E. (2009). Acculturation and wellness of Native American adolescents in the United States of North America. *Perspectivas Sociales*, *1*1(1 y 2), 41-67.

Glass, N. & Davis, K. (2004). Reconceptualizing vulnerability deconstruction and reconstruction as a postmodern feminist analytical research method. *Advances in Nursing Science, 27*(2), 82-92.

Glesne, C. (1999). *Becoming qualitative researchers: an introduction.* New York, NY: Longman.

Goldberg, K. C., Simel, D. L., & Oddone, E. Z. (2005). Effect of an opioid management system on opioid prescribing and unscheduled visits in a large primary care clinic. *JCOM, 12*(12), 621-628.

Gone, J. P. (2004). Mental health services for Native Americans in the 21st century United States. *Professional Psychology: Research and Practice, 35*(1), 10.

Gone, J. P. & Trimble, J. E. (2012). American Indian and Alaska Native mental health: diverse perspectives on enduring disparities. *Annual Review of Clinical Psychology, 8,* 131-160.

Goodkind, J. R., Gorman, B., Hess, J. M., Parker, D. P., & Hough, R. L. (2015). Reconsidering culturally competent approaches to American Indian healing and well-being. *Qualitative Health Research, 25*(4), 486-499.

Gore, M., Brandenburg, N. A., Dukes, E., Hoffman, D. L., Tai, K. S., & Stacey, B. (2005). Pain severity in diabetic peripheral neuropathy is associated with patient functioning, symptom levels of anxiety and depression, and sleep. *Journal of Pain and Symptom Management, 30*(4), 374-385.

Gray, L. (2004). *Reading the mind of nature*. In Ausubel, K., & Harpignies, J. P. eds. Ecological Medicine. Sierra Club Books.

Graneheim, U. H. & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today, 24*(2), 105-112.

Green, C. R. & Hart-Johnson, T. (2012). The association between race and neighborhood socioeconomic status in younger black and white adults with chronic pain. *The Journal of Pain, 13*(2), 176-186.

Greensky, C., Stapleton, M. A., Walsh, K., Gibbs, L., Abrahamson, J., Finnie, D. M., ... & Hooten, W. M. (2014). A qualitative study of traditional healing practices among American Indians with chronic pain. *Pain Medicine, 15*, 1795-1802.

Grijalva, R. (2011). Grijalva hails federal grant for Tohono O'odham rural health. Retrieved from http://www.standwithraul.com/grijalva-hails-federal-grant-for-tohono-oodham-rural-health-network-upgrade-%E2%80%93-mirrors-his-call-to-address-health-disparities/

Gulbrandsen, P., Madsen, H. B., Benth, J. S., & Laerum, E. (2010). Health care providers communicate less well with patients with chronic low back pain – a study of encounters at a back-pain clinic in Denmark. *Pain, 150,* 458 – 461.

Haegerich, T. M., Paulozzi, L. J., Manns, B. J., & Jones, C. M. (2014). What we know, and don't know, about the impact of state policy and systems-level interventions on prescription drug overdose. *Drug and Alcohol Dependence, 145*, 34-47.

Haozous, E. A., Doorenbos, A. Z., & Stoner, S. (2014). Pain management experiences and the acceptability of cognitive behavioral strategies among American Indians and Alaska Natives. *Journal of Transcultural Nursing, 27*(3), 233-240.

Haozous, E. A., & Knobf, M. T. (2013). "All my tears were gone": suffering and cancer pain in Southwest American Indians. *Journal of Pain and Symptom Management, 45*(6), 1050-1060.

Haozous, E. A., Knobf, M., & Brant, J. M. (2011). Understanding the cancer pain experience in American Indians of the Northern Plains. *Psycho-Oncology, 20*(4), 404-410.

Hariharan, J., Lamb, G. C., & Neuner, J. M. (2007). Long-term opioid contract use for chronic pain management in primary care practice. A five-year experience. *Journal of General Internal Medicine, 22*(4), 485-490.

Harris, S. (2013). Legal updates: As opioids for pain treatment come under greater scrutiny, controlled substance agreements matter more. Retrieved from http://www.the-rheumatologist.org/article/legal-updates-as-opioids-for-pain-treatment-come-under-greater-scrutiny-controlled-substance-agreements-matter-more/

Hausmann, L. R., Gao, S., Lee, E. S., & Kwoh, C. K. (2013). Racial disparities in the monitoring of patients on chronic opioid therapy. *PAIN®, 154*(1), 46-52.

Hodge, D. R. & Limb, G. E. (2011). Spiritual assessment and Native Americans: establishing the social validity of a complementary set of assessment tools. *Social Work, 56*(3), 213-223.

Housing Assistance Council (2012). Housing on Native American lands. Retrieved from http://www.ruralhome.org/storage/documents/rpts_pubs/ts10_native_lands.pdf

Huether, S. E. (2010). Pain, temperature regulation, sleep, and sensory function. In McCance, K. L., Huether, S. E., Brashers, V. L., Rote, N. S. (Eds.), *Pathophysiology: the biologic basis for disease in adults and children* (pp. 481-524). Missouri: Mosby Elsevier Health Sciences.

Hui Lin, T., Hong-Gu, H., Lau, L. S. T., Hui, T. K., Tsen, M., & Chan, S. W. C. (2014). Research in brief experiences of older adults with chronic low back pain descriptive qualitative study. *Singapore Nursing Journal, 41*(2), 45-47.

Inciardi, J. A., Surratt, H. L., Lugo, Y., & Cicero, T. J. (2007). The diversion of prescription opioid analgesics. *Law Enforcement Executive Forum, 7*(7), 1-14.

Institute of Medicine (2011). *Relieving pain in America: a blueprint for transforming prevention, care, education, and research.* Retrieved from http://www.nap.edu/openbook.php?record_id=13172

Ives, T. J., Chelminski, P. R., Hammett-Stabler, C. A., Malone, R. M., Perhac, J. S., Potisek, N. M., ... & Pignone, M. P. (2006). Predictors of opioid misuse in patients with chronic pain: a prospective cohort study. *BMC Health Services Research, 6*(1), 46.

Jackson, J. E. (2005). Stigma, liminality, and chronic pain: Mind–body borderlands. *American Ethnologist, 32*(3), 332-353.

James, A. S., Filippi, M. K., Pacheco, C. M., Cully, L., Perdue, D., Choi, W. S., et al. (2013). Barriers to colorectal cancer screening among American Indian men aged 50 or older, Kansas and Missouri, 2006–2008. *Preventative Chronic Disease*. Retrieved from http://www.cdc.gov/pcd/issues/2013/13_0067.htm.

Jimenez, N., Garroutte, E., Kundu, A., Morales, L., & Buchwald, D. (2011). A review of the experience, epidemiology, and management of pain among American Indian, Alaska Native, and Aboriginal Canadian peoples. *The Journal of Pain, 12*(5), 511-522.

Kangovi, S., Barg, F. K., Carter, T., Levy, K., Sellman, J., Long, J. A., & Grande, D. (2014). Challenges faced by patients with low socioeconomic status during the post-hospital transition. *Journal of General Internal Medicine, 29*(2), 283-289.

Kapoor, S., Thorn, B. E., & Thorn, S. K. B. (2014). Healthcare use and prescription of opioids in rural residents with pain. *Rural Remote Health, 14*(3), 2879.

Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative Health Research, 19*(2), 279-289.

Katz, N. P., Sherburne, S., Beach, M., Rose, R. J., Vielguth, J., Bradley, J., & Fanciullo, G. J. (2003). Behavioral monitoring and urine toxicology testing in patients receiving long-term opioid therapy. *Anesthesia & Analgesia*, *97*(4), 1097-1102.

Katzman, J. G., Comerci, G., Boyle, J. F., Duhigg, D., Shelley, B., Olivas, C., ... & Kalishman, S. (2014). Innovative telementoring for pain management: Project ECHO pain. *Journal of Continuing Education in the Health Professions*, *34*(1), 68-75.

Kaufman, A., Powell, W., Alfero, C., Pacheco, M., Silverblatt, H., Anastasoff, J., ... & Alverson, D. (2010). Health extension in New Mexico: an academic health center and the social determinants of disease. *The Annals of Family Medicine, 8*(1), 73-81.

King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: the underlying causes of the health gap. *The Lancet*, *374*(9683), 76-85.

Koithan, M. (2009). Matrix analysis [Powerpoint]. Retrieved from (course, unable to access)

Krebs, E. E., Bergman, A. A., Coffing, J. M., Campbell, S. R., Frankel, R. M., & Matthias, M. S. (2014). Barriers to guideline-concordant opioid management in primary care—a qualitative study. *The Journal of Pain*, *15*(11), 1148-1155.

Krippendorff, K. (1980). *Content analysis: an introduction to its methodology*. Newbury Park, CA: Sage.

Larson, P. J., Carrieri-Hohlman, V., Dodd, M. J., Douglas, M., Faucett, J., Froelicher, E. S., Gortner, S. R., Halliburton, P., Janson, S., Lee, K. A., Miaskowski, C., Savedra, M. C., Stotts, N. A., Taylor, D., Underwood, P. R. (1994). A model for symptom management. *IMAGE: Journal of Nursing Scholarship, 26*(4), 272-276.

Larson, E. L., Cohn, E. G., Meyer, D. D., & Boden-Albala, B. (2009). Consent administrator training to reduce disparities in research participation. *Journal of Nursing Scholarship, 41*(1), 95-103.

Lauche, R., Cramer, H., Häuser, W., Dobos, G., & Langhorst, J. (2015). A systematic overview of reviews for complementary and alternative therapies in the treatment of the fibromyalgia syndrome. *Evidence-Based Complementary and Alternative Medicine*, *2015*.

Lee, M., Silverman, S., Hansen, H., & Patel, V (2011). A comprehensive review of opioid-induced hyperalgesia. *Pain Physician*, *14*, 145-161.

Lincoln, Y. & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.

Link, B. G. & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology*, 363-385.

Long, K. A. (1993). The concept of health. Rural perspectives. *The Nursing Clinics of North America, 28*(1), 123-130.

Lucero, E. (2011). From tradition to evidence: decolonization of the evidence-based practice system. *Journal of Psychoactive Drugs, 43*(4), 319-324.

Lutfiyya, M. N., McCullough, J. E., Haller, I. V., Waring, S. C., Bianco, J. A., & Lipsky, M. S. (2012). Rurality as a root or fundamental social determinant of health. *Disease-a-Month, 58*(11), 620-628.

Macartney, S., Bishaw, A., & Fontenot, K. (2013). Poverty rates for selected detailed race and Hispanic groups by state and place: 2007-2011. Retrieved from US Department of Commerce, United States Census Bureau website http://www.census.gov/prod/2013pubs/acsbr11-17.pdf

Manchikanti, L., Manchukonda, R., Damron, K. S., Brandon, D., McManus, C. D., & Cash, K. (2006a). Does adherence monitoring reduce controlled substance abuse in chronic pain patients? *Pain Physician, 9*(1), 57-60.

Manchikanti, L., Manchukonda, R., Pampati, V., Damron, K. S., Brandon, D. E., Cash, K. A., & McManus, C. D. (2006b). Does random urine drug testing reduce illicit drug use in chronic pain patients receiving opioids? *Pain Physician, 9*(2), 123.

Matthias, M. S., Bair, M. J., Nyland, K. A., Huffman, M. A., Stubbs, D. L., Damush, T. M., & Kroenke, K. (2010). Self-management support and communication from nurse care managers compared with primary care physicians: a focus group study of patients with chronic musculoskeletal pain. *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 11*(1), 26-34.

Matthias, M. S., Krebs, E. E., Collins, L. A., Bergman, A. A., Coffing, J., & Bair, M. J. (2013). "I'm not abusing or anything": patient-physician communication about opioid treatment in chronic pain. *Patient Education and Counseling*. Advance online publication. doi:10.1016/j.pec.2013.06.021.

Meghani, S. H. & Cho, E. (2009). Self-reported pain and utilization of pain treatment between minorities and nonminorities in the United States. *Public Health Nursing, 26*(4), 307-316.

Meghani, S. H., Polomano, R. C., Tait, R. C., Vallerand, A. H., Anderson, K. O., & Gallagher, R. M. (2012). Advancing a national agenda to eliminate disparities in pain care: Directions for health policy, education, practice, and research. *Pain Medicine, 13*(1), 5-28.

Meltzer, E. C., Rybin, D., Saitz, R., Samet, J. H., Schwartz, S. L., Butler, S. F., & Liebschutz, J. M. (2011). Identifying prescription opioid use disorder in primary care: diagnostic characteristics of the Current Opioid Misuse Measure (COMM). *PAIN®, 152*(2), 397-402.

Miles, M., Huberman, A. M. & Saldana, J. (2014). *Qualitative data analysis: a sourcebook*. (3rd ed.). Thousand Oaks, CA: Sage.

Moghaddam, J. F., Momper, S. L., & Fong, T. (2013). Discrimination and participation in traditional healing for American Indians and Alaska Natives. *Journal of Community Health, 38*(6), 1115-1123.

Morse, J. M. & Field, P. A. (1995). *Qualitative research methods for health professionals*.

Mossey, J. M. (2011). Defining racial and ethnic disparities in pain management. *Clin Orthop Relat Res, 469*(7), 1859-1870.

Munhall, P. (2012). *Nursing research: a qualitative perspective* (5th ed.). Jones & Bartlett Learning. Sudbury, MA.

Murthy, V. (2016). *Turn the tide: the surgeon general's call to end the opioid crisis*. Retrieved from http://turnthetiderx.org/#

National Institute on Drug Abuse (2014). *Prescription drug abus*e. Retrieved from https://d14rmgtrwzf5a.cloudfront.net/sites/default/files/prescriptiondrugrrs_11_14.pdf

National Institute on Drug Abuse (2015). *Prescription and over-the-counter medicati*ons. Retrieved from https://www.drugabuse.gov/publications/drugfacts/prescription-over-counter-medications

National Institute on Drug Abuse (2016). *Understanding drug use and addiction*. Retrieved from https://www.drugabuse.gov/publications/drugfacts/understanding-drug-use-addiction

New Mexico Department of Health (NMDH) (2016). *Health indicator report of drug overdose deaths*. Retrieved from https://ibis.health.state.nm.us/indicator/view/DrugOverdoseDth.NM_US.html

NM Department of Workforce Solutions (2015). *State of the workforce report*. Retrieved from https://gonm.biz/uploads/documents/2015SOTW.pdf

NMHD (2012). *American Indian Health Disparities in New Mexico: from the 2012 racial and ethnic health disparities report card*. Retrieved from https://nmhealth.org/publication/view/report/427/

Noble, M., Treadwell, J. R., Tregear, S. J., Coates, V. H., Wiffen, P. J., Akafomo, C., & Schoelles, K. M. (2010). Long-term opioid management for chronic noncancer pain. *Cochrane Database Syst Rev, 1*(1).

Nuckols, T. K., Anderson, L., Popescu, I., Diamant, A. L., Doyle, B., Di Capua, P., & Chou, R. (2014). Opioid prescribing: a systematic review and critical appraisal of guidelines for chronic pain. *Annals of Internal Medicine, 160*(1), 38-47.

Office of Minority Health (2016). American Indian/Alaska Native profile. Retrieved from http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=62.

Olson, B. (2010). Meeting the challenges of American Indian diabetes: anthropological perspectives on treatment and prevention. In *Medicine ways: disease, health and survival among Native Americans*. Trafzer, C. E. & Weiner, D. (eds) Walnut Creek, CA: Alta Mira.

Palit, S., Kerr, K. L., Kuhn, B. L., Terry, E. L., DelVentura, J. L., Bartley, E. J., ... & Rhudy, J. L. (2013). Exploring pain processing differences in Native Americans. *Health Psychology, 32*(11), 1127.

Partnership for Drug Free Kids (2011). *Opioid pain contracts can damage patient trust, bioethics panel says*. Retrieved from http://www.drugfree.org/news-service/opioid-pain-contracts-can-damage-patient-trust-bioethics-panel-says/

Patton, M. (2000). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Payne, R., Anderson, E., Arnold, R., Duensing, L., Gilson, A., Green, C., ... & Christopher, M. (2010). A rose by any other name: pain contracts/agreements. *The American Journal of Bioethics, 10*(11), 5-12.

Penko, J., Mattson, J., Miaskowski, C., & Kushel, M. (2012). Do patients know they are on pain medication agreements? Results from a sample of high-risk patients on chronic opioid therapy. *Pain Medicine, 13*(9), 1174-1180.

Pesut, B., Robinson, C. A., Bottorff, J. L., Fyles, G., & Broughton, S. (2010). On the road again: patient perspectives on commuting for palliative care. *Palliative and Supportive Care, 8*(02), 187-195.

Pijoan, T. (2010). *Healers on the mountain*. Little Rock: August House.

Portenoy, R. K., Ugarte, C., Fuller, I., & Haas, G. (2004). Population-based survey of pain in the United States: differences among White, African American, and Hispanic subjects. *The Journal of Pain: Official Journal of the American Pain Society, 5*(6), 317-328.

Prunuske, J. P., Hill, C. A. S., Hager, K. D., Lemieux, A. M., Swanoski, M. T., Anderson, G. W., & Lutfiyya, M. N. (2014). Opioid prescribing patterns for non-malignant chronic pain for rural versus non-rural US adults: a population-based study using 2010 NAMCS data. *BMC Health Services Research, 14*(1), 1.

Prussing, E. (2014). Historical trauma: Politics of a conceptual framework. *Transcultural Psychiatry, 51*(3), 436-458.

Racine, M., Dion, D., Dupuis, G., Guerriere, D. N., Zagorski, B., Choinière, M., ... & Gordon, A. (2014). The Canadian STOP-PAIN project: the burden of chronic pain—does sex really matter? *The Clinical Journal of Pain*, *30*(5), 443-452.

Reinecke, H., Weber, C., Lange, K., Simon, M., Stein, C., & Sorgatz, H. (2015). Analgesic efficacy of opioids in chronic pain: recent meta-analyses. *British Journal of Pharmacology, 172*(2), 324-333.

Robinson, C. A., Pesut, B., & Bottorff, J. L. (2010). Issues in rural palliative care: views from the countryside. *The Journal of Rural Health, 26*(1), 78-84.

Rouse, C. & Rouse, C. M. (2009). *Uncertain suffering: racial health care disparities and sickle cell disease*. University of California Press.

Sampselle, C. M. (2007). Nickle-and-dimed in America: underserved, understudied, and underestimated. *Family and Community Health, 30*(1 Suppl), S4-S14.

Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *ANS Adv Nurs Sci., 16*(2), 1-8.

Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing and Health, 23*(4), 334-340.

Sandelowski, M. (2010). What's in a name? Qualitative description revisited. *Research in Nursing & Health, 33*(1), 77-84.

Sanders, L. M., Shaw, J. S., Guez, G., Baur, C., & Rudd, R. (2009). Health literacy and child health promotion: implications for research, clinical care, and public policy. *Pediatrics, 124*(Supplement 3), S306-S314.

Sando, J. S. (1998). *Pueblo nations: eight centuries of Pueblo Indian history*. Santa Fe: Clear Light Pub.

Savage, S. (2010). The patient-centered opioid treatment agreement. *The American Journal of Bioethics, 10*(11), 18-19.

Sawyer, L., Regev, H., Proctor, S., Nelson, M., Messias, D., Barnes, D., & Meleis, A. I. (1995). Matching versus cultural competence in research: Methodological considerations. *Research in Nursing & Health, 18*(6), 557-567.

Sehgal, N., Manchikanti, L., & Smith, H. S. (2012). Prescription opioid abuse in chronic pain: a review of opioid abuse predictors and strategies to curb opioid abuse. *Pain Physician, 15*(3 Suppl), ES67-ES92.

Shah, V. O., Ghahate, D. M., Bobelu, J., Sandy, P., Newman, S., Helitzer, D. L., ... & Zager, P. (2014). Identifying barriers to healthcare to reduce health disparity in Zuni Indians using focus group conducted by community health workers. *Clinical and Translational Science, 7*(1), 6-11.

Shavers, V. L., Bakos, A., & Sheppard, V. B. (2010). Race, ethnicity, and pain among the US adult population. *Journal of Health Care for the Poor and Underserved, 21*(1), 177-220.

Shelley, B. M., Sussman, A. L., Williams, R. L., Segal, A. R., & Crabtree, B. F. (2009). Behalf of the Rios Net Clinicians: they don't ask me so I don't tell them": patient clinician communication about traditional, complementary, and alternative medicine. *Ann Fam Med, 7*, 139-147.

Siegel, R. (2015). *Draft Of CDC's new prescribing guidelines stirs debate*. Retrieved from http://www.npr.org/2015/12/29/461409296/draft-of-cdcs-new-prescribing-guidelines-stirs-debate

Sotero, M. M. 2006. A conceptual modal of historical trauma: implications for public health practice and research. *Journal of Health Disparities Research and Practice, 1*(1), 93-108.

Spitaels, D., Vankrunkelsven, P., Desfosses, J., Luyten, F., Verschueren, S., Van Assche, D., ... & Hermens, R. (2017). Barriers for guideline adherence in knee osteoarthritis care: a qualitative study from the patients' perspective. *Journal of Evaluation in Clinical Practice, 23*(1), 165-172.

Spradley, J. P. (1980). *Participant observation.* Fort Worth, TX: Harcourt College Publishers.

Starrels, J. & Cunningham, C. (2016). *Controversy over CDC opioid guideline reflects a fractured field*. Retrieved from http://blogs.einstein.yu.edu/controversy-over-cdc-guideline-reflects-a-fractured-field/

Starrels, J. L., Becker, W. C., Alford, D. P., Kapoor, A., Williams, A. R., & Turner, B. J. (2010). Systematic review: treatment agreements and urine drug testing to reduce opioid misuse in patients with chronic pain. *Annals of Internal Medicine, 152*(11), 712-720.

Starrels, J. L., Wu, B., Peyser, D., Fox, A. D., Batchelder, A., Barg, F. K., ... & Cunningham, C. O. (2014). It made my life a little easier: primary care providers' beliefs and attitudes about using opioid treatment agreements. *Journal of Opioid Management, 10*(2), 95.

Substance Abuse and Mental Health Services Administration (SAMHSA) (2016). *Opioids*. Retrieved from http://www.samhsa.gov/atod/opioids

Teh, C. F., Karp, J. F., Kleinman, A., Reynolds III, C. F., Weiner, D. K., & Cleary, P. D. (2009). Older people's experiences of patient-centered treatment for chronic pain: a qualitative study. *Pain Medicine, 10*(3), 521-530.

The Joint Commission (2016). *Joint commission statement on pain management*. Retrieved from https://www.jointcommission.org/joint_commission_statement_on_pain_management/

Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Turk, D. C. (2002). Clinical effectiveness and cost-effectiveness of treatments for patients with chronic pain. *The Clinical Journal of Pain, 18*(6), 355-365.

Turk, D. C., Wilson, H. D., & Cahana, A. (2011). Treatment of chronic non-cancer pain. *The Lancet, 377*(9784), 2226-2235.

U.S. Census Bureau (2015). *State and county quick facts: New Mexico*. Retrieved from http://quickfacts.census.gov/qfd/states/35/35049.html

US Census Bureau (2016). *Quick facts: New Mexico*. Retrieved from http://www.census.gov/quickfacts/table/PST045215/35

US Commission on Civil Rights (2004). A quiet crisis: federal funding and unmet needs in Indian country. Retrieved from http://www.usccr.gov/pubs/na0703/na0204.pdf.

US Department of Health & Human Services (2017). *Healthy people 2020: social determinants of health*. Retrieved from https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health

Warne, D., Kaur, J., & Perdue, D. (2012). American Indian/Alaska Native cancer policy: systemic approaches to reducing cancer disparities. *Journal of Cancer Education, 27*(1), 18 – 23.

Vallerand, A. & Nowak, L. (2009). Chronic opioid therapy for nonmalignant pain: the patient's perspective. Part I—life before and after opioid therapy. *Pain Management Nursing, 10*(3), 165-172.

Vallerand, A. & Nowak, L. (2010). Chronic opioid therapy for nonmalignant pain: the patient's perspective. Part II—barriers to chronic opioid therapy. *Pain Management Nursing, 11*(2), 126-131.

Volkow, N. D. & McLellan, A. T. (2016). Opioid abuse in chronic pain—misconceptions and mitigation strategies. *New England Journal of Medicine, 374*(13), 1253-1263.

Wiedemer, N. L., Harden, P. S., Arndt, I. O., & Gallagher, R. M. (2007). The opioid renewal clinic: a primary care, managed approach to opioid therapy in chronic pain patients at risk for substance abuse. *Pain Medicine, 8*(7), 573-584.

Willmon-Haque, S. & BigFoot, S. D. (2008). Violence and the effects of trauma on American Indian and Alaska Native populations. *Journal of Emotional Abuse*, *8*(1-2), 51-66.

Yurkovich, E. E. & Lattergrass, I. (2008). Defining health and unhealthiness: Perceptions held by Native American Indians with persistent mental illness 1. *Mental Health, Religion and Culture, 11*(5), 437-459.