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SURVIVING AND THRIVING: AN INTEGRATED CRITICAL THEORY
OF CHRONIC PAIN FROM STORIES OF URBAN AMERICAN
INDIANS LIVING WITH CHRONIC PAIN

BY

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DISSERTATION

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Abstract

Purpose: This study seeks to inform better care practices and policies for American Indians living off-reservation by discerning relationships between chronic pain and colonization and developing an integrated critical theory of chronic pain. *Methods:* This study uses a concurrent transformative mixed methods design with in-depth interviews and a survey (n=40) from self-identified American Indian adults in Indiana, Chicago, and Tulsa who report pain for greater than 3 months. The in-depth interview elicits participants' stories of their pain, including pain characteristics, origin, treatment, and daily life experience. The survey battery consists of a demographics questionnaire, McGill Pain Questionnaire (Melzack, 1975), Historical Loss Scale (Whitbeck, Adams, Hoyt, & Chen, 2004), Texas Revised Inventory of Grief (Faschingbauer, 1981), Resilience Scale (Wagnild & Young, 1987), Stressful Life Events Screening Questionnaire (Goodman, Corcoran, Turner, Yuan, & Green, 1998), and questions regarding use of traditional and biomedical healing practices. Interviews were iteratively coded with a grounded theory approach. Statistical analyses include correlation, Chi-Square, and binary logistic regression. *Results:* A number of dichotomies arose from the data: good and bad days with pain, things that help pain and things that make pain worse, and pain with a physical etiology and with an emotional etiology. This fragmented conceptualization of pain provides participants with sought-after legitimacy to guard against the many places of tension and conflict in their lived experience of chronic pain. Connections between chronic pain and colonization occur at the level of abuse, poverty, and sorrow. Despite the fragmentation of pain conceptualization and the tensions and conflicts that being in chronic pain causes, participants manage their pain with very integrated care. On average, participants utilize almost 7 different healing practices, demonstrating the active role they take in caring for their chronic pain. Participants call upon strength from understanding that

American Indians as peoples have always survived to bolster their individual strengths, push through the pain, and keep on living using self-care practices that demonstrate remarkable resilience. They seek to function without further debility and to maintain their economic, spiritual, social, and physical wellness. This is care for survival not care for cure. *Conclusion:* In an Equilibrium Model of Chronic Pain, which emerges from this research, surviving on the worst days with chronic pain balances in a steady state with thriving on the best days with chronic pain, while self-care practices catalyze the relationship. Ultimately this research found that chronic pain theory needs to tell more profound, critical, and world-changing stories; research methods in American Indian communities need to uncover more complete and powerful stories; and healthcare providers for marginalized populations need to spend time attending to stories in overcoming patient barriers to treatment, adherence, and full thriving.

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Introduction

Linda Hogan, a Chickasaw poet, novelist, essayist, playwright, and activist writes, “History is our illness. Those of us who walked out of genocide by some cast of fortune still struggle with the brokenness of our bodies and hearts. Terror, even now, for many of us, is remembered inside us, history present in our cells that came from our ancestor’s cells, from bodies hated, removed, starved, and killed (Hogan, 2001 p59).”

1.1 Statement of the Problem

This study seeks to inform better care practices and policies for American Indians living off-reservation by discerning relationships between chronic pain and colonization—a chronic history of US empire that I characterize through ongoing encounters with violence and trauma—and developing an integrated critical theory of chronic pain. The problem is multiplicative: a chronic pain epidemic embedded within consequences of colonization. The 2011 Institute of Medicine (IOM) Report “Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research” accentuates pain’s burdensome nature. Pain clinically costs millions of dollars per year, and socially costs billions per year in the United States. Twenty percent of physician visits are for a chief complaint of pain, and 10% of prescription medication sales are to treat pain. Since not all pain is handled through a physician visit or prescription, there is a significant quantity of pain in the United States not included in these percentages. Current tools available to clinicians for pain assessment and management frequently fail to alleviate pain and its burden on the social world. Poor pain assessment and management increases pain’s economic and humanitarian cost for society. The lack of resources to address pain, such as physical therapy, complementary/alternative medicine, inter-

disciplinary pain clinics, and spiritual counselors, leaves providers, especially in underserved areas, with a limited treatment arsenal.

Unequal burdens of disease, violent neighborhoods, and poor access to healthcare shape how pain is experienced in an entire population (Pizzo & Clark, 2011). Pain disproportionately burdens racial and ethnic minorities, and healthcare providers disproportionately undertreat racial and ethnic minority pain (Jimenez, Garrouette, Kundu, Morales, & Buchwald, 2011). American Indians experience unmet needs related to chronic pain care. Compared with the rest of the US population, American Indians are twice as likely to suffer from chronic pain syndromes (Strickland, 2001). Critically American Indians have a higher prevalence of pain than the overall US population (15%) as well as experience pain from diseases that less frequently cause pain. The unequal burden of pain in AI/AN compels a social justice imperative for this research.

Past research suggests numerous reasons for an unequal burden of pain in American Indians, including cultural beliefs, poor provider-patient relationships, and poverty (Lasch, 2000). Walters & Simoni, 2002, from University of Washington's Indigenous Wellness Research Institute, assert that failure to consider the socioenvironmental context of American Indian pain experiences risks reinforcing stereotypes of native stoicism, dependency, and entitlement. Though demographically a small population, American Indians have one of the most potent and tragic histories among racial/ethnic minorities in the US in addition to ongoing encounters with removal, genocide, and cultural devastation. They have endured and continue to endure forced assimilation, physical violence, broken treaties, and genocide—in the context of settler colonialism (Gone, 2009; Walters et al., 2011). Wolfe, 2006 defines settler colonialism as a structure not an event—a structure that restricts and destroys, that conditions political, economic, social, and cultural process, that marks bodies, and that works toward making the settler the native thus eliminating the native. The entire system oppresses even the oppressors. It devours itself and all in it. It executes violence differentially but against everyone. There is absolutely no way not to be in the system, yet there are those in the system who are unhappy and there are those who are suffering—a critical differentiation. Settler colonialism prevents and prevented care for sacred lands, for heritage, and for kinship.

Million, 2013 writes, “What colonialism actually is in Indigenous terms: a

painful dismembering of families and societies (p20).” Fanon, the great anti-colonial psychiatrist, reminds us that “colonialism is not satisfied merely with holding a people in its grip and emptying the native’s brain of all form and content (in Alfred & Corntassel, 2005 p602).” These actions seem sufficient for absolute destruction of American Indians. But colonialism further seeks excision from history for the colonized. “By a kind of perverted logic, it turns to the past of the oppressed people, and distorts, disfigures, and destroys it. This work of devaluing pre-colonial history takes on a dialectical significance today (Alfred & Corntassel, 2005 p602).” American Indians themselves may devalue, disfigure, and distort their own history, not intentionally but as a symptom of the settler colonial structure. Chronic pain also may occur as a symptom of the settler colonial system.

This symptom of the settler colonial system—chronic pain—American Indians often conceptualize as not only physical but also emotional, spiritual, and psychological. As such they are more likely to pursue alternative pain management that seeks to treat the physical as well as emotional and spiritual causes of the pain. Past literature provides an imperative for this current research. Strickland, 2001 discusses the broad conceptualization of pain as simultaneously physical, psychological, emotional, and spiritual in a western Washington tribe. She concludes with recommendations for improved patient-provider communication and pain policy for those living on reservations. Elliott, Johnson, Elliott, & Day, 1999 interviewed Ojibwe elders in Minnesota regarding pain associated with cancer. They found that elders report pain only when pain intensity is greater than six, and that elders perceive pain as a inevitable component of life, always associated with cancer. Traditional healers may provide relief from pain but painless cancer cannot occur. Haozous, Knobf, & Brant, 2011 also examined perceptions of cancer pain in the Northern Plains and Southwest—distinct native cultures. They noted that participants told stories of pain that “vividly recounted the manner through which pain moved through their bodies (p407).” Participants policed against overt displays of pain, especially chronic and persistent pain not in immediate need of attention. This policing guarded privacy and saved face in the community. The resultant isolation, guilt, and suffering led many participants to prayer and traditional healing for their pain. Kramer, Harker, & Wong, 2002 recruited a convenience sample of American Indians living in LA and Orange County to talk about self-care beliefs regarding arthritis.

Participants conceptualized their arthritis as arising from genetics, comorbid illnesses, work injuries, environment, and aging. When pain became chronic, participants less actively pursued relief from pain, opting for ignoring the pain while continuing to function. One participant commented, “We don’t feel comfortable talking about ourselves and usually don’t let people know our pain (p592).” Kramer et al., 2002 concluded this American Indian community wanted more self-care education regarding arthritis pain.

Extending on the above past research, this research aims: 1) to describe the pain experience (from initial diagnosis through treatment seeking) for American Indian chronic pain sufferers living in off-reservation or urban settings, 2) to determine the influence of background, explanatory factors (historical trauma, disenfranchised grief, and normative violence) on pain as reported with the McGill Pain Questionnaire by American Indians living in off-reservation or urban settings, and 3) to identify treatment modalities (biomedical and traditional models of healthcare) used by American Indians living in off-reservation or urban settings to cope with chronic pain. I accomplish these aims through a concurrent embedded mixed methods study with 40 American Indians living in Indiana, Chicago, and Tulsa. Ultimately I model the broadest and deepest lived experience of chronic pain, exploring the chronic pain itself, how the chronic pain impacts on identity, psychology, social world, and culture of participants, and what participants do to cope with the chronic pain on a day to day basis. I seek to avoid pathologizing chronic pain sufferers in this research and instead write a cacophony of experiential pain stories that fertilize across disciplines and uncover often invisible causal pathways for chronic pain. I imagine the process to be as Million, 2013 describes:

The pain of the individuals affected had been shared face to face with her and joined with her own reaction to her own pain in turn. This has been and can be the effective transfer point between the witness, the telling, and the research instrument, the telling for social change (p96).

In what follows, I present research that may compel social change. Given the concepts at play in this statement of the problem, I discuss in the introduction existing literature on colonialism, health inequalities as a symptom of colonialism, models of chronic pain, and resilience and healing practices.

1.2 Colonialism

1.2.1 Where is the Indian?

Participants in this research struggled with externally maintaining their identity as American Indians, often passing as white since it was easier. If a child is asked to imagine and draw an Indian, then, thanks in part to Indian school mascots, the resultant drawing will probably include feathers, war paint, arrowheads, leather, muscles, bow and arrow, moccasins, pottery, colorful blankets, horses, tepees, etc. Likely American Indian women will not be in the drawing at all. “It seems that cultural authenticity for Native peoples,” Barker, 2011 writes, “exists only in a pre-colonial—indeed pre-historical—moment that has been forever lost to the natural, inevitable, compromised, or tragic ends of colonialism and imperialism (p16).” Not only does the American Indian person have a fixed identity in the past, but also colonialism has erased that fixed identity rendering the person nonexistent. According to the child and many others in the places and spaces that these research participants live, Indians do not exist.

Povinelli, 2011 contends that American Indians exist in an alternative social space. “They are the part that has no part—the noise of the unsayable—found neither on one side nor on the other of the temporal division of social space, but in the space that cannot be contained by this division (Povinelli, 2011 p73).” Lyons, 2010 even calls himself liminal. Hokowhitu, 2009 locates indigeneity in a profoundly painful place: “The location of indigeneity in the primitive past marks the Indigenous body in tourist sites and cultural performances (p111).” Hence the images of tepees, headdresses, and bows and arrows. Just as the physician makes diagnostic judgments based on years of experience with people who have the same disease, colonial discourse conjectures American Indians as authentic only when they demonstrate origin in a primitive or traditional time and place. Barker, 2011 writes about the deviance possible when fixing American Indians to a particular time and place: “The belief is that if Native cultures and identities can be fixed in a specific time and place, they can be measured for degrees of deviation and loss from that place to another (p197).”

Barker, 2011 goes on to conceptualize the origin(al) (p221). Hokowhitu, 2009, and other Indigenous scholars, critique their colleagues for canonizing

an “unchanging and immutable” Native identity and for searching for a “secure and ‘authentic’ precolonial Indigenous culture (p103).” The search for authentic culture proceeds from the “destabilization and rupture of culture and identity caused by colonization (Hokowhitu, 2009 p103).” Barker, 2011 asserts, “Natives are never quite Native enough (p6).” In more extended terms, “our families, histories, and personal ethics are constantly called into question as everyone else seems to know exactly what a Native person is and looks like and just how far any one of us deviates from it (Barker, 2011 p3).” Lyons, 2010 offers an intriguing expansion to the concerns about cohering a Native identity—that of the “existing diversity of Indian life (p12).” In his preface to *X-Marks*, he introduces himself as liminal and admits to perceiving a non-Indian actor playing an Indian as the most authentically Indian one could be.

A result of the liminality of being American Indian is erasure. Alfred & Corntassel, 2005 speak about rendering Indigenous peoples inhuman through erasure of the time and space that Indigenous peoples inhabit. They argue that Indigenous peoples become inhuman “not by attempting to eradicate the physical signs of Indigenous peoples as human *bodies*, but by trying to eradicate their existence as peoples through the erasure of the histories and geographies that provide the foundation for Indigenous cultural identities and sense of self (p798).” Many others argue that Indigenous peoples are—most fundamentally—particular and em-placed (Million, 2013). The opposite is true for Holland, 2012 who finds humanity in the erotic touch of bodies regardless of time and space. For Holland, 2012 “how we become ‘human’ then is mediated by an ever-present ‘touch’ of the material, the object, the non-us, threatening incorporation (p104).” In what both Alfred & Corntassel, 2005 and Holland, 2012 write, to be inhuman is to be surviving, just surviving.

In addition to colonialism rendering American Indians inhuman, not allowing American Indians to be who they are enacts what M. Jackson, 2002 calls stealing the pain of strangers. “There is a deep need to take in the pain of strangers, to turn it into a story—and then to pass it on. We need to pass it on. Nobody wants to be left holding the hot potato of pain (p36).” This neglect and fetishization of the pain of others is an ethical dilemma. “The big ethical question is why we fail to allow ourselves to experience the pain of others—why we turn away and ignore their faces (Coakley & Shelemay, 2007 p381).” American Indians are among the most ignored and neglected

to the point of not even considering them as human. Likewise pain often is ignored and neglected in the clinical encounter because of its invisibility and unspecified cause. A challenge of this research, then, is “to be deeply embedded in life...to stop free riding on the pain of others (D. B. Rose, 1999 p185),” in particular to locate and celebrate the humanity of American Indians with chronic pain.

1.2.2 Structure of Settler Colonialism

Tragic irony underpins settler colonialism—law is broken in order to keep law. “Colonization is a relationship after all,” reminds Gloria Bird quoted in Million, 2013 (p26). The entire law itself was based initially on the dispossession of Native peoples. Wolfe, 2006 provides a concise definition for settler colonialism as a useful starting place: “Settler colonizers come to stay: invasion is a structure, not an event (p388).” The structure is about universalizing Western governance even at the level of biology and bodies. One can theorize pain, also, as a structure not an event (M. Jackson, 2002), and those suffering from pain encounter marginalization within the structure of healthcare. Duran, Firehammer, & Gonzalez, 2008 asserts, “When the soul or culture of some persons are oppressed, we are all oppressed and wounded in ways that require healing if we are to become liberated from such oppression (p288).”

Settler colonialism restricts the inherent right that Million, 2013 argues for: “Indigenous peoples believed in their inherent right to self-determination as given in creation. These were powers that were not derived from any state or western power, nor could they be granted by them (p128).” This is the right for sovereignty. Sovereignty corresponds with self-determination, self-governance, Native rights, and social justice. It serves as a liberatory concept, as a step toward self-representation, and as a tactic for addressing Native health inequities and the material conditions of current Native life. Yet Berlant, 2007 calls the “current discussion of sovereignty...a condition of and blockage to justice (755),” while Barker, 2011 demonstrates that, in the name of sovereignty, the health and well-being of entire families is extinguished. Barker, 2011 further provides evidence that sovereignty has historically contingent meanings. Barker, 2011 questions, “Will this Nation’s

sovereignty and self-determination replicate the relations of domination and dispossession defined for Native peoples within the United States (p214)?” Sovereignty, at the moment, serves as a synecdoche for Nation—the Colonizer’s Nation not an Indigenous Nation—struggling with the transition from self as sovereign to community as sovereign. Million, 2013 breaks down sovereignty into a positive and a negative: “At this point much of humanity remains outside of this positive sovereignty as the stateless, or refugees, or those marginalized within states too poor or too weak to provide for or defend them (p10-11).” She also notes how self-determination can and should function for healing and justice:

Often informed reflexively within UN campaigns for justice, community healing movements, Indigenous spiritualities, and Indigenous polity, present self-determination movements are rich with alternative visions and performances that, like life itself, might exceed any neoliberalism that seeks to appropriate it (Million, 2013 p32).

In past understandings, the sovereign possessed the power to give life and take away life (Berlant, 2007). This giving and taking away of life occurs in discussions of tribal recognition and membership. Barker, 2011 spends all of *Native Acts* simultaneously aligning with and critiquing recognition and membership so I do not need to here. I will foreground her concern in the impermanence and fragility of the current creations of sovereignty. In particular, she notes how blood quantum as a measure of Indian-ness benefits the state, because, as biological fact, Indians will lose Indian blood over time. Berlant, 2006 is also wary of this predictable demise:

And yet: at a certain degree of abstraction both from trauma and optimism, the experience of self-dissolution, radically reshaped consciousness, new sensoria, and narrative rupture can look similar; the emotional flooding in proximity to a new object can also produce a similar grasping toward stabilizing form, a reanchoring in the symptom’s predictability (p30).

One might use this conceptualization to diagnose sovereignty and as such settler colonialism. Most participants did not acknowledge particular events of settler colonialism. Instead they understood their social location, both socioeconomically and racially, as a result of the structure of settler colonialism.

1.2.3 Decolonization

Million, 2013 discusses one of the goals of my research—to examine a symptom of the wound colonization. “I think that while healing has become a ubiquitous word, there is less examination of the terms of this ‘healing’ from a wound characterized as colonization (p12).” This research begins an examination of decolonized care and hybrid healing practices that remove “the actual hindrances that impede groups’ striving (Povinelli, 2011 p160).” “One’s door should be opened from the inside (p26),” asserts Lyons, 2010 as a primary principle of decolonization. “We will begin to realize decolonization in a real way,” write Alfred & Corntassel, 2005, “when we begin to achieve the re-strengthening of our people as individuals so that these spaces can be occupied by decolonized people living authentic lives (p605).” This quote represents why discussions of decolonization so often lead to non-strategies, non-interventions, and hopelessness. What is real decolonization? How do you re-strengthen? What spaces need to be occupied? Who are authentic decolonized people?

Then there is the hopeful recognition that if decolonization results in misunderstanding, that too can be a generative space. “It is precisely experiences of misunderstanding,” argues C. J. Throop, 2010, “that potentiate possibilities for new horizons of mutual understanding to arise, even if fleetingly so (p772).” Misunderstandings require an intentional wrestling with victimization and victim mentality. According to Rael, 2003:

Decolonization is the intentional, collective, and reflective self-examination undertaken by formerly colonized peoples that results in shared remedial action. Such action traces continuity from ‘traditional’ (precolonial) experiences even as it embarks on distinctive, purposeful, and self-determined (postcolonial) experiences. The key to decolonization is community emancipation from the hegemony of outside interests (p759).

The body is a territory that colonialism has overtaken. Thus the body can function as a territory where resilience, resistance, and decolonization occur. In fact, the body functions as the first site of resilience, resistance, and decolonization. At the site of the body, care demonstrates itself, defines itself, and extends itself. “Ever since the duties of the monk infirmaries had been split between doctor and nurse, and the Latin *curare* split into cure and care, there’d been a battle going on for control (p106),” argues historian

Sweet, 2012. Hokowhitu, 2009 assists with conceptualizing how traditional care encounters the material individual in contrast with biomedical care's concern with the individual as organ systems, pathologies, and statistics. He presents a critique and clarification:

While many Indigenous scholars have challenged the mind/body dichotomy by describing holistic Indigenous epistemologies that typically include the physical, spiritual, mental and material reality of place, almost without fail such holistic theorising seeks to authenticate an Indigenous tradition in opposition to the imposition of mind/body dualism. Thus, the Indigenous body has remained a traditional spectre in Indigenous scholarship while lacking any material presence (p111).

Participants attest to the materiality of their chronic pain and the necessity of resilience for continued functioning at baseline as well as extended care for thriving with chronic pain.

Gone, 2009 summarizes Native healing and decolonization—the necessary concomitant to Native healing. “Native healing moves well beyond mere clinical concerns with distress and coping toward a more robust state of wellness, as indicated by strong Aboriginal identification, cultural reclamation, spiritual wellbeing, and purposeful living (p759).” Therefore traditional care resonates ecologically throughout all aspects of life (and death). Smylie et al., 2004 asserts that traditional care in Indigenous communities upholds scientific excellence simultaneous with community relevance, identifying community, experience, and land as key components of Indigenous knowledge creation. “Indigenous knowledges inform an actually existing lived difference, not one reducible to western abstraction (Million, 2013 p160).” Stories coalesce into knowledge in bidirectional and cyclical relationships with wisdom. The stories come from the particularities of Indigenous suffering. Produced is what Million, 2013 calls a ceremonial life: “a ceremonial life that shores up and gives meaning to individuals, adaptive or nonadaptive ‘realities’ that are left unnamed so that development can occur (p139).” Therefore participants in this research sought healing for their pain through decolonial ancestral and ceremonial strength.

1.3 Health Inequalities and Other Consequences of Colonialism

1.3.1 What is a Health Inequality

A health inequality arises when the difference in health is avoidable, unjust, unfair, and inequitable (Braveman, 2006). Therefore health inequalities occur when social disadvantages systematically reduce the health of a particular population, or when individuals or populations do not experience the best potential health when controlling for age and medical care (Adler, 2006). In some regards, biology dictates differences, both for individuals and populations, in disease burden and mortality regardless of social and environmental factors. Even with an ideal social environment, health extremes would exist. In addition to social disadvantages, cultural ideologies and attitudes as well as institutions co-create health inequalities (DelVecchio Good, James, Good, & Becker, 2007). Research addressing health inequalities disentangles the complex and often similar pathways that lead from the social, historical, biological, and political environment to specific diseases, which exhibit disparities in particular populations (Adler, 2006).

The National Institutes of Health define health inequalities as “differences in the incidence, prevalence, mortality and burden of diseases and other adverse health conditions that exist among specific population groups.” That older people are less healthy than younger people or that women have a higher prevalence of certain diseases than men are not health inequalities (Adler, 2006). In contrast, that people of color have a greater burden of depression, diabetes, heart disease, and chronic pain than their white socioeconomic-status matched partners is a health inequality. James, Strogatz, Wing, & Ramsey, 1987 characterized the John Henryism hypothesis: too much coping with high-stress situations causes physiological assault and thus continued health inequalities. Chronic pain makes health inequalities particularly apparent.

In a traditional perspective on health inequality, all variables are either health enhancing or health damaging with non-intersecting impacts on health. Public health research usually examines each system—social, behavioral, or biological—that affects health independently, negating the experience of

those who navigate through multiple systems simultaneously (Bowleg, 2012). Additionally a traditional perspective separates micro determinants (individual risk factors, genetics, pathophysiology) from meso determinants (family, neighborhoods, work environment) from macro determinants (policy, institutions, and social constructions) (Adler, 2006). Instead micro, meso and macro determinants work together to determine both individual health and population health disparities.

As I pursue an intersectional perspective, I recognize how the literature privileges certain categories in order to avoid these biases. “In short, any one health outcome has many determinants and any one determinant might have many outcomes, and all of these interact in complex ways at multiple levels, from cells to social structure (Perry, 2011 p545).” The traditional approach does recognize the impact of social structure but fails to understand spheres of oppression as interlocking. In order to avoid reifying and essentializing social categories and social structures, each social relation must be understood in terms of all other social formations beyond rudimentary links between just race and class, class and gender, and race and gender for example.

Health inequality research, argues Krieger, Williams, & Moss, 1997, must seek a theoretical ground, frame itself within a particular time and place, and consider intersectional influences. An intersectional approach reveals much more information about health inequities than explanatory paradigms that seek cause and effect relationships between biology, race, and lifestyle choices (Mullings, 2005). One might be advantaged toward better health in one way but constrained in other ways. A traditional approach neglects this complexity.

Because social, psychological, and biological factors interact at every level of analysis, the ‘chain’ metaphor and the distal/proximal distinction does not accurately convey the convoluted nature of disease processes, and may unintentionally facilitate complacency among medical sociologists. Arguments that advocate restricting theoretical or empirical focus to any one level, be it individual or social structural, run the risk of generating an incomplete or inaccurate understanding of health and illness (Perry, 2011 p546).

Intersectional theory particularly in combination with a socio-psychobiological approach more deeply documents the distribution of resources that facilitate or degrade health simultaneously for individuals and populations. It also

enables the study not of large numbers of individuals in a community but of the community itself (Popay, Williams, Thomas, & Gatrell, 1998).

An intersectional perspective considers that the matrix of domination exists at both macro and micro levels, transforming social structure and marking particular bodies at particular points in time. Bowleg, 2012 defines the approach as “a theoretical framework for understanding how multiple social identities such as race, gender, sexual orientation, SES, and disability intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression (i.e., racism, sexism, heterosexism, classism) at the macro social structural level (p1267).” Intersectionality seeks to shift the center from which most research questions originate and to dispute the essentialization of difference. It reconstructs knowledge, how we think, and how we behave in order to develop better social policy and better health policy. Intersectionality requires inclusive and relational thinking.

Because of their simultaneity in people’s lives...we conceptualize race, class, and gender as different but interrelated axes of social structure....A matrix of domination posits multiple, interlocking levels of domination that stem from the societal configuration of race, class, and gender relations (Andersen & Hill Collins, 1998 p3).

Health inequalities in addition to historical trauma, everyday continued violence, and disenfranchised grief are symptoms of the wound colonization has created. Arthur et al., 2012 asserts that, “Indigenous communities live at a precarious intersection between unresolved historical injustices [the pastness of colonial contact] and the contemporary incursion of industry and political violence [the present of colonial contact] (p1).” I discuss each concept in turn.

1.3.2 Historical Trauma

Leslie Marmon Silko writes of “a loss so complete / even its name has escaped you (Silko, 2012, p104).”

Underlying American Indian health inequalities is a history of injustice that includes forced migration, forced assimilation, and overt physical violence.

Native scholars consider the history of colonization as pathogenic particularly of psychological distress and call this pathogenesis “historical trauma”. The concept of historical trauma is similar to accumulated trauma in life course studies, Adverse Childhood Experiences (ACES) in public health, and epigenetics. For American Indians, however, “trauma was not a given (Million, 2013 p78);” rather American Indians intentionally adopted trauma language in order to shift concerns about health to concerns about social justice and right relationship. Gone, 2009 defines “historical trauma,” “unresolved grief”, or “soul wound” as a “collective, cumulative, and intergenerational transmission of risk for adverse mental health outcomes (p752).” Therefore historical trauma is a psychological, social, ecological, and structural phenomenon that shapes cultural differences in illness prevalence and illness experience on both an individual and community level (Walters et al., 2011; West, Williams, Suzukovich, Strangeman, & Novins, 2012). Like Wolfe, 2006 defined settler colonialism as a structure, Mohatt, Thompson, Thai, & Tebes, 2014 define trauma as a “representation as opposed to an event (p129)” that lingers within the lineage of a population—a transgenerational effect. The effect results “because massive trauma on a collective level disrupts the fabric of communal life, challenging core social institutions and cultural values (Kirmayer, Lemelson, & Barad, 2007 p10).” In this research, I seek to understand how trauma correlates with chronic pain on an individual and social level.

Krieger, 2012’s ecosocial theory argues that social experiences throughout life become incorporated physically into the body and that this incorporation affects an entire population’s health. Therefore trauma experiences manifest with physical, psychological, and social symptoms such as “fear, pain, loss, grief, guilt, anxiety, hatred, sadness, and the dissolution of everyday forms of sociality, language, and experience (Desjarlais & Kleinman, 1997 p1143).” It becomes a challenge to tease out social problems from medical and psychiatric diagnoses; ultimately seeking to witness another’s pain from trauma creates social, medical, and psychological problems (Desjarlais & Kleinman, 1997). Even after healing and recovery, trauma has broken the body and disoriented the mind so much that “indelible marks” remain (Kirmayer et al., 2007 p1). Evans-Campbell, Lindhorst, Huang, & Walters, 2006 suggest other health effects seen with trauma: decreased immunity with increased susceptibility to infectious disease, higher STI rates, self-neglect, poor med-

ical adherence, and HIV/AIDS vulnerability. The experience of trauma is a sociological process whereby an injury causes pain for an entire group of people, who differentiate victim from saved, determine responsibility for the initial injury, and sort through the ideological and material consequences. Once trauma enters a population, institutions convey it, hierarchies maintain it, and cultures signify it (Alexander, 2004).

To study trauma and violence, the researcher must be a “pathologist of human nature (Scheper-Hughes, 1992 p26).” Million, 2013 asserts trauma as a pathology, deriving from “systemic inequality and endemic social suffering (p6).” The researcher must also accept the “vicarious pain” of listening to narratives that most wish to avoid—narratives of routinized suffering (Kirmayer et al., 2007; Scheper-Hughes, 1992). The trauma participants experienced results in emotional and psychological pain that still has not completely healed. Participants do not know if it will ever heal. Experiences of trauma, for the purposes of this research, refer to not only loss of life but also “fragmentation of families, the displacement [and destruction] of populations, and the disruption of social and economic institutions (Desjarlais & Kleinman, 1997 p1143).”

This research wonders at a link between pain and trauma in chronic pain sufferers’ experiences of their pain. Greenhalgh, 2001 summarizes the psychological experience of chronic pain as “distress is transformed into disease, and the ‘diseasing’ of social life moves ineluctably forward (p3).” Million, 2013 writes about how I operationalize suffering: “Trauma supposes a violence that overwhelms, wounding individual (and collective) psyche, sometimes suspending access to memory. The victims of traumatic events suffer recurrent wounding if their memory/pain is not discharged. A theory of trauma is embedded in an internationally recognized economy of justice that reconciliation belongs to (p2).” As demonstrated by participants varied self-care practices, “Intergenerational trauma is a diagnosis in which healing is now enacted through myriad practices of self (p31)” just as Million, 2013 asserts.

1.3.3 Grief and Affliction

There is comfort regarding the loss so complete it has no name. Silko, 2012 writes: “And it is together— / all of us remember

what we have heard together— / that creates the whole story /
the long story of the people. // I remember only a small part. /
But this is what I remember (p7).”

J. Jackson, 1999 suggests that we stretch our concept of pain to include unembodied pain—like grief. Additionally, Fordyce, 1988 argues for the distinctiveness of pain from grief. Pain exceeds the injury, and grief exceeds pain’s suffering. In the pain of tortured bodies, Eng & Kazanjian, 2003 “hears not a silence in tortured bodies, but rather a ‘mo(ur)ning(g)’...a potential site of resistance to racist authority and national violence (p12).” Here “the past is brought to bear witness to the present—as a flash of emergence, an instant of emergency, and a moment of production (Eng & Kazanjian, 2003 p5).” Disenfranchised grief emerges from the loss of loss itself—an unrecognized loss—in which new representations for healing must grow from concrete soil. The worst health effects arise when prevented from grieving properly and sufficiently for the many traumas and losses.

Das, 2015 argues for grief as affliction. Metaphorically grief “live[s] in the body of her [the woman who died] children like a parasite, eating on from within as the local rhetoric of grief puts it (Das, 2015 p54).” Many participants experience grief, but few articulate the grief in their interviews. During pilot data collection for the dissertation, I noticed that conversations about pain began the initial day of the relationship. I was unable to do the interview about grief, though, until hundreds of hours and cups of tea later, months into the relationship. Once re-opened the grief wound bled for days and then clotted. Therefore I am not surprised that participants only reluctantly talked about grief.

“Devastating losses such as loss of community, culture, and family may,” write Charmaz & Milligan, 2006, “for a period, lie beyond an individual’s ability to comprehend. Thus, it becomes impossible to place a frame on such a massive assault on one’s being in the world and ways of knowing the world in a similar way as individuals frame the loss of a partner or child (p530).” In the space of grief exists, according to Brault & Naas, 2001, “the possibility of an interiorization of what can never be interiorized, of what is always before and beyond us as the source of our responsibility (p11).” While mourning, the one (or thing) mourned exists within our thoughts and yet totally beyond us so that no physical contact will ever occur. Butler, 2003 echoes Charmaz & Milligan, 2006 and Brave Heart & DeBruyn, 1998 that,

despite the distance and nearness in the loss of a friend, the most difficult loss is of loss itself.

Somewhere, sometime, something was lost, but no story can be told about it; no memory can retrieve it; a fractured horizon looms in which to make one's way as a spectral agency, one for whom a full 'recovery' is impossible, one for whom the irrecoverable becomes, paradoxically, the condition of a new political agency (Butler, 2003 p467).

This is the loss Indigenous peoples will grieve. The loss, for example, when those carrying embers from the first fire were killed (Byrd, 2011). Those embers can never be recovered. Therefore the "community *cannot* overcome the loss without losing the very sense of itself as community (Butler, 2003 p468)."

Million, 2013 writes about this grief as Freud's melancholia, which "is haunted and does not heal, never pass[ing] into mourning to let go of the lost object (p90)." Grieving this kind of loss requires new circular and knotted models, relocation, rethinking, innovation, and actions beyond and beside chronicling the total embodied loss (Eng & Kazanjian, 2003). There is a lot to overcome "as they continually *get nowhere*, they continually lose kids to prison, bodies to addictions, and toes, feet, and then kidneys to diabetes (Povinelli, 2011 p116)." Yet the hope in grief, even grief for the loss of loss itself, is that "avowals of and attachments to loss can produce a world of remains as a world of new representations and alternative meanings (Eng & Kazanjian, 2003 p5)." In this research I am particularly interested in this grief from the loss of loss itself that proceeds chronic pain, fostering chronicity of pain. Kugelmann, 1999 articulates, "As we say, 'grief hurts,' so we could also say 'hurt grieves' (p1672)."

Everyday Violence Violence operates in the interstices between the problematic and troubling dichotomies: public/private, legitimate/illegitimate, and visible/invisible. Violence is not solely about the infliction of pain or the physicality of conflict. Instead violence "operates along a continuum that spans structural, symbolic, everyday, and intimate dimensions"—the forms of violence defined in this section and conceptualized for this research as normative violence (Bourgeois & Schonberg, 2009 p16). The continuum of violence reflects the human capability—even duty—to murder, marginalize, and

torture, and the human tendency to construct particular vulnerable persons as dispensable nonpersons (Scheper-Hughes & Bourgois, 2004). “Violence is a slippery concept—nonlinear, productive, destructive, and reproductive. It is mimetic, like imitation magic or homeopathy....Violence gives birth to itself. So we can rightly speak of changes, spirals, and mirrors of violence (Scheper-Hughes & Bourgois, 2004 p1).” I refer to violence as normative in order to reflect Scheper-Hughes & Bourgois, 2004’s theorization as well as incorporate all forms of violence (structural, symbolic, overt, and everyday) discussed in what follows. Normative violence, the kind of violence participants describe, considers what continues to occur with respect to trauma and grieving in the mundane spaces of their everyday lives. As (M. S. Kelley, Rosenbaum, Knight, Irwin, & Washburn, 1996) describes regarding violence against women and methadone treatment programs, “violence is a traumatic experience (p156).” The violence may be separate from the trauma and grieving or it may be the trauma and grieving—one and the same.

1.4 Chronic Pain

According to the International Association for the Study of Pain, “if they regard their experience as pain, and if they report it in the same ways as pain caused by tissue damage, it should be accepted as pain.” Because pain and failures of pain treatment challenge biomedical hegemony and because pain sufferers, quoting Jason Throop an anthropologist engaged with culturally-determined orientations to pain and suffering, contend with “some of the most dramatic, unassumable, and compelling forms of human experience (J. C. Throop, 2010 p3),” pain exerts substantive and measurable impact on the social world economically, interpersonally, physically, and psychologically. Over 100 million American adults are known to suffer from chronic pain—a disease burden that permeates individuals, families, caregivers, populations, and the healthcare system, diminishing quality of life, changing ability to work, and reducing economic health. Chronic pain encompasses a variety of pain conditions with various locations and etiologies. Western medicine views pain as individual and physical despite sociological evidence for pain as a collective experience with a holistic impact on the sufferer (Scarry, 1985). For G. A. Bendelow, 2006, a total pain experience prevails upon the psycho-

logical, spiritual, and sociological wellness of the pain sufferer as well as on his/her interpersonal and financial status.

In 1995 the American Pain Society Quality Care Committee pushed for pain to become a fifth vital sign, providing the United States' pain crisis with increased visibility (Davidhizar & Giger, 2004). Pain is still a universal human experience, but now it needs to be fought, it requires invasive treatments, and it demands legitimation in the laboratory. It is less clear how chronic pain—as opposed to acute pain—is a universal human experience. “Chronic pain, in particular, has long been cast as a moral weakness,” writes M. Buchbinder, 2011. “In the 1970s and 1980s, the psychological literature depicted ‘the pain patient’ as a singular type: dependent, isolated, malinger, and self-defeating (M. H. Buchbinder, 2010 p459).” This type of patient did not deserve treatment. Other types of patients in pain, particularly those cast as virtuous persons, experience legitimate pain and therefore deserve treatment. Thus chronic pain delimits the deserving from the non-deserving and the legitimate from the illegitimate. I present two models of chronic pain—biomedical and sociopsychobiological—which help establish the dichotomy between mind and body that participants perpetuate in their conceptualization of physical pain versus emotional pain.

1.4.1 Biomedical Model of Chronic Pain

In the medical model viruses, bacteria, immortal cells, deterioration, and physiological changes infect a population (Popay et al., 1998). The medical model ascribes to mind-body dualism, privileging the physical body (Freund, 1999). Sweet, 2006, a historian and internal medicine physician, writes:

Perhaps its most salutary conclusion is that medical models ‘work’ when they reflect the world they are in. In a world of machines, bodies will be understood as machine; in a world of computers, bodies will be understood as computers; and in an agrarian world, bodies will be understood as plants (p165).

In the medical model, the body is a machine that sometimes breaks down and requires fixing. An identifiable and singular agent causes disease and a related magic bullet treats that disease. Championing one cause of pain over another or striving to enact the one disease and magic bullet relationship

of biomedicine merely entrenches the pain and lessens the effectiveness of interventions.

Pain physiology occurs through nociception, the felt experience of pain, or pain as a sense. Acute pain occurs when tissue damage is visible. Chronic pain appears biologically different from acute pain. To be called chronic, pain persists for more than three months (Beck & Clapp, 2011). A-delta nerve fibers, as myelinated nerves, carry information rapidly about acute pain in a single location, while C-type fibers convey deeper, more profuse pain. These fibers transmit the pain impulse from the periphery to the spinal cord. In the spinal cord, pain messages travel in the spinothalamic tract to the brain. With enkephalin, a protein bound to delta opioid receptors, the brain can stop peripheral pain signals from reaching consciousness (Koenig, 2003). The thalamus is the spinothalamic tract endpoint in the brain that relays sensory signals between the cerebral cortex and spinal cord. The anterior cingulate cortex functions in rational cognition for decision-making, empathy, and impulse control. The seahorse-shaped hippocampus operates for learning and memory while the almond-shaped amygdala regulates emotions, especially fear, love, anger, and sadness. Finally, the insula is the seat of consciousness or self-awareness as well as social emotions such as disgust regarding torture or empathy for another's pain. All these brain regions may be involved in pain nociception.

Melzack and Wall, famous pain researchers, complicate a one-symptom/one-lesion/one-pathway/one-treatment model for pain through the Gate Control Theory that bridges psychological and biological concerns and implications. There exist numerous possibilities for the relationship between initial injury and pain response. Some injuries fail to cause pain. Other seemingly harmless injuries cause intractable pain. At times pain arises without any injury. The latter situation presents a particularly difficult treatment challenge. The McGill Pain Questionnaire used for this research enables one to uncover this multidimensionality of pain. M. Jackson, 2002 asks: "Why are we, the most medicalized of societies, a culture in pain (p5)?" M. Jackson, 2002 provides her response, "Pain will never come down to a matter of nerves, chemicals, and tissues. Pain is also made of time and the echo of one's earliest injuries and trauma (M. Jackson, 2002 p87)."

A clinician's assessment of pain (from Koenig, 2003), when taking a history on a patient who complains of pain, begins with a description of the

pain, including sensation, intensity, and presence. The clinician asks about the location of pain, the first incidence of pain, and activities or interventions that worsen or alleviate the pain. Activities or interventions include pharmaceutical treatments, complementary or alternative medicine, chiropractic manipulation or physical therapy, and surgical procedures. The clinician asks the patient to objectively rank pain severity, comparing current pain to past experiences of pain. After the history, the clinician conducts a physical exam often followed by more invasive imaging. During the assessment, the clinician must keep in mind four key considerations. First, what underlying pathology might explain the pain? Second, how is the patient conveying their perception and subjective experience of pain? Third, how are psychosocial factors perplexing the pain? Fourth, what does the patient expect from the healthcare system regarding relief of pain?

Without a diagnosis, pain sufferers struggle through the clinical encounter. “In Western society, a key player in the legitimation of illness is the medical doctor,” argues Glenton, 2003, “a gatekeeper function that is justified with reference to the medical profession’s ability to identify objective biological or pathological findings, that is, signs of disease (p2244).” Because the clinician has the power to diagnose or not diagnose, the clinician also determines the pain sufferer’s access to social acceptance and financial benefits. Therefore “the...pain sufferer must strive to live up to the doctor’s expectation (Glenton, 2003 p2251).” Past research reveals that pain sufferers often execute their agency in demanding extraneous tests in their search for the legitimation of diagnosis. Nevertheless failure of a clinician to diagnose a pain sufferer tends to result in a prolonged engagement between the clinician and the pain sufferer. Baszanger, 1998 calls the clinical encounter surrounding the symptom of pain a deciphering process. Pain requires extra deciphering, because no one talks about pain with the same language, and because pain resides in the sufferer’s subjective experience. Baszanger, 1998 found that the vagueness with which clinicians’ approach the definitional process for chronic pain tends to irritate the patient, who wonders if body or mind is in pain and which type of pain would most please the clinician. A tension emerges between medical and lay perceptions of the problem(s) underlying chronic pain.

The trope for clinicians is that pain sufferers always exaggerate their pain, and that they most often are underfucked and fat women. Additionally pain

sufferers, according to the trope of clinicians, are in poor physical shape, have secondary gains, socially isolate themselves, are related to others with chronic pain, have unresolved conflicts, and cannot hold down a job. Depressed, vague, fatalistic, and hopeless best describe pain sufferers from the trope of biomedicine (Baszanger, 1998). Legitimizing the pain is a huge step and task for providers in providing better pain care. No pain sufferer wants to be weak or crazy, to dramatize and corporealize for legitimate attention.

Perhaps biomedical providers react with such vile tropes about pain sufferers, because chronic pain represents the systematic failure of biomedicine. Regarding chronic pain, medicine fails Kotarba, 1983 points out. Medicine fights against pain and yet pain prevails while medicine retreats, duped (Baszanger, 1998). Chronic pain resists fragmentation customary in biomedicine. “Chronic pain thus challenges the central tenet of biomedical epistemology: namely, that there is objective knowledge, knowable apart from subjective experience (Good, Brodwin, Good, & Kleinman, 1992 p6).” One can argue that chronic pain is iatrogenic. In fact Greenhalgh, 2001 spends her book *Under the Medical Gaze* telling the auto ethnographic story of her iatrogenic fibromyalgia. Chronically using the treatments for pain is often just as problematic as the pain persisting (Hilbert, 1984). “Many people find it quite difficult to reconcile the dissonance,” notes Kotarba, 1983, “between organized medicine’s economic, political, and cultural preeminence in our society and its inability to effectively deal with pain (p21).”

1.4.2 Socio-psychobiological Model of Chronic Pain

In contrast to the biomedical model of chronic pain, the socio-psychobiological model of pain recognizes the entrenchment of chronic pain in the human condition. The socio-psychobiological model integrates the mind with the body thereby addressing physical pain simultaneous with social and psychological pain. A socio-psychobiological model privileges social factors of illness such as cultural practices, gender, historical condition, and racial identity over individual factors of illness such as what to call the pain, how the pain affects one’s life, the origin of the pain, feelings of control over the pain, and emotional reactions to pain. In the socio-psychobiological model of chronic pain physical pathways to pain (age, genetics, injuries) run alongside emotional

pathways to pain (loss of close friends, stress, hopelessness), and spiritual pathways to pain (loss of cultural connectedness).

A socio-psychobiological model of pain recognizes the entrenchment of chronic pain in the human condition. The Socio-Psychobiological Model proposed by Chae, Nuru-Jeter, Lincoln, & Francis, 2011 “specif[ies] determinants at multiple ecological levels of analysis (p63)” through a cross-disciplinary approach. The ecological levels concern both the origin of the determinants and the location of outcomes and are the individual, the community, and the population. Chae et al., 2011 presents this model as an update of the biopsychosocial model (Clark, Anderson, Clark, & Williams, 1999) that privileged the biological origin of health over social and psychological modifying factors. A socio-psychobiological model revises a biopsychosocial model by privileging social factors of illness such as access to healthcare, cultural practices, socioeconomic status, and education over individual factors of illness such as what to call the pain, how the pain affects one’s life, the origin of the pain, feelings of control over the pain, and emotional reactions to pain. Thus the individual, who is a social, psychological, and biological being, experiences pain as physical symptoms, psychological distress, and social meaning.

Chae et al., 2011 aims with the socio-psychobiological model to expand web of causation models that focus primarily on biological and behavioral factors of disease. Cohen, 1999’s call for “a more complex theoretical model—one that not only makes central concerns over dwindling resources, or multiple crises, or community homophobia, but also incorporates the historical experiences of exclusion and marginalization (p35)” can be realized with the socio-psychobiological model. The model demonstrates the interlocking, overlapping, and constraining role of historical experience and macro and micro contexts in determining health inequality. The model is a more complex theoretical model. Finally, the socio-psychobiological model establishes a directional relationship between social inequalities and unjust disease distribution that leads to more effective interventions for health improvement and disparity elimination. Therefore I use a socio-psychobiological model for this research that considers both the biological pathogens of the medical model in addition to the psychosocial pathogens of the social model. Chronic pain cannot be understood from a biomedical or sociological perspective alone. A socio-psychobiological model of pain addresses simultaneously the underlying social influences on pain such as race, socioeconomic status, and culture, the

psychological impact of pain, and the biomedical cause of pain, privileging sociological concerns such as sociological models of health.

Pain permeates all levels of existence and relationship: individual, group, societal, and cultural. As Silko, 2012 writes in the story of Arctic, “The old woman whose body had been stiffening for as long as the girl could remember. Her knees and knuckles were swollen grotesquely, and the pain had squeezed the brown skin of her face tight against the bones; it left her eyes hard like river stone (p19).” She continues, “She held her mouth even tighter, set solidly, not in sorrow or anger, but against the pain, which was all that remained (25).” Sociology enables a collective analysis of these levels without generalizing that cultural meanings of pain determine an individual’s experience of pain.

“Why do we treat such an apparently individualistic and biological experience as a sociological phenomenon (p16)?” questions Kotarba, 1983. His answer is because coping is an inherently social task, albeit a micro social task. Kotarba, 1983, one of the few sociologists who studies chronic pain, motivates a sociological approach to chronic pain with two reasons: 1) Chronic pain sufferers seek out meaning for their pain and healing, which involves dynamic interactions with biomedical and/or traditional healthcare systems; and 2) chronic pain sufferers live with their pain constantly. Therefore it enters every social interaction as an additional member of the interaction. The sufferer negotiates a comfortable presentation of self despite that self always experiencing an incommunicable discomfort—an argument Kotarba, 1983 makes gesturing to Goffman. Kotarba, 1983 further links the theory he develops from studying chronic pain to predominant theories in the sociology of health and illness—Parsons on professionalization and physician/patient relationship, the symbolic interactionists on meaning making, and phenomenological sociologists on the role of language in social order. As an example, failure to enact the sick role with chronic pain leads to self-blaming and illegitimacy—the same occurs for pain that originates in the mind. Being sick is temporary, treatable, and physiological. Enacting the sick role enables one to take off work and sign out of other productive duties while getting better. Without external proof of sickness and with illness that lasts beyond the time limit for being sick, the pain sufferer cannot achieve the sick role (Glenton, 2003; Hilbert, 1984; Monsivais & Engebretson, 2011).

Pain sufferers exist in a liminal space without expert knowledge produc-

tion, without the sanction of society, and without knowable patterns in their pain (Hilbert, 1984). The social problems for chronic pain sufferers result from “the invisibility of pain, narcotic use stigma, [and] sick leave running out (Glenton, 2003 p2249).” The pain itself does not threaten social status but “the suspicion that the pain does not really exist (Glenton, 2003 p2249)” does. Nonexistent pain, psychological pain, social pain, cultural pain—all those pains that don’t really exist—facilitate the stigma of character blemishes as opposed to the stigma of physical deformity. Therefore “anthropologists [and sociologists] concerned with...everyday experience and the embodiment of cultural categories of distress are drawn to pain in order to understand how bodily experience itself is influenced by meanings, relationships, and institutions (Good et al., 1992 p7).” The idea that nothing is wrong and that the pain makes no biomedical sense socially isolates the sufferer and tragically the “pain persists in all occasions as a somatic reminder that things are not right and may never be right (Good et al., 1992 p370).” Others ignore this liminal space, perpetuating the sufferer’s social isolation. Thus the pain sufferer “precariously and continuously approach[es] the amorphous frontier of non-membership (Good et al., 1992 p375).” All those who experience pain are “trapped in the same larger systems of power, which for a very long time no one could see and no one could understand (Greenhalgh, 2001 p5).”

Burdened with an invisible chronic illness and no way to enact the sick role, pain sufferers wonder how do I tell that I’m in pain without crying out as with acute pain? Hilbert, 1984 argues that “chronic pain management involves simultaneous strains toward disclosure and concealment (p370).” Disclosure of pain explains aberrant behavior related to the presence of pain, such as removing oneself from particular social situations. Many others in those social situations are not interested in constant reminders about a pain they cannot understand. Those who disclose their pain worry about being marked as a complainer. Being marked as stoic often seems the better option. “Their efforts reflected a subtle bodily and gendered balance,” Werner, Isaksen, & Malterud, 2004 found in pain sufferer support groups, “not to appear too strong or too weak, too healthy or too ill, or too smart or too disarranged (p1037).” Das, 2015 also reports her experience with how those she interviewed described their own illness experience:

Some illnesses were passed over in a casual manner; others led to more stories about engagement with different social and therapeutic contexts. Illness in the latter sense revealed itself to be profoundly social. To capture this aspect of illness experiences and to understand the relation of failures of the body to failures of one's social world (Das, 2015 p32).

Chronic pain subcultures and social movements arise to provide meaning for those with atypical persistence of pain. Those with persistent pain become more and more removed from the social world since pain is a “knowable yet private reality (Hilbert, 1984 p366).” The chronic pain subculture allows pain sufferers to experience transformations in their social world and their identity within a group of others who understand. Additionally the subculture creates a place for the subjective experiences of pain to be situated within local systems of knowledge, morality, and practice. G. A. Bendelow, 2006 notes that the subculture may provide access for marginalized groups who have less access to expert knowledge and often expensive, non-medical treatments. Brown et al., 2004 discusses how embodied health movements, for example social movements regarding autism and HIV/AIDS, provide movement participants with a way of seeking biolegitimacy—a concept from Didier Fassin. N. Rose & Novas, 2004 refer to collectivities formed around a biological conception of identity as biosocial groups. One seeks and maintains biological citizenship through policing and disciplining their bodies thus maintaining the social body's health. Theories of causation for the illness differentiate biosocial groups within the same illness.

1.5 Preview of Chapters

This dissertation contains three parts: pain, suffering, and surviving, which map the progression from initial diagnosis or realization that pain is chronic through cyclical reevaluations of the way pain impacts lives to fostering strength for living well with the pain. In elucidating experiential links between colonization and chronic pain, I track the following processes: 1) causal and experiential narratives about pain including meaning of pain [Chapter Three], 2) the impact of chronic pain experience on identity, psychology, social world, and culture [Chapter Four], and 3) pain treatment through integrated traditional, complementary and alternative, and biomedical healing

practices [Chapter Five]. This research aims: 1) to describe the pain experience (from initial diagnosis through treatment seeking) for American Indian chronic pain sufferers living in off-reservation or urban settings, 2) to determine the influence of background, explanatory factors (historical trauma, disenfranchised grief, and normative violence) on pain as reported with the McGill Pain Questionnaire by American Indians living in off-reservation or urban settings, and 3) to identify treatment modalities (biomedical and traditional models of healthcare) used by American Indians living in off-reservation or urban settings to cope with chronic pain. The results of this research will inform patient-centered and structurally-competent care practices and policies for chronic pain sufferers in the American Indian population. Below are summaries of each chapter.

Chapter Three deals with the chronic pain itself, including diagnosis and meanings for the pain. Participants illustrate their relationship with their chronic pain through images of the pain as well as through ways of describing what the pain feels like. This chapter also contains the various ways that participants conceptualize what causes their chronic pain. Chapter Four explores the various impacts chronic pain has on participants—on their identity, on their mindset, on their relationships, and on their culture. The impact occurs bidirectionally. In other words, chronic pain shifts how participants envision themselves and how participants envision themselves also impacts their experience of chronic pain. Chapter Five presents how participants are able to survive and thrive with the chronic pain, focusing in particular on their self-care practices that serve as resources for endurance and strength. Finally, I model an integrated critical theory of chronic pain in Chapter Six.

Methodology

2.1 Research Design

In order to answer my research questions about the relationships between chronic pain and colonization in the lives of American Indians living off-reservation, I use both quantitative and qualitative data. I collected the interview data simultaneous with the survey data. In data analysis, the quantitative data embeds within the qualitative data, triangulating through numbers what participants shared in their interviews. Therefore I utilize a concurrent embedded transformative mixed methods strategy (Creswell, 2009). A primary goal of the dissertation is to suggest an integrated critical theory of chronic pain.

2.1.1 Guiding Framework

The mixed methodology of this research employs a social constructivist framework following Creswell, 2009's research design considerations. A social constructivist framework weds with critical theory, because I ground the data in existing literature and interpret the data for the communities in which I worked. Medical sociologists have long employed social constructivism in the understanding of illness experience, namely how social forces shape illness meaning and behaviors in response to illness (Brown, 1995). The way that this research foregrounds how participants create meaning from their experiences of pain and then determine their actions in response to the pain places this research within a social constructivist worldview. I seek therefore to present the data as an amalgam of complexity with an eye toward commonalities that emerge despite the vastly different and diverse experiences, social positions, ages, and identities of participants. I regard participants' ex-

periences with chronic pain as embedded within a particular social location, historical time, and cultural connectedness. I inductively generate themes grounded in the participants' stories. In particular Chapter Three describes the meaning participants attach to their chronic pain, while Chapter Four explores the embedded position of participants, and Chapter Five considers how the meaning-made within a particular context determines healing practices used.

In addition to a social constructivist framework, I also employ a critical theory framework since this cross-disciplinary research spans sociology, medical sciences, and Indigenous studies. I use critical theory to understand the local simultaneous with the global, because a critical theory framework reinterprets politics and culture and reconceptualizes space and history through the performance of stories. Critical theory demands engagement with who has power to generate knowledge, use knowledge, and dismiss knowledge. Critical theory assesses a system wrought with inequality, striving to act on the world through research not be acted upon by the world. A critical theory framework acknowledges the researcher's positionality and limitations, while empowering the research community to examine experiences of chronic pain and how cultural resources may be tapped to overcome chronic pain. Giacomini in Bourgeault, Dingwall, & DeVries, 2010 writes, "Critical theorists view socially constructed realities as the products of power relations. Power is distributed unequally, to the detriment of the powerless." In this way a critical theory framework enmeshes with a social constructivist framework. Povinelli, 2011 interprets the role of critical theory: "Critical theory provides positive content through the parasitical activity of stating 'not this' (p192)." Finally, critical theory gets at the foundation of what we taken for granted in our world. Within a critical theory framework, I recognize the entrenchment of chronic pain in the human condition. Thus the individual, who is a social, psychological, biological, spiritual, and cultural being, experiences pain in mind, body, and soul simultaneously.

2.1.2 Overview of Research Design

I collect both qualitative and quantitative data in a concurrent embedded transformative mixed methods model. Qualitative and quantitative data

collection and analysis occurred simultaneously—a concurrent mixed methods approach. I collected data concurrently in order for the quantitative and qualitative data to triangulate results. With a handful of participants (n=3) selecting to provide either an interview or complete the survey, the remaining participants (n=38) completed both the interview and survey with one participant excluded, because he did not meet the screening criteria (race Latino not American Indian). I gathered data in Chicago, Illinois (n=11) with key informant contacts at Trickster Gallery, American Indian Association of Illinois (AIAI) and Kateri Center introducing me to community members. In Indiana (n=17), I recruited through volunteering to provide health screenings at state-wide Powwows through the American Indian Center of Indiana (AICI). Finally in Tulsa, Oklahoma (n=12), I worked through a key informant friend and her sister to recruit participants at the Tulsa Indian United Methodist Church and at my friend’s home. Indigenous scholarship urges acknowledgement for the Indigenous people of the land in which you reside as a settler. Therefore my fieldwork occurs local to where I am studying.

Figure 2.1 provides a visual overview of the research design. The qualitative data analysis structures the majority of themes presented in the chapters that follow. Quantitative data analysis embeds within the framework set up by qualitative data analysis to reinforce findings. All data analysis emerged inductively from the data collected. In the section on Steps of the Study, I refer back to this Overview of the Research Design and expand on each component. UIUC’s Institutional Review Board approved the study. All participants consented to what they completed: the survey, the interview, or both.

2.1.3 Rationale for Research Design

This study joins an emerging body of mixed methods research in the sociology of health and illness, because of mixed methods’ ability to test hypotheses through quantitative methods and provide rich experiential data through qualitative methods. Sociologist and pain researchers G. Bendelow & Williams, 1998 assert that “the diversity and flexibility of both theoretical and methodological approaches within the sociology of health and illness are highly appropriate to the analysis of pain as an ongoing structure of lived

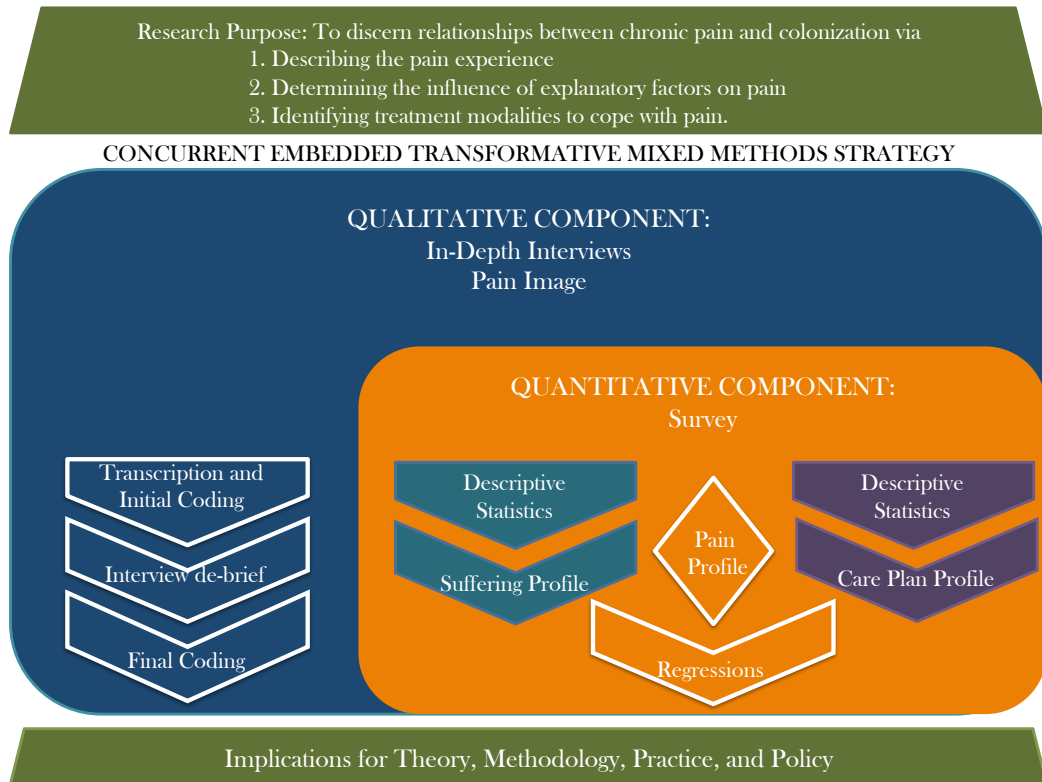


Figure 2.1: Overview of the Research Design

experience (p254)” P. Kelley & Clifford, 1997 in research on narrative treatment for fibromyalgia patients utilized mixed methods to assess treatment functionality, thereby setting a precedent for mixed methods research in contested illnesses and chronic pain with a particular emphasis on treatment—a precedent this research follows. L. T. Smith, 2015 writes of a sociology of absences that comes from the “legal sociologist Boaventura de Sousa Santos [who] calls for an ecology of knowledge/s that enables alternative ways of knowing and scientific knowledge to coexist, and argues that there can be no global social justice without global cognitive justice (p214).” The quantitative data represents the scientific knowledge to coexist with the qualitative data or the alternative ways of knowing in order to impact both global cognitive and social justice, respectively.

The IOM Report on Pain further justifies a mixed methods approach. Quantitative data provides concrete measures of pain, trauma, violence, grief,

and resilience. Qualitative data supplies stories of experience. The IOM Report notes that gathering a number measurement for pain intensity alone fails to demonstrate a complete experience of pain and discourages patients from telling the stories they need for their healing (Pizzo & Clark, 2011). Gathering both numbers and experiential stories multiplies the data's function as complete evidence.

Mixed methods research focuses on a single subject for inquiry. In this study that key topic is how American Indians conceptualize chronic pain with respect to their individual, social, and cultural life. Data analysis for this study follows a narrative methodology in order to bridge disciplinary and community concerns. Indigenous epistemologies think with and through stories. Relatedly, every progress note generated in a healthcare setting delivers a narrative of a patient. Charmaz & Paterniti, 1999 prominently call attention to narrative methods in healthcare. Frank, 2004 defines a “narrative imperialism (p212)” that constrains which stories are told, heard, and recorded in a hospital room. Frank, 2004 encourages healthcare practitioners to understand a continuum. The latter end of the continuum regards stories as stable or fixed objects upon which a disconnected expert gaze asserts a diagnosis, forsaking the patients' lived experiences. The former end of the continuum embraces the nested and complex nature of stories that form through dialogue, shape relationship, and claim patients' lived experiences. L. T. Smith, 2015 asserts another rationale for collecting stories as data especially with an Indigenous community: “A large part of the research stories that need to be told are small stories from local communities across time and space, in other words the stories that map devastation across generations and across landscape, or the stories of transformation and hope that can also be tracked in this way (p225).”

As shown in the substantive chapters, the interviews collected for this dissertation are small stories from diverse spaces that tell both of devastation and transformation. Sometimes the stories sound alike, almost redundant, and yet two people from remarkably different social locations are telling the stories. I therefore preserve the redundancy of the stories for two reasons. First, I present some component of every participant's story in order to honor and respect that participant for their time and energy sharing about their chronic pain. Second, one of the remarkable conclusions from this data is that very different people tell very similar stories.

With this research I document the buildup of circumstances leading to the manifestation of chronic pain. The chronic pain sufferer is in a crisis that converses with how others, in particular healing practitioners, understand the sufferer's crisis (Bonham, 2001). Chronic pain is an illness imbued with social meaning, not just a biological malfunction (Conrad & Barker, 2010). Allowing someone to tell their illness narrative fosters healing, closure, restoration, and understanding (Hall, 2011; Morse, 2010). Werner et al., 2004 writes in particular about causal narratives for chronic pain: "As a plot, their stories attempt to cope with psychological and alternative explanations of the causes of their pain (p1035)." The storytelling is a recognition, not an interrogation, of the pain experience (Frank, 2004). When the conversation concerns a person's entire life, then the pain links with personality, culture, and social structure, and the personal narrative becomes a social narrative that can then recognize the particular social context of being an American Indian in the United States (Baszanger, 1992; Frank, 2004). Utilizing narrative techniques for this research furthers the critical theory impetus for social justice. Greenhalgh, 2001 argues for stories generating change: "An epilogue suggests that storytelling by the ill is one of the most promising paths to changing the cultures and politics of chronic pain (p16)."

2.1.4 Research Purpose

To find links between colonization, chronic pain, and resistance, I track the following processes: 1) causal and experiential narratives about pain including meaning of pain [Chapter Three], 2) the impact of chronic pain experience on identity, psychology, social world, and culture [Chapter Four], and 3) pain treatment through integrated traditional, complementary and alternative, and biomedical healing practices [Chapter Five]. This research aims: 1) to describe the pain experience (from initial diagnosis through treatment seeking) for American Indian chronic pain sufferers living in off-reservation or urban settings, 2) to determine the influence of background, explanatory factors (historical trauma, disenfranchised grief, and normative violence) on pain as reported with the McGill Pain Questionnaire by American Indians living in off-reservation or urban settings, and 3) to identify treatment modalities (biomedical and traditional models of healthcare) used by American Indians

living in off-reservation or urban settings to cope with chronic pain.

2.2 Steps of the Study

2.2.1 Sampling

Data collection occurred from June 2014 through February 2015. During this time, I advertised for participants on the listserv for the American Indian Center of Indiana (AICI). Through AICI, I also volunteered at Shakamak State Park Powwow, Vigo County Conservation Club Powwow, IU-Bloomington American Indian Wellness Day, and IU-Bloomington Powwow, providing health screenings (blood pressure checks, blood glucose checks, and cholesterol checks) as well as education regarding test results and healthy living. Health screenings were provided independent of recruitment for this study. I also connected with participants through flyers posted at Trickster Gallery in Schaumburg, IL, American Indian Association of Illinois, Kateri Center in Chicago, Miami Tribal Offices in Peru, and Ho-Chunk Tribal Offices in Chicago. I spent one day at American Indian Association of Illinois collecting data from participants found by the director. I also spent a day at Trickster Gallery collecting data from participants found by the gallery director and attended a Christmas volunteer celebration to recruit. Finally I worked with a friend and her sister in Tulsa, Oklahoma to gather participants for an intensive weekend of data collection. Saturday of that weekend, I collected data at my friend's house and Sunday at the Tulsa Indian United Methodist Church before, during, and after the church service.

I chose to work in Chicago and Indiana because of the proximity to UIUC. One of the ethics established in Indigenous research is the impetus to work locally and thus acknowledge that you are a settler. Chicago has a substantial population of American Indians, many who established a community there in the 60s following the one-way bus ticket assimilation policy of the US Government. Indiana is continued home to the Miami Nation. I expanded data collection to Oklahoma, because I was encouraged by a friend. I met this friend through Joy Harjo, Professor of English and American Indian Studies, at a Lomilomi Course in Hawaii.

The criteria for the study were yes answers to the following questions: 1)

Have you experienced pain for more than 3 months at a time?; 2) Are you 18 years or older?; 3) Do you identify as American Indian/Alaska Native, Native American, First Nations, and/or Aboriginal?; and 4) Do you live off-reservation? I distributed a flyer for “Paid Research on Chronic Pain: tell stories about your experience with chronic pain” at Powwows where I volunteered and through emails to key informants in Tulsa and Chicago. The flyer described the research process as “The study consists of a survey and an interview. The study will take place at a location that you choose so that it is comfortable, quiet, and private for you to talk. You will be asked questions about your experience with chronic pain.” I sought maximum variation in recruitment.

Appendix C specifies characteristics of the participants. Table 2.1 provides descriptive statistics for participants. I collected data from a total of 43 people, living in rural places to large cities off reservations, 67% women, 38% multiracial, average 14 years of education with pain for over 16 years. Most participants were no longer working either due to retirement or their disability from their chronic pain. A few participants were going back to school or very much desired to go back to school. Participants were primarily well educated in a way that mismatched their class standing (often living just off social security or disability benefits). One participant did not complete either the survey or interview and thus was excluded. Another participant identified himself as only Latino on the demographics questionnaire and thus was excluded. Three participants only completed the survey. One participant only completed the interview. The remaining participants completed both the survey and interview.

All participants were compensated \$20 for completing the survey and \$20 for completing the interview. Funding for participant reimbursement came from the O’Morchoe Leadership Fellowship through the University of Illinois College of Medicine at Urbana-Champaign as well as from the research funds of Adele Proctor, Associate Professor of Speech and Hearing Science. Funding for transcription of five interviews came from the research funds of Margaret Kelley, Associate Professor of Sociology.

The majority of data collection took place at participants’ homes. Three interviews occurred over the phone due to distance and travel constraints. Surveys were emailed for phone interviews and returned through either mail or email. Other places for data collection included libraries, galleries, muse-

Table 2.1: Descriptive Statistics of Study Sample

	N	Mean	Std. Deviation	Interpretation
age	40	54.03	13.174	
female	40	0.7	0.464	70% female
education_yrs	39	14.79	2.949	associates level
off_res_yrs	37	49.81	14.598	most of life
urban	40	3.03	1.593	mid-size town
occup_curr_yr	29	14.07	10.696	
live_with	40	1.85	1.968	range: 0 to 7
health_selfrated	40	4.46	1.337	average health
pain_yrs	39	16.2	13.281	
wellness_exam	40	0.72	0.452	72% had wellness exam
multiracial	40	0.4	0.496	40% multiracial

ums, churches, restaurants, and workplaces. Participants selected a quiet and convenient location to meet. Participants primarily reported pain related to musculoskeletal dysfunction or chronic illness processes. They all knew of resources in their areas for mental healthcare should unwanted feelings arise during the survey and/or interview. Many participants noted a time in the past, often early on when they realized the pain was not going away, that they actively needed mental healthcare, some even trying to kill themselves. At the time of data collection, most participants had a story to tell for how they dealt well with their chronic pain on a daily basis.

2.2.2 Qualitative Component: In-Depth Interviews

In-depth, open interviews with 38 urban American Indians captured detailed first order narratives about individual lived experiences of chronic pain as well as second order narratives about social pain of historical trauma, disenfranchised grief, and normative violence. Keira noted in her interview that “you and I sit here together in humbleness.” Iggy expressed gratitude for the opportunity, “I just, talking about this, I’m learning a lot of stuff about me. Thank you.” I discuss some more participant responses to the process in the section on Methodological Concerns. The interview included questions

about participants' experiences, their perceptions, their health, their spirituality, and their culture as they relate to participants' lives with chronic pain. Participants were briefed on the interview's purpose within the larger study and provided consent. I began the interview with questions that recognize and interrogate the pain itself (Jeannette Armstrong quoted in Million, 2013 comments, "I want you to tell me how you deal about it, how it affects you, the things you know about how it affects you (p27)") and then moved to uncovering causal narratives and modeling the impact of pain on their life Frank, 2004. See Appendix A for interview guide (questions adapted from Lasch, 2000). Interviews lasted between thirty minutes and three hours.

Pain Images As part of the interview, I asked participants to draw a picture of their pain. I used this alternative method of investigating pain because of the nature of pain. Pain often renders wordless the person describing pain. Scarry, 1985 argues that pain destroys language, for example. Therefore to fully and deeply understand the lived experience of chronic pain required multiple modes of expression. In addition the clinical assessment of pain, especially in multidisciplinary pain clinics, often includes a visual component. Patients are asked to mark on an image of a body the location of their pain. This enables patients to show multiple pain sites as well as radiation of pain. I am also a visual person. In sharing stories with those in chronic pain, I gathered a better understanding of their pain when they were able to express that pain visually. Though you can never feel another's pain, seeing a lightning bolt or fire on a hip or a clamp on a shoulder enabled me, as the listener and receiver of the story to connect better with the pain described. Cross, Kabel, & Lysack, 2006 and Kirkham, Smith, & Havsteen-Franklin, 2015, following a phenomenological methodology, asked participants to first draw their pain and then interviewed participants about their images about pain. They comment that the pain images are "one small step closer to bridging the divide 'between what is seen and what is felt (Cross et al., 2006 p192).'"

I provided participants a blank sheet of paper and pen for this interview question. A few participants interviewed in classrooms had access to colored pencils and markers for their image. Color is therefore not a standard dimension of the drawings that I can analyze. In analyzing the pain images, I looked primarily for similarities between images in shape, size, human fea-

tures, and intensity. Many images had faces, either faces of the pain itself or faces of them in pain. Other images had sharp elements—knives, arrows, and lightning bolts. Despite the differences in pain stories, the images of pain shared many similarities. Like Cross et al., 2006 and Kirkham et al., 2015 I linked pain images with comments from the interviews. Though I did not ask specific follow-up questions regarding the pain image, my next question after asking participants to draw their pain was about what participants call their pain. The image usually represented what participants would say in words as the name of their pain. Pain images are provided throughout the substantive chapters as a supplement to interview data. Because the task of drawing the pain came early on in the interview, participants often spoke about their pain drawing as a visual aid when telling me further details about their pain.

In collecting this visual data, I have begun to advocate for collection of visual data when studying phenomena that defy words. In the future I would ask participants to describe their pain images during the interview. I would also provide color to all participants as I found color to be an important part of demonstrating the nature of pain. The way participants drew their image was important and in the future I would collect field notes on this element of the interviews. Some participants waited until the end of the interview to draw their pain image. Others spent the entire interview coloring on the pain image. Still others very quickly created an image and handed it over. Some pressed their pencils to the paper with intensity. Others had no idea what to draw and left the page blank.

Transcription and Initial Coding The interviews, both phone and in-person, were audio recorded with a digital voice recorder if participants consented. One participant did not consent to audio recording. During the interviews, I took brief notes. For the phone interviews and during the non audio recorded interview, I took more extensive notes in case the digital recording failed to save. I identified the notes, the survey, and the interview recording and transcription with an assigned number. Only I have access to the raw data files. Only one password-protected spreadsheet links participant number with participant name. Hard copies of materials are kept in a safe and will be stored for 5 years after data collection, according to APA regulations. Data on the computer will be kept indefinitely with a backup on an external

hard-drive as well as password-protected in the cloud.

Analysis of interview data occurred iteratively during data collection in order to revise the interview guide. Once data collection was complete, I transcribed all but five of the interviews. Therefore I transcribed the recordings six to nine months following data collection. A professional transcriptionist transcribed the five remaining interviews due to time constraints. During transcription, I recorded major themes that emerged from each interview at the end of each interview transcript. This served as initial coding. The themes emerged completely from each interview as I coded for main points of each participant's story. Example themes include stress as cause of pain, boiling blood, beauty for healing, non-negativity, and isolation. Therefore I grounded my data analysis from the start in each participant's account of the lived experience of their chronic pain.

Interview De-briefing Participants had the opportunity to review their interview transcripts and provide definitions for the themes I had uncovered in their interviews during initial coding. This is in keeping with what Creswell, 2007 questions, "Who owns the story? Who can tell it? Who can change it? Whose version is convincing? What happens when narratives compete? As a community, what do stories do among us (p57)?" Once I completed transcription of a particular interview, I sent an email to the participant with a word doc of the interview attached. The email followed this general template: "Please find attached the transcript of your interview from the chronic pain study. By [insert date], I would like you to read over the transcript and give me comments or clarification. If you modify the document, please use track changes so I can see the original plus the modifications. I also noticed a few themes in the interview, which I put at the end of the transcript. For these themes, please write a definition (i.e. what they mean to you). This is the most important part." Therefore I increased the validity of themes through participant de-briefing. The process helped answer the question: Were the elements in this interview that stood out to me really the most important components and therefore an honest distillation of the participant's lived experience of chronic pain? I gave participants this opportunity to revise their story in order to heed Das, 2015's observation that "stories could change shape, be picked up or discarded much as the therapies could be picked up or discarded (p63)."

Due to the method of recruitment, I did not have contact information for the participants (n=7) interviewed at Tulsa Indian UMC so their interview transcripts were not returned to them for review. Of the remaining 31 participants, I heard back from 20 participants, acknowledging the receipt of the interview transcript. Out of those I received a response from, half provided edits on their interviews and definitions for the themes in their interviews. I had a 52.6% response rate on the transcript feedback, including those participants that I could not contact via email. I include the definitions of themes provided by participants in the substantive chapters of this dissertation often word for word.

A few participants noted that they had reopened wounds completing the interview and were not interested in reliving or reopening again by reading through the transcript. Others asserted the absolute need for truth regardless of reopening wounds or reliving trauma. Azure told me:

I would rather give you truth as there has been a lot of white washing. There has been a lot of assumptions. There has been a lot of misinformation. And lies and not truth that has been put out there. I would rather cry and go for the gut and go for the truth both as a writer, as an artist, as a person, as a native, and as a woman. I would rather speak about what is uncomfortable and have that out there. Because if something is going to be done. We can't have anything done based on lies. I would much rather give you the truth be it uncomfortable. With what's happened to me, I've always said it doesn't matter how uncomfortable it is, if it's the truth I can deal with it. I can get through it. It's ok. I've had to deal with a lot of lies and a lot of covering up in my day. And you can't make an informed decision based on a lie. So it may be difficult to talk about. I might cry but we'll go there. It's OK we'll go there.

Participants had familiarity with and access to mental health services in their communities, if they experienced out of the ordinary distress from the interview. At the conclusion of the interview no participants showed evidence of extraordinary distress.

Final Coding After all transcription was complete, I compiled an initial codebook organized by participant number with all codes designated during transcription included. The definitions provided by participants in the debriefing process were listed as the definitions in the initial codebook, except

where a participant did not provide a definition. I then generated the theme's definition. On the initial codebook I imposed an external organization based on theory about illness progression. Presentation of the interview data follows Veena Das' theorization of the illness narrative as a plot of land. Life emerges and then dies back into the soil just as pain has an origin point and a place of healing. Water, wind, and sunlight nourish growth just as pain impacts all components of a person's life socially, psychologically, and culturally. Das, 2015 writes, "Narratives of illness did not have a teleological orientation—perhaps demonstrating that it is life that weaves stories that are themselves points at which a person may rest or move on (p56)."

Three parts (pain, suffering, and surviving) comprise the final codebook. These parts correspond with the substantive chapters in this dissertation. Within each part, I compile the codes from the individual interviews in an Excel spreadsheet and heed the thematic organization of the interview guide for unifying codes. I also adopt the definitions participants gave and note which interviews exemplify each code in order to provide congruence between data collected and the results of analysis. The codebook determines the organization of each substantive chapter in the dissertation. I tell all of the diverse stories without privileging those stories that most aligned with my expected results. This at times reads as redundant since diverse participants relate similar experiences. I also do like Sanderson et al., 2012 did in work with Indigenous elders on diabetes. Sanderson et al., 2012 writes, "The stories are provided with minimal editing to allow the word choices, relationships and thoughts of the elder to emerge." With diverse voices telling unedited stories together, I reveal a meta-story about chronic pain and colonization from embodied people with inherited wounds embedded in colonialism's continued history and living at society's margins.

2.2.3 Quantitative Component: Survey

I collected a paper and pencil survey from 40 participants, including all but one interview respondent, to test the following hypotheses:

Hypothesis 2a: Participants with lower grief, lower trauma, and lower violence will have a lower pain score on the McGill Pain Questionnaire.

Hypothesis 3a: Participants who engage in both biomedical and tradi-

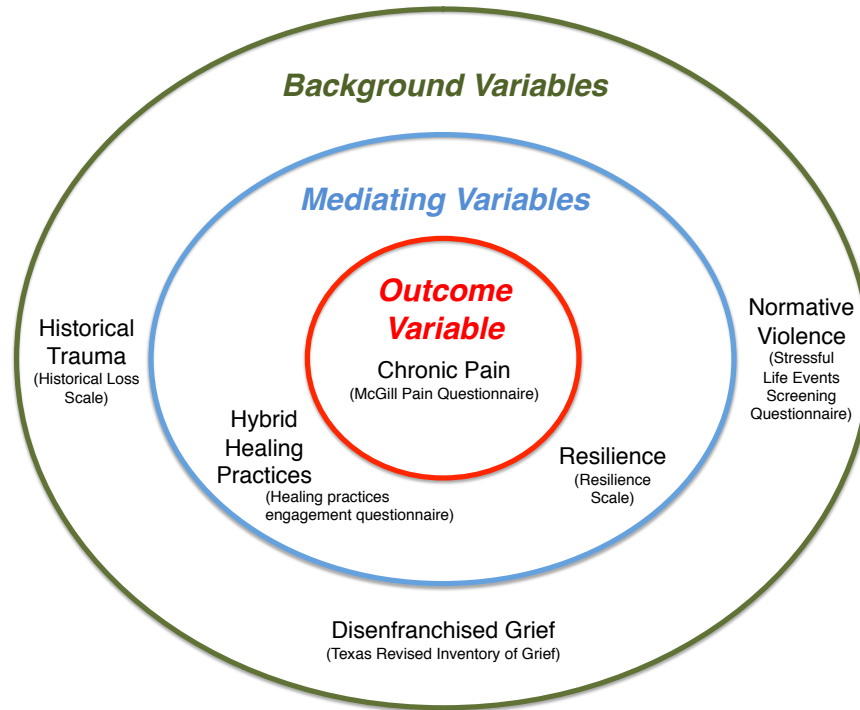
tional healing practices will have a lower pain score and report better coping than those who engage in either biomedical or traditional practices alone.

The questionnaire took between thirty minutes and an hour to complete. In an embedded mixed methods model, the survey supports the themes from qualitative data analysis, triangulating the phenomenon under study—the experience of chronic pain, causal narratives of chronic pain, and healing modalities. Figure 2.2 provides the proposed conceptual model on which I built the questionnaire and base my statistical analyses.

Background variables for chronic pain that I measure are historical trauma, disenfranchised grief, and normative violence. The Historical Loss Scale (Whitbeck et al., 2004), Texas Revised Inventory of Grief (Faschingbauer, 1981), and Stressful Life Events Screening Questionnaire (Goodman et al., 1998) measure historical trauma, disenfranchised grief, and normative violence, respectively. Whitbeck et al., 2004 created the Historical Loss Scale from focus group interviews with elders of Northern Plains tribes in order to measure perception of historical trauma. The scale measures frequency of thoughts about cultural loss. The scale demonstrates internal reliability with a Cronbach's alpha of 0.92. The Texas Revised Inventory of Grief is a well-worn measure of present feelings, past behaviors, and disbelief regarding grief, focusing in particular on normal versus pathological responses to grief. I have manipulated the questionnaire to reflect a broad range of grief and not just grief from loss of a person. The inventory consistently has Cronbach's alpha over 0.8. The Stressful Life Events Screening Questionnaire provides participants with space to elaborate on many forms of abuse and traumatization—physical, psychological, and social. The questionnaire demonstrated test-retest reliability (median kappa=0.73) and convergent validity (median kappa=0.64).

Mediating variables for chronic pain are hybrid healing practices and resilience. Resilience Scale (Wagnild & Young, 1987) describes quality of life in old age and thus documents resilience. Most of the scale concerns individual resilience. I added a question about community-level resilience. The Resilience Scale has internal reliability with a range of Cronbach's alpha from 0.72 to 0.94. Participants also responded about use of 13 biomedical and traditional healing practices, including frequency of use.

Figure 2.2: Conceptual Model for Quantitative Component



Chronic pain itself is the outcome variable. The McGill pain questionnaire (Melzack, 1975) measures chronic pain, especially pain severity, pain characteristics, pain location, and modifying factors for pain. Demographic questions at the beginning of the survey include: years of residence off-reservation, months with chronic pain, prescription medications for chronic pain, last annual wellness exam from a primary care provider, current medical complaints and diagnoses, gender, age, years of education, occupation, self-rated health, number of persons with whom they live, and primary caretaker at home (if any). See Appendix B for the survey. See Appendix D for the variables in the quantitative data analysis as well as their transformations.

Descriptive Statistics All statistical analysis occurred with SPSS. I found range, mean, and standard deviation for the demographics variables. Table 2.1 provides the descriptive characteristics of the sample. Age ranged from 25 to 78 and nearly all participants had lived off reservation their entire lives. A few participants lived on reservations in early childhood only. Par-

ticipants lived in rural communities, small towns, mid-size cities, large cities, and very large urban areas with a good distribution across all these types of communities. They lived with between 0 and 7 other people with most participants living alone or with 1 or 2 other people. The majority of participants were women and 38% described themselves as multiracial (usually American Indian and white). Years of education completed ranged from 9 to 21. Therefore participants completed, on average, an associates degree. Average self-rated health was mid-range on a 1 to 7 Likert scale—not very healthy or very unhealthy. Three quarters of participants had received a diagnosis for their chronic pain from a healthcare provider, had annual wellness checks, and took some kind of analgesic medication as needed for pain. Participants had dealt with chronic pain for 16 years on average with range 1 to 58 years.

Profiles of Pain, Suffering/Trauma, and Care Strategies I generated descriptive profiles of participant’s pain, stressful life events, grief, historical trauma, resilience, and treatment practices. The pain profile comes from variables in the McGill Pain Questionnaire. This includes the words participants used to describe their pain, factors that alleviate or worsen the pain, present intensity and maximum intensity of pain, and location of pain. The trauma profile comes from variables in the Stressful Life Events Questionnaire, the Texas Revised Inventory of Grief, and Historical Loss Scale. This includes various types of stressful life events, total stressful life events, present feelings about grief, present behaviors for grief, emotional reaction to grief, pain from grief, continued grieving, and all the ways that historical loss is assessed. The treatment profile comes from variables in the treatment survey and the Resilience Scale.

I created dummy variables for high pain, high number of years with pain, poor health, high historical trauma, still grieving, high pain from grief, high number of treatment practices, and high stressful life events. The exact transformation of these variables is detailed in Appendix D. I then assessed relationships between the items in the profile with my main outcome variables of interest being self-rated health, worst overall pain, and present pain intensity. To assess these relationships I did Chi-square analyses and Pearson’s two-tailed correlations depending on whether the variable was categorical or continuous.

Relationships between Profiles Given the hypotheses, I asked the following questions of the data: Are less violent and traumatic events in life associated with lower pain maximum intensity, and fewer pain sites as well as a more limited description of pain? Is less historical trauma associated with lower pain maximum intensity, and fewer pain sites as well as a more limited description of pain? Is less grief associated with lower pain maximum intensity, and fewer pain sites as well as a more limited description of pain? To assess these questions, I performed correlation analyses and noted the correlations of significance when presenting the data. In order to determine how pain, trauma, resilience, and treatment all fit together, I performed OLS regressions and binary logistic regressions with present pain intensity and worst pain intensity as the dependent variables. The regression analyses failed to yield significant results. In addition the regression analyses also had a lot of collinearity issues, especially between the individual difference variables, and the pain variables.

2.3 Methodological Concerns

2.3.1 Community Relationship Building

In order to foster my relationship with the American Indian communities around Illinois and Indiana, I attended powwows (IU-Bloomington American Indian Wellness Fair, Lebanon Powwow, Shakamak Powwow, Vigo County Powwow, and Bloomington Powwow). At the powwows, I volunteered for AICI, discussing services the center offers as well as providing health screenings such as blood pressure and blood glucose checks. After just two powwows, I came to recognize many members of the American Indian community in Indiana. In turn, they recognized me as knowledgeable about health and dedicated in volunteering. I quickly learned how to set up and take down AICI's booth by myself. In Chicago, I accessed the community through two key informants, the director of AIAI and the director of Trickster Gallery. Both allowed me to recruit through their connections and use their respective spaces for long days of interviewing. I attended the Trickster Gallery Holiday Appreciation Party to recruit as well. Finally in Tulsa, I connected through a key informant and her sister. The key informant is a shaman in the

community, and her sister dedicates herself to the church where I interviewed many participants.

I felt immense privilege to witness to participant's stories of chronic pain. Many participants talked of how they told me so much more about their pain than they had ever shared even with their closest loved ones. Philip went deep into his pain, when he was usually quiet with others. He said, "Some pain is expressed to my friends and family. But it isn't over the top. I've probably told you quite a bit more than I've told them. But it's just a. It's tough for people to handle. I mean they don't want to talk to someone or love someone that's going to die tomorrow." Other participants remarked on the newness of the experience. They had never been a part of research before. They had not answered questions like in the survey. They were not sure what to expect but ended up enjoying the process like Rikki, who related, "I've been curious about this. It's always interesting to learn new things and try something different. You never know what you're going to learn about something. Cause you can be talking about something and then you solve your problem." Still other participants consented to the study, because they saw the need in the wider community for someone to do something about chronic pain. Verbena described, "I'm pretty open just because I feel like so many people out there deal with this. And for a long time it was like it was a secret or mistake or whatever. And theres a lot of anger that goes with that. And if more people would understand it, then maybe some of that might go away. In honor of their stories, I hope that those who read this dissertation do go away with a bit more understanding.

2.3.2 Researcher Positionality

The process depicted above proceeds with the undercurrent that Million, 2013 describes, "The pain of the individuals affected had been shared face to face with her and joined with her own reaction to her own pain in turn. This has been and can be the effective transfer point between the witness, the telling, and the research instrument, the telling for social change (p96)." The last day of data collection, I heard seven stories of chronic pain. The stories resonated with stories I had heard from previous participants so I managed their intensity by categorizing. Nevertheless fatigue welled up from

my gut to my head. By the end of the day, I could barely see clearly because of a headache. I knew, with much gratitude, that I had enough stories, that I had reached my threshold for holding onto and processing suffering. Many participants cried during the interviews—tears of remembering and tears of release. We would pause, and let the tears soak the difficult story, softening the story to emerge less painfully.

A. Smith, 2014 writes, “Western writers are granted rhetorical agency, analysis and theory—the ability to tell truths that are not contained in their bodies (p210).” I do not have chronic pain. For one summer as a teenager, I woke up with knees so stiff and painful that I would collapse getting out of bed. A few blood tests and some investigation by my physician father and nurse mother revealed that I had acquired a lupus-type reaction to a long-term medication for acne. Nevertheless I can never have the embodied understanding of Indigenous persons with chronic pain.

I grew up atop a drumlin in the glaciated prairie land of Wisconsin. Five miles from my house, the mounds of the Aztalan settlement rise up from the earth. I played as a child in a circular virgin prairie, imagining American Indian women in buckskins and moccasins dancing with me. I am white, German, Swiss, English, and Dutch. Through my paternal grandmother, I have relatives who were settlers before the American Revolution. The spirits that dance with me, though, understand so much more than the white privilege in which I was brought up. They try to teach me in the frogsong and windvoice. As Lorine Niedecker, who grew up in the same place as I did, writes:

I grew in green
slide and slant
of shore and shade
Child-time—wade
thru weeds

The seventy acres of pond, marsh, prairie, woods, orchard, and mowed lawn on which I grew up gives me life and gives me death. It gives me air, and it gives me muddy wellies.

Given the nature of my academic training in medicine, sociology, and American Indian studies and my position as an ally, I can not only bridge dichotomies that contribute to health inequities persistence, but also build

mutually beneficial relationships. I have immense privilege and inherent expertise in pursuing two prestigious degrees—that of a medical doctor and a PhD. Both my parents have advanced degrees in medicine. My father’s parents attended four-year colleges. My husband and brother are pursuing their PhDs. I have not met with adversity in pursuing my educational dreams. From this place of privilege, I strive with the disparate degrees in medicine and sociology to cross boundaries in order to provide some benefit. Joy Harjo once told me, “People who cross boundaries become dangerous, because they exist in the dangerous in-between spaces.” Being dangerous means one has been wounded and is capable of wounding. In another wrinkle of the rug, something wounded my soul. I wander into interstices, trying to heal.

Pain: Bone Deep Fried Nerves

The Chronic Pain Itself

“But in order to make you understand, to tell you my life, I must tell you a story.”

– Virginia Woolf, *The Waves*

Abstract

From the interviews arose a number of dichotomies: good and bad days with pain, things that help pain and things that make pain worse, and pain with a physical etiology and with an emotional etiology. This fragmented conceptualization of pain provides pain sufferers with sought-after legitimacy. It also demonstrates how vast pain is. I first present how my American Indian respondents define physical, emotional, and spiritual pains. The chapter will also explore how they describe their pain, understand the origin of their pain, and make meaning from the difficult experience of being in pain every day. In this chapter I will introduce the participants, focusing in particular on their ways of describing pain and creating embodied knowledge. I will also begin to identify connections between chronic pain and colonization at the level of abuse, poverty, and sorrow—tensions that I will explore in the context of identity and culture in Chapter Four and in the context of surviving in Chapter Five.

3.1 Pain Profile

Using the results from the McGill Pain Questionnaire I developed a pain profile for my participants. Table 3.1 shows the descriptive statistics specific to the chronic pain itself. Participants were 70% female with an average age of 54. They are educated to the Associates degree level on average. Seventy percent have received a diagnosis for their pain while 45% have some pain that has not been diagnosed. Their pain occurs in an average of four places on

Table 3.1: Pain Profile Descriptive Statistics

	N	Mean	Std. Deviation
age	40	54.03	13.174
female	40	0.7	0.464
education_yrs	39	14.79	2.949
pain_dx	40	0.7	0.464
pain_yrs	39	16.2	13.281
pain_nodx	38	0.45	0.504
analgesic	35	0.71	0.458
pain_#sites	31	4.35	3.886
PRI_sensory	40	19.37	9.377
PRI_affective	40	4.33	4.028
PRI_evaluative	40	2.15	1.626
PRI_miscellaneous	40	6.53	4.326
NWC_#wordschosen	40	15.02	10.501
PPI_presentpainintensity	40	1.75	0.84
pain_worst	40	3.97	1.187
pain_least	40	1.68	0.797
pain_joints	40	4.25	1.104
pain_head	40	3.88	1.181
pain_stomach	39	3.54	1.253

their bodies. From the McGill Pain Questionnaire, 45% of participants had pain that was not diagnosed and 71% used some kind of analgesic medication, usually on the absolutely worst days with pain. At the time of completing the questionnaire, most participants had mild to discomforting pain—almost the level of the least amount of pain they could have. Their worst pain was

horrible. The worst pain they feel is in their joints, then head, then stomach. They needed 15 words on average from the McGill Pain Questionnaire to describe their pain. In all categories of the McGill Pain Questionnaire (sensory, affective, evaluative, and miscellaneous), they selected words that were mid-range on intensity—not the most severe words or the least distressing words. Participants also selected activities, events, and items that increased or decreased their pain. Note that if the item did not either increase or decrease their pain, they left the response blank (Table 3.2). The activities, events, and items that decreased participants pain the most were: alcohol, coffee, heat, massage, and distraction. The activities, events, and items that increased participants pain the most were: cold, damp, weather, pressure, tension, and work. For a huge majority of participants the weather and being fatigued increased their pain, while massage decreased their pain. There is judgment about how good a particular coping mechanism is, although in the qualitative data one can appreciate beneficial versus deleterious self-care.

I performed correlation analyses in order to demonstrate associations between demographics and chronic pain as portrayed with the McGill Pain Questionnaire (Appendix E). Those who were younger had the most intense pain at the present moment and the worst pain overall. I think this is likely due to less developed coping among those who are younger. Also with increasing age, participants accepted increasing pain as a natural part of life. Women had had pain for more years. Those who have received a pain diagnosis are more likely to take an analgesic and have more pain in all accounts. It follows then that those who take an analgesic also have more pain in all accounts. The components of the McGill Pain Questionnaire correlate as expected with a higher number of words chosen associated with more intense words chosen on each subset of the questionnaire, and selecting more intense words on one subset of the questionnaire associated with selecting more intense words on each subset of the questionnaire (sensory, affective, evaluative, and miscellaneous).

Table 3.2: What Increases or Decreases Participants' Pain

	N	Mean	Std. Deviation	Percent
liquor	15	0.2	0.414	80% decrease
eating	10	0.5	0.527	50% increase
cold	30	0.83	0.379	83% increase
weather	36	0.97	0.167	97% increase
pressure	26	0.85	0.368	85% increase
moving	32	0.69	0.471	69% increase
lying_down	26	0.42	0.504	58% decrease
urin_defec	11	0.18	0.405	82% decrease
bright_lights	13	0.62	0.506	62% increase
work	17	0.82	0.393	82% increase
mild_exerc	28	0.57	0.504	57% increase
coffee	10	0.2	0.422	80% decrease
heat	25	0.12	0.332	88% decrease
damp	27	0.85	0.362	85% increase
massage	33	0.12	0.331	88% decrease
stillness	26	0.38	0.496	62% decrease
sleep	25	0.4	0.5	60% decrease
distraction	15	0.2	0.414	80% decrease
tension	27	1	0	100% increase
loud_noises	15	0.6	0.507	60% increase
sex	13	0.31	0.48	69% decrease
fatigue	27	0.89	0.32	89% increase

3.2 Types of Pain

In this section I present how participants classify their pain in their own words, how they react to a diagnosis, and how poorly others understand their pain. Participants divide their pain into physical, emotional, and spiritual. These classifications assist with coping; the physical coping strategy works best for the physical pain and likewise with emotional and spiritual pain and coping. Ultimately, in the body of the one afflicted, all types of pain intertwine like pea, bean, and hop vines climbing a fence.

Pain Is Misunderstood Though we currently live in the age of the chronic intractable pain epidemic in which we divide acute pain from chronic pain, pain was once seen as a natural struggle, a mark of the human condition, and a “normal companion to illness and aging (Baszanger, 1998 p2).” In

part because society no longer sees chronic pain as normal or natural, all participants worked to portray themselves as legitimate to me in the interviews and to the larger community through their pain behaviors. Throughout this research I mark various points where participants battle for legitimacy as an American Indian person with chronic pain.

Cassia, Keira, and Fern spun legitimacy in their own ways. For Cassia, my oldest participant who grew up on a reservation in South Dakota, to know pain is to experience pain. “Nobody understands pain I don’t think until they go through it. And like if you’re trying to explain it. It’s up to that person to try. But if they’re not really into it or serious. Then they won’t understand.” Therefore without experiential knowledge, Cassia believed others could not and would not understand her pain. Likewise for Fern, a woman with restless leg syndrome, if others do not experience pain that occurs everyday without fail, then they will not understand her chronic pain: “But it’s every day. There’s not a day that goes by that I’m not affected by it. Most people don’t understand it if they don’t experience it.” Fern also told about her reduction in legitimacy from a healthcare provider’s perspective, because her pain was due to a contested illness.

A lot of doctors don’t consider it a real deal. They think it’s all in your head. I’ve heard a lot of people say that. It ain’t in my head. It’s in my legs. You can’t tell me it’s not hurting. And it doesn’t matter what kind of shoes I wear....It’s not caused by anything outside like what I do....I can do things or not do it. It doesn’t make any difference. It’s still there.

Finally, many do not understand the pain that participants endure, because they do not perceive pain as multifactorial like my participants did. Keira, a storyteller with scleroderma, asked for clarification: “When you speak of pain, do you speak of physical pain or all pain in general? Physical, emotional, spiritual?” Because my participants speak of all pain in general, this research speaks of all pain in general but that often feels like the minority perspective that calls into question pain’s legitimacy.

Pain Has Many Identities and Wide Spreading Effects Society delegitimizes pain, in particular, when the pain originates in someone’s mind and not their bodies. “Physical and psychic pain,” C. J. Throop, 2010 asserts, can be seen “as poles along a continuum of possibilities, both personally

and culturally influenced (p7).” Psychogenic pain makes treatment difficult and causes pain sufferers to question the legitimacy of what they feel and the sanity of their mind (Dworkin, 1994). “The more difficult the pain problem to be treated and the more it escapes any identifiable organic origin,” notes Baszanger, 1998, “the more likely it is that individuals who suffer the most are called in a variety of ways to account as persons and their pain is re-framed as either psychiatric pathology or as inadequate adaptation (p302).” The emotional and spiritual pains that the participants talk about in the following paragraphs are all psychological, psychic, or psychogenic pains like the literature above mentions.

What the existing literature fails to address is how types of pain interact. Every participant identified ways that their chronic physical pain lead to or resulted from other types of pain. I define below the three most common types of pains participants mentioned: physical, emotional, and spiritual. Abby, a pastor with rheumatoid arthritis, conceptualizes how these three types of pain intertwine:

To me they follow each other. Like if I’m stressed, I’m more than likely to have the inflammation kick in. It will kick in the disease process I guess. So I try to watch ways to try to manage my stress. But I think one of the dangers of that is that you try to ignore it and act like it’s not really there....To me if the stress, whether it’s spiritual distress or your life is kind of out of balance, you have to do something to get that. I always want to talk in energy, to get that energy out of you that’s causing that feeling or that emotion...And then to get good rest, you know enough sleep. So I think when I don’t take care of my physical body, emotionally I’m kind of weakened. I can’t handle situations as well. At the same time emotionally I’ve got to be able to take time for myself to keep my physical body up.

Numerous triggers, participants related, either in the present moment or from the past, can shift one type of pain to another. Keira discussed how her pains from abuse and sadness became physical symptoms: “But these guys are talking to me about how my physical symptoms could be emotional too. With all the lumps in my throat, no wonder I can’t swallow.” For Cassia the moments of most extreme pain radiate into other parts of her being so that she doesn’t just hurt physically: “When the pain comes bad is when it starts affecting all your flesh, like you said your spiritual, your emotional, that’s

when it's bad." Alma, a chef with rheumatoid arthritis, over the years, has become very perceptive of her triggers for both physical and emotional pain.

I notice that if I'm emotionally upset, the physical pain emanates...like I'll start having spasms in my back or my joints will start hurting. Like the more emotionally worked up I get, the more physical pain I feel. So it's almost like one triggers the other. But then like the physical pain will trigger the emotional pain, because I'll like cry and oh my God I want my mommy.

For Keira, Cassia, and Alma physical and emotional pains beget one another reciprocally.

In a similar way, Azure defined physical pain as a manifestation of spiritual hurt and noted that society refuses to legitimize this manifestation because existing technology will not show the pain. "My shoulder hurts. Not my shoulder hurts, but my spirit hurts and maybe it's just manifesting in my shoulder. There's a line that I don't think we have the technology to perceive that yet." On the other hand, at least a few participants rejected the enmeshment of physical, emotional, and spiritual pains. Dorothy, who believes in the interactions of the spirit world and the physical world, argued against interactions between different kinds of pains. "No it doesn't manifest into from what I felt doesn't manifest into anything like that. If it doesn't manifest like now if I cry, might get a headache, because of my sinuses. That's the only thing." Abby, Cassia, Alma, Keira, Azure, and Dorothy all demonstrated how pain has many identities and wide spreading effects.

Reactions to Diagnosis By diagnosis I refer to that precipitous moment when participants realize that their pain is now chronic and no longer acute. I do not necessarily mean the point of receiving a diagnosis from a healthcare provider as this occurred for few participants. All participants experienced a transition in conceiving of their pain as chronic versus acute. I asked about this transition specifically in the interviews. Das, 2015 theorizes the moment of diagnosis as a translation from symptoms to disease process: "The making of medical knowledge cannot be isolated. It is true that once a diagnosis is put on the symptoms after the act of translation from discomfort to symptom and therapy have been accomplished, new ways of understanding the disease will be generated (p220-1)." For the participants this new

way of understanding involved recognizing oneself as person with pain that lasts and therefore requires daily attention.

Participants who received a diagnosis from a healthcare provider approached the diagnosis itself with skepticism. Cheryl, an engineer with deep cultural beliefs and a lot of distrust, explained the lengthy process healthcare providers followed before diagnosing her pain:

Well they did some x-rays and found out that I have severely degenerative arthritis in my neck. And I do have herniated discs. And he was pretty surprised to find that out. So well I guess I did do ok. Then he sent me for an MRI and diagnosed me at that point and that's only been about two years ago. But I've been dealing with it since when my kids were little...at least ten years.

Cora cannot determine the reason for her chronic pain. That reason must come from a physician, and since she has never seen a physician, she does not know the reason. "I've never gone to the doctor to see where it stems from, because I always just figured it's because I'm tall."

Sometimes the clinical work-up for pain causation and diagnosis failed the participants. Gus, a painter with post-herpetic neuralgia, related, "I got myself examined, an x-ray. That's when they found out that there's nothing really wrong with me." Gus does, however, have another diagnosis that might explain his chronic pain. "But those shingles are what's really making me, what's hurting me every day. And it's no fun." For Morgan, a diagnosis of scoliosis meant surgery, which should have been a cure. Since it wasn't, she has to seek out other explanations for her pain.

Oh you have scoliosis. Yeah you told me that last year. I played a lot of sports in high school. I played basketball and softball....So now you know when you have back surgery and you have back problems your back is never going to be what it was. A lot of people don't understand that. It's never going to be 100%....The doctor told me it was playing too many sports in high school and that wasn't a good excuse for me. I mean it just wasn't. But at that point I wasn't worried about the excuse, I was worried about the cure. I was just ready to feel better....I think it's hereditary. I really do.

Having a label for the pain provides some legitimacy, despite the intensive diagnostic work-up, but so often the label fails to align with easy treatment solutions. Therefore post-diagnosis, participants still wonder now what?

Azure, a young woman first diagnosed with fibromyalgia and then later with systemic erythematous lupus, related, “Everything just hurt and was stiff, and I’m going something’s wrong. And I remember not having any health insurance and kind of going in and refuting the diagnosis of fibromyalgia. I kind of go to a low income clinic. Oh you have fibromyalgia. Ok that’s nice, now what?” Azure perceived fibromyalgia as a cop-out diagnosis and therefore continued to pursue an explanation for her chronic pain. For Fern, in contrast, the diagnosis of RLS allowed her to cope, because she knows the condition will continue to worsen. “RLS it is progressive. It is not something that gets to a certain point and that’s as bad as it’s going to get. It’s something you’re going to deal with your whole life. I mean there’s no getting away from it, even with the medicine.” Cheryl acknowledged the diagnostic label as purely a label, essentially worthless in encouraging successful treatment. “Ok now I’ve got the diagnosis, but I’m not really going to get any help anyway. At least I have that [the diagnosis].” A diagnosis provides a definitive line item on a patient’s problem list that allows healthcare providers to bill. A diagnosis is not necessarily the truth of what is going on. Keira assumed that her healthcare providers would question further why she has chronic pain; “But again no one ever asked why.” Throughout this chapter I seek to uncover the what and why of chronic pain.

3.2.1 Physical, Emotional, and Spiritual Pains

When I asked participants to tell me the story of their pain in the interview, all participants initially discussed physical pain. They identified a body part or parts that felt pain. They talked about the feeling of the pain in their body. When asked to think about other ways that pain enters their life, then participants intentionally spoke about ways pains connect together. Therefore minimal data defines physical pains alone without making a comparison to the less well understood and less legitimated emotional and spiritual pains. Andrew depicted physical pain as the easiest for his mind to overcome.

With physical pain, I put it to the back of my mind. When I’m in pain, it’s just like, I know I’m in pain, but I throw it to the back of my mind, and I leave it there until I forget about it. Then next thing you know, I don’t feel no more pain. Because out of sight, out of mind, type of thing, mentality that I have for that

sort of.

Even in these examples physical pain requires the mind in some sense.

Physical pain is tangible with a clear causation, while emotional pain is often not explainable. Jason, considered a traditional healer in his community, conceptualized his physical pain as separate from his emotional pain. His physical pain comes from injury. His emotional pain comes from the following: “I have an emotional pain of my grandchildren not following the traditions so much sometimes.” Bailey, who has intermittent muscular pain, reminds that emotional and physical pains connect. “The massage therapy. That guy was great. He explained how emotional and mental stress, what it does to muscles. How muscles react in the body. So and then umm. But he was really good at the whole concept mind-body-soul, how it may show up here and it’s going to start affecting this and this and this physically.” In the story of her initial years with pain, Cheryl connected emotional and physical pains, noting how the emotional pains masked the physical pains, making it difficult for her to determine her pain’s origin, triggers, and thus care practices.

I mean I was pregnant in the Marine Corps and was on leave with him and my ex-husband went bipolar on me cause there was a big change in his life, and he had been previously diagnosed. So I’m stuck with being on leave, dealing with this, gotta newborn and two little ones. So it was a crazy time. And I can remember being in pain, but I think it was more emotional stuff going on there that kind of masked you know the physical pain....it was hard for me to decide if the pinching was causing all the back problems was that from all the emotional crap or was that really a physical problem you know.

To establish a definition for one category of pain, participants, like Cheryl, frequently referred to another type of pain for comparison.

Andrew, for example, defined emotional pain through how he, a young mover and painter with pain in his muscles, dealt with emotional pain. “For emotional pain, over time it tends to just. It doesn’t always linger, when you go and you learn to let somebody pass in that sort of aspect. You let somebody. You let it go. You learn that somebody is in a better place now. That’s how I deal with that.” Unlike the emotional pain that Andrew defines, where time and intentionally letting it go reduced the pain, the pains Keira

and Barrett have are embedded deep in their childhood. They have struggled with and through emotional pains since a very young age. Keira related all of her pain to secrecy, which then led to grief and cultural disconnection. Therefore her emotional pain arose, in part, because her family buried other pains.

Well my pain started as a child. I was a sickly child. I always had leg pains really bad. I would cry a lot and mummy would rub my legs down to try to alleviate the pain. Most of the time she only used warm water. And then other pains...emotional, mental pains came with that, because I was raised not on the rez and so we dealt with a lot of issue in our family of secrecy. Ok, which brings a lot of grief. A lot of secrecy. So I deal with personally a lot of emotional pain, a lot of even spiritual pain because we were kept from the traditional ways. So a lot of things were hidden. So I dealt with pain from a very early age. Physical and mental. Emotional and spiritual.

Secrecy intensified and compounded Keira's pain.

When he tried to find a time that he did not have pain, Barrett, a black American Indian with back and hip pain, recalled his childhood pain. Like Keira, his emotional pains occurred because of loss at an early age.

If there's a time that I didn't have any pain, maybe when I was a small child, but then I had psychological pain so when you talk about pain, then you start getting into the psychological pains. I had to deal with that from say as a small child to an adult, I had to deal with the psychological pains of not having family, being at Boys Town Nebraska for four years, being in a Children's Home six and a half years. So. So. There's really it's those times when it's not really pain of some sort, whether it's psychological or physical. So you, how do you separate those 'cause you were there?

Alma asserted that her childhood challenges now program her to respond in emotional ways. Any new trigger may cause her accumulated emotional burden to erupt. "I've dealt with a lot in the last 6 years. Like I had a really rough life growing up. The things I've experienced. So like the simplest of things pretty much torture my head. I can be the biggest cry baby ever, because I just get too emotionally overwhelmed by everything."

Like Keira, Barrett, Alma, and Jason, Cora correlated struggles and stresses in her daily life with the continued presence of emotional pains. "My emo-

tional pain, I don't think that will ever go away, because that's just something that's there. And my brain just can't block it out, even how much I try to do it. But it's still. And you know, as long as you keep struggling, it's still going to be there." Like Cora suggested, Dorothy tried to block out her emotional pains from her divorce and loss of her mother and was also unsuccessful. "But to help with the pain of emotional. Not dwelling or thinking about it a lot. It does come up. Like now. I talk about it. Or having time to go past that pain like when it's really fresh. Just time would take care of a lot of that." Participants learned to recognize the many situations that triggered the reemergence of emotional pain.

Emotional pain was not unified in its presentation for participants. For Shanta, who is pursuing higher education, her emotional pain welled up from inside her in the form of doubt.

I wasn't sure, because I had a doubt. That was the worst thing, is the doubt. It's like being in the dark and not knowing where you are. You can't feel your way, because you don't know what you're gonna touch. You don't know where the wood stove is. You don't know where the steps are. You don't know if you're gonna slam into a stepladder or somebody's bed. It's horrible. Scary feeling, that doubt. Then something happens, and the doubt goes away, and then it's all better. It gives you something to go on. It took a long time though. I said, 'How you been?' I remember saying that too. I'm like, 'How have you been?'

Likewise for Cassia, the emotional pain compounded with the physical pain led her to prefer death to continued living. "Yeah if I didn't believe in the Creator, the Father, I think I would have. I think I would probably think 'oh death would be better'....Cause I believe maybe there's an afterlife after this one. And emotional I get depressed like because I can't do what I think I could have been doing like going out to outings and mingling with, socializing." Cassia is not alone in responding to emotional pain with suicidal thoughts. Azure, Kelly, and Verbena also considered and/or attempted suicide many years before I interviewed them. They found ways to heal, some of which I describe in Chapter 5. The consensus among participants is that emotional pain is much worse than physical pain and much more difficult to remedy. Bailey made the connection between her physical pain lingering and the added stress of her daughter struggling in life. "Just well when you're a parent and you have kids and they are screwing up, that's

always painful....So you've got to be strong for that. It takes it's toll a lot. So anyhow so trying to be rational and not trying to be judgmental is extremely hard to do and that sits somewhere in your body so you know that's probably why....That's probably why it's taken a lot longer to heal, because you're compressing something." A key component of emotional pain therefore is the resistance of emotional pain to timely healing, which in turn causes physical pain to linger. Rosaline talked about her success dealing with the much worse emotional pain. For example, she would kick hay bails in the barn.

Oh the emotional pain can be ten times worse than any of the other. Because the other you can get up and move and maybe stop it or with the appendix, they remove it. When it's emotional, they can't cut it out. They can't. You just have to learn to deal with it. And the only way you learn to deal with it is by time. And like I said it doesn't make it less. You just learn to deal with it in a different manner.

Dealing with the emotional pain, then, for Rosaline, requires an entirely different wisdom than figuring out how to live with the physical pain.

Unlike emotional pain, which participants root in their brain, that intensifies physical pain, which participants ground in their bodies, and makes it harder to feel better, spiritual pain does not exist in mind or body. Many participants described themselves as spiritually connected and loved, but their physical and emotional pain was separate from any spiritual pain. For example, Rosaline asserted, "But I've never actually equated pain with my spirituality, because it's just a physical thing it's not a spiritual thing." Fauna, though she has emotional and physical pains, has never experienced spiritual pains. She provided an explanation: "Not spiritual. I don't think I've ever had, because I've always had this close rapport with God, like we call him, the Creator. Maybe I was a rebel in some ways, cuz I never felt you needed to go through a second party to talk to God." Jason's spiritual balance not only enables him to cope better with his physical pains but also reduces his emotional pains.

But I do follow that way very religiously. And so I can honestly say spiritually I'm in tune. I'm not saying that everything's perfect every day. I mean things happen. But because of my spiritual balance, my Creator helps me understand or have the patience of

understanding of certain things and acceptance of certain things. So there I mean as far as spiritually and emotional I think I'm pretty good there.

Dorothy depicts two types of spiritual pains—light and dark. Light spiritual pains rarely occur unless one becomes disconnected from the light and love of a God and/or Creator. Dark spiritual pains manifest when evil from the spiritual world enters one's body. Just before she trips and falls in a dark office at night after everyone has left, Dorothy sees the image of a woman. Dorothy believes this woman made her fall—a manifestation of evil. Despite that encounter with evil, Dorothy related that she has few spiritual pains. “But emotionally, spiritually, that's only the darker side I have seen [the lady who made her fall]. But spiritually, no I don't have that. It's around. I know it's around, but I protect it. I have a lot of things that come. I've seen a lot of things, but I know I'm protected.”

The most common spiritual pain that participants mention is grief. Grief manifests as physical and emotional pains as well. Many participants conceptualize grief as the cause of all their pains: physical, emotional, and spiritual, which I describe later. Dorothy told about her spiritual pain from her mother passing, despite her mother's continued presence.

My mom. She passed away in October. It was hard but then it wasn't. Because I knew where my mom was. I miss my mom. I told the preacher. I'm selfish. I want my mom here. But I miss her. I'm sorry. And I want my mom here, but I knew where she was and she's not in pain anymore. But that kind of emotional pain I do have. And it also manifests it in a spiritual pain. Because I told someone I can't feel my mom.

From the ways that participants parse their pain into physical, emotional, and spiritual, it becomes clear that defining pain requires tracking pain's origin. I discuss the origins of pain later in this chapter.

3.3 Pain Descriptors and Knowledge

In this section, I present both the visual depictions of pain and the words used to describe those depictions. I gathered images of pain as part of the interview in order to better conceptualize the components of pain that are difficult to

convey with words. I begin with participants' resolute dislike of pain and end with participants' realization that pain can take pain away. In between I illustrate ways of describing pain. The images of pain that participants drew fall into three categories: their own face in agony, an external assault by a tool or animal on their body, and a sharp object like a lightning bolt. The verbal images of pain uncovered in the interviews also span these three categories.

Dislike of Pain Though, as conveyed in Chapter Four, pain becomes a critical part of participants' identities and every aspect of their lives, participants dislike their pain. Their pain limits them. Their pain moves them to desperation. Even if they believe that their pain has made them a better person—the person they needed to be—they will not wish pain on another person just so that other person could also become a better person. For Dorothy, a Navajo woman, her chronic pain diagnosis meant she had to give up running. Her mother ran. Her father ran. Her brother ran. All of her ancestors ran. Running is a cultural practice in her family and, according to her, for the Navajo. Dorothy depicted her sorrow at losing running because of pain. “He [a doctor] said your running is like alcohol to an alcoholic. And you need to quit or you’re going to make it worse. So I said I hear you. So I had just bought brand new running shoes and I had to just put them aside. It was like I was in mourning.” Similarly Barrett also gave up a lot of his exercise, including long bike rides, because of the pain. Therefore Barrett declared, “I don’t like pain. I think I told you before when I first communicated with you. It seems that I have total body pain, just all over.” Barrett dislikes pain, but like every other participant interviewed, his pain is here to stay so he strives to develop his experiential and biomedical knowledge about his pain. Then he institutes practices that seek alleviation of the pain.

Many participants (n=10) drew faces when asked to illustrate their pain. The faces in particular convey dislike of pain. The faces are either of the participant or of the pain. The faces often have hollow eyes with mouths open to represent the guttural noises made in pain. The mouths often have teeth, jagged edges, and strong jaws because, according to participants, pain can feel like a continuous bite. The following images of faces of those in pain depict participants' dislike of pain.

Luke has pain primarily in his joints from years of playing football pro-



Figure 3.1: Face in Pain drawn by Luke



Figure 3.2: Face in Pain drawn by Kelly

professionally. His face of pain has a sharp mouth and angry eyes (Figure 3.1). Kelly's dad was exposed to Agent Orange in the Vietnam war. Her pain comes from the many sequelae of being a child of Agent Orange. Her face of pain rolls its eyes and utters 'uhhh' as a way of coping (Figure 3.2). Iggy masked her pain for many years with drugs and alcohol. Now sober, she feels the hurt of pain more. Her face of pain has hollowed out eyes and a jagged mouth (Figure 3.3). Pain makes her feel empty.

Nerves For many participants ($n=5$), pain lives in the nerves, which participants represent with fire in their pain images. When a host of factors damage the nerves, then the pain sensation emerges. Kelly's father received extensive Agent Orange exposure in Vietnam. As his only child, Kelly suffers from the residual affects of Agent Orange on the X chromosome she received from her father at conception. She conceptualized how Agent Orange attacked her entire body by focusing on the nerves. "It[Agent Orange] eats away at the nerves," she asserted. For Carmen, who has hip pain, the



Figure 3.3: Face in Pain drawn by Iggy

sensation from her nerves when in pain is not like being eaten but like being on fire. “It’s like a burn.” Figures 3.4 and 3.5 both visualize Carmen’s description. Morgan, who attributed her pain to athletics and heredity, also illustrated her pain as fire in her hips.

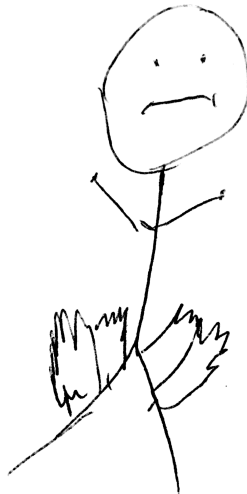


Figure 3.4: Pain Burning in Hips drawn by Morgan

Maynara also conceptualized her pain as heat in her nerves and blood. Like Kelly asserting Agent Orange as her pain’s causal factor, Maynara believed her abuse cycle fried her nerve endings. Maynara related:

Right now, it just feels like my blood is boiling in my veins. It’s



Figure 3.5: Pain Burning in Hips drawn by Carmen

just boiling. But all the way down in my hands...It just feels like it's in my blood vessels, in both of them, just boiling. But the doctor says it's my nerve endings. They are fried. And I had a PTSD night last night. I was up nearly all night. And I come in here and I have my coffee. And I'm still wired.

Maynara sees her body as electrically wired and pain as a mis-wiring. When the pain acted up, it felt like blood vessels boiling, Maynara described. Maynara visualized the entire body disruption of pain in her pain image. When I asked her to draw her pain, she grabbed the pencil in her fist and, as hard as she could, scribbled everywhere on the sheet of paper (Figure 3.6). The scribbles resemble blood vessels and nerves so inflamed they are charred.

In contrast an irritation of nerves—or nervousness—might result from having pain. Luke's nervousness regarded fear of injury. "Well you are always really nervous because I know my knee can just go out at any time. Or my ankles. I mean I can step on a little piece of sand, and I can twist my ankle. They are that delicate." Verbena believed that the boiling blood sensation of pain arose externally from her anger over all the losses pain creates.

So there was a lot of anger just because I went from being a caregiver. Cause my line of work was I was a home healthcare person. Taking care of a very sick husband to all of a sudden I couldn't take care of myself. And so there's a lot of anger with it. And for them to not really be able to fix it was really hard.

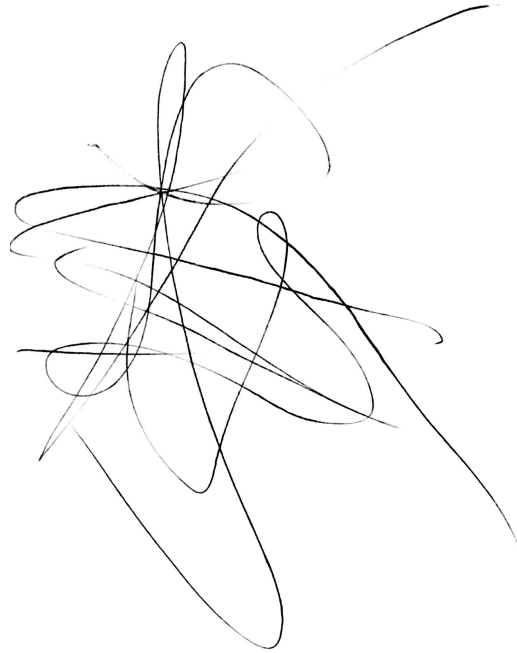


Figure 3.6: Pain as Hard Dark Squiggled Pencil Streaks by Maynara

And every time I tried to do something and realized I couldn't,
there was a lot of anger. It was almost like reliving it.

She spent years eradicating the anger in an effort to change what pain meant
for her.

Devouring It follows logically from pain conceptualized as fire, boiling, and frying—all processes that change chemical properties—that many participants (n=4) consider their pain devouring. Iggy envisioned herself as an almost entirely disembodied body (Figure 3.3), since pain has devoured the rest of her body. “That’s how much pain it is,” she argued, “I don’t even have a head just my eyes, nose, and mouth.” For Verbena, the pain is in the process of devouring her body by cutting off circulation from knots tied around every point in her body (Figure 3.14). “She says when she looks at me so that’s what she sees...knots and knots and knots and knots and more knots and knots and knots and knots. And that’s what it feels like.” Cassia correlated her pain with cancer—something that everyone considers real and devouring. Relating pain to cancer legitimized her pain and helped others understand what she feels. She asserted the reality of pain: “Yeah pain is just real. Like a cancer like I said. It’s just eating you up. Like eating your

bones. Eating your flesh. And it's very painful." In addition to pain eating, Cassia also felt her pain sizzling and aching deep inside of her. "Oh they feel like maybe you've got cancer or something you don't know because it's so deep inside of you. And especially the spine. It's just the pain goes like zzz, like a thermometer up your spine and it just hurts real bad....And then the bones they hurt with the weather. Mine just kind of hurt all the time now." Barrett considered pain less the source of the devouring and more the result. He believes that over time the wear and tear on his body has devoured his body in such a way that pain arises. "They tell you when you're young, wait til you're older and then you look at them like you're crazy but you know. Your body takes a beating after awhile since it's had enough. Of course the reverse of that is rigor mortis so you'd rather have the pain than that."

Droopy and Empty If the pain devours completely, participants (n=6) feel droopy and empty, which they depict in their pain images. Abby described the residual sensations of pain burning and sizzling:

I feel like a droopy flower, because the pain. I feel like my little petals. Cause the pain kind of slows me down mentally and I think it leads me more down a negative path. It's really hard for me to see the rosy glow cause I feel like I'm looking through the pain. And I'm not sure anymore if the chronic pain and tiredness if it doesn't lend to kind of. I don't want to call it depression or just more of a negative outlook. Kind of a sadness. So I'm not. I don't feel as strong spiritually or emotionally or mentally able to handle the same challenges that you know you face everyday.

Figure 3.7 illustrates her droopy flower pain.

The constant presence and awareness of pain drains participants. Philip, with full body pain from a complex chronic illness, noted how his energy level constantly shifts and determines his overall pain level. "It's just like the energy level is up and down, the pain is constant and when the energy level is up high I can deal with the pain easier. It gives me more umph to keep moving. I'll feel it the next day but at least I have that one day."

The pain that drains participants until they are empty may also be understood as a permanent awareness—pain always there. Dorothy called her pain nagging. "Nagging. It's a nagging pain. It's a irritating pain. It's not so much a sharp pain. It's not a sharp pain. It's just a constant flow of how can I put it a low grade pain, a constant low grade pain, but when it gets



Figure 3.7: Pain Like a Drooping Flower by Abby

irritated it becomes more of a medium. It's been very rare times where it's a sharp sharp pain." Gwen, a teacher with a recent injury that would not heal, also constantly noticed her pain, asserting how frustrating that is. Gwen has experienced pain for less than two years, making her hopeful, unlike most other participants, that the pain will subside.

I'm constantly aware of it. It's frustrating....Some days, I'm like, oh, this thing's never gonna go away. Other days, it's like, come on. There's gotta be something you can do to make this go away. I mean, I'm hopeful. At this point, I'm 60 percent hopeful, but 40 percent of me is like, this may be with me permanently. I'm turning 50 this year. All I hear is like, as you get older, your aches and pains stay longer.

Those, like Keira, who know the pain will never go away cry out from the emptiness inside. "Agonizing emptiness. Constant pain. Emotional, physical, all of them. But it's empty inside. And my body screams, you know, all the time for some kind of release." Sometimes the only way to deal with the droopiness and emptiness, the nagging and frustration is to consider pain "like an old companion" as Verbena asserted.

External Assault Instead of a process that proceeds from the inside outward, many participants (n=4) pictured their pain as an external assault with internal damages. The external assault came from animals, bats, and even sharp weapons. For Gwen, her pain is like an elephant sitting on her shoulders. It weighs her down and changes her posture. “It feels like an elephant’s sitting on my shoulder....I’m not holding my body up ‘cause I’m hunching in. It’s like I’m being pulled and pushed. Like something heavy on me.” Figure 3.8 visualizes Gwen’s description.

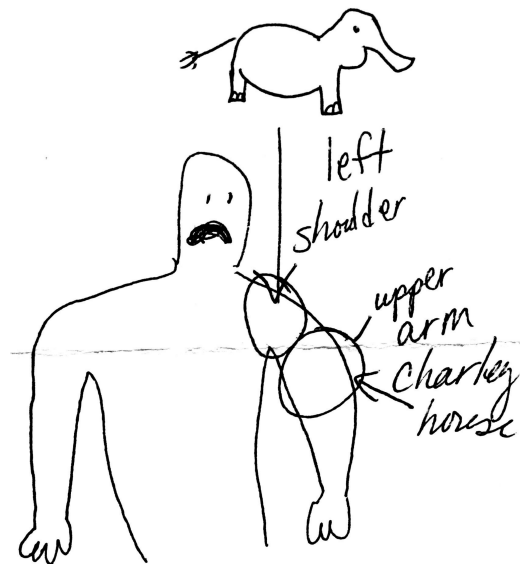


Figure 3.8: An Elephant Sitting on Her Shoulders by Gwen

Tuck imagined his pain as “a dang mule kicking me in the back constantly,” while Luke strayed a bit from a purely animal visualization to envision his degenerative arthritis as “just a nasty little monster that just eats away your cartilage.” Shanta, whose pain is simultaneously physical and emotional, detailed how her pain is an animal assault.

To me it’s pain. It’s that icky little thing that’s always scratching at you. Like a mouse, like a rat, gnawing at a bloody rope, and you’re hanging from the rope, and you’re gonna go into this pit of fire as soon as the rat gnaws his way through the rope. It’s that constant fear of when is it—if it’s ever gonna be too much. Hopefully it won’t be.

Barrett’s pain feels like an ogre punching him. “In terms of drawing a picture, like an ogre. Kind of reverse. Both ways. An ogre. Umm. I guess I’m trying

to show punching. That's wrong. This ogre is constantly punching at the body. So this is me out here."

The external assault need not be from an animal. For Raz, it came from TNT and a baseball bat as shown in Figure 3.9. Strider depicted three



Figure 3.9: Pain Like a Bomb and Bat by Raz

different nerve changes from external sources in his image of pain that results from overuse of joints and muscles while working out (Figure 3.10). The arrow represents a sharp and piercing pain in the side of his neck. The clamp demonstrates a squeezing and tight pain in his shoulder. And the fire in his knee recalls Carmen and Morgan's images of a burning sensation in their hips.

In addition to animal, tool, and TNT assaults, many participants (n=11) visualized their pain as a pointed object, like Strider's arrow, assaulting their body. Figure 3.11 provides a collage of pain images with pointed objects and shapes. Jason, who works a physical job, envisioned his pain as a stiff thorn in his heel that progressed on bad days to thousands of needles sticking into his entire body.

My normal pain that I live with just imagine you walking with



Figure 3.10: Pain in Neck, Shoulders, and Hips drawn by Strider

a cactus thorn in your foot all day long. And that would be my bearable pain believe it or not. And then the metaphor up to when it's really really bad would feel like hundreds and thousands of needles just sticking you and these like sharp, I don't know, like sharp, like needles, like cuts going all the way up and just.

Peony, who understands pain as energy, drew her pain as a knife cutting and stabbing into her as well as a bolt of electricity through her legs. "Sometimes, sometimes not all the times, but sometimes it's like there's a knife that's cutting into my back. Like a stabbing pain and sometimes, like when that

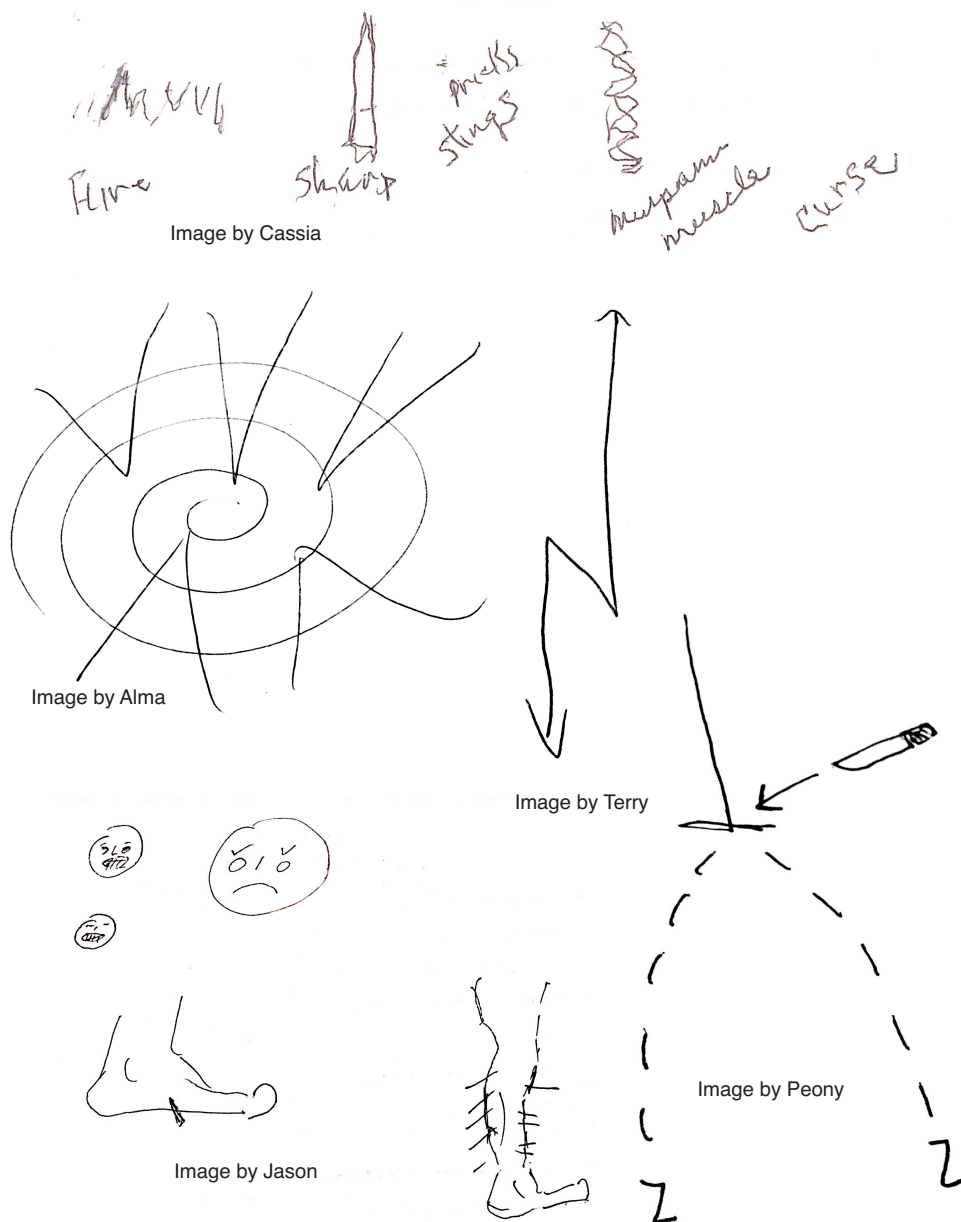


Figure 3.11: Collage of Images of Pain as a Pointed Object

happens, usually I feel like a little electric shots going down through my legs.” Finally Terry sees his pain as a bolt of lightning that worsens into a ball of fire throughout his body. “It would just be like a bolt of lightning. It would be like that. That’s the pain going both ends, top to bottom, just

shoot right through my whole body. Even gets my mind. I don't know if I'm hurting in my back or my knees, it just seems like I'm a ball of fire sometimes." Participants divide their pain into physical, emotional, and spiritual. They visually depict pain as disembodied faces, devouring, pointed, drooping, empty, and externally assaulted. These diverse understanding of pain argue for the complexity of pain. But they also demonstrate that those with very different pain (with respect to location or causation) can feel their pain in similar ways (for example like a knife or a fire in their hips).

3.4 Embodied Knowledge

This section on embodied knowledge concerns the internal knowing, feeling, and understanding that participants have for how their bodies in pain work. It involves awareness of when one system is not functioning as it usually does or when the body needs rest. Embodied knowledge differs from disembodied knowledge, with those aware of their body having more embodied knowledge than those disconnected from their body. My participants are acutely aware of their bodies, because pain is always reminding them of their corporality. Metaphorically, acquiring embodied knowledge involves sinking down into one's body and asking it, "How are you doing? What do you need right now?" This section broadens from the typologies and visualizations of pain I presented in the last section, focusing instead on how participants understand their entire bodies.

Body Awareness and Body Memory Body awareness or sensitivity involves knowing the limits of one's body. Close monitoring of their bodies enables participants to respond quickly and effectively to changes, pain-related or not, in their body. Azure described her close monitoring, "That is when I noticed things weren't working. Things were starting to be different within my own body." She went on to characterize the different things she noticed with her body, both before receiving the chronic pain diagnosis and after as she becomes accustomed to dealing with the pain.

My body will tell me what I can and cannot do. Being able to have that body awareness. The stress causes it, changes in weather will cause it, extreme barometric. When a storm will

suddenly come on, I'll notice my body will suddenly cramp up. Ummm. Cold. I don't like cold at all—that will cause everything to cramp up. Vitamin deficiency will probably have something to do with it. I know stress does. Like there needs to be something that addresses stress management and getting that psychological peace. It really is peace and that mental feeling of freedom and being safe.

Azure has extensive body awareness through which she parses where her pain comes from and what triggers worsening pain or lessens the pain.

Being in pain necessitates for many participants that they be attentive to their bodies. For Andrew, his pain increased his awareness of emotional harm that leads to emotional pain. “Well it makes me more aware of what I might do and what might physically harm me. I mean that’s definitely. For emotional pain, you know, same thing, it makes me much more aware of what may emotionally harm me. It’s like I have to be aware.” Verbena described physically recognizing how pain prevents her body from doing and receiving certain types of touch.

I mean even if somebody would come up and touch me. It would send me into spasms. Like sometimes people touch my back without realizing they were coming up behind me, I would land on the floor if they just would touch me in the wrong spot. So I got really funny about anybody touching me. I wouldn't shake nobody's hands because my hands always hurt.

Yet for Verbena there was a time before she became more aware of her body. Her pain management was much worse then. “My health has gone down from the sleep disorder and the chronic pain and the body trying to heal all the time. And the medications made everything worse. Cause it got to the point, I was sometimes I would still be in pain and I'd take more pills not knowing if I had already taken them.” Her health directly correlated with her ability to recognize her body's shifts.

A particularly acute moment of awareness occurs when the body remembers past experiences. Carmen shared her belief that bodies have memory. “I tend to think that maybe past lives are a good possibility or cell memory.” With this belief, Carmen holds onto the possibility that her pain may arise from a cell memory of genocide or the Trail of Tears. Bailey expanded the idea of cell memory by describing how stress settles in the body and how drained energy prevents the body from healing.

Mental stress, emotional stress, it settles in your body, somewhere. That energy field just. Something's getting zapped in it. Anyhow it's like I have to be strong for myself to be able to handle whatever she's doing to. It does drain your energy so maybe that's why it's taken longer to heal, because your energy's being drained and you got to be sure and get a good night's rest.

Like Verbena, Bailey's health also directly correlated with her body's energy.

The body memories are carried on the body and then limit the body. Verbena argued that body memories constantly need to heal which immunocompromises her. "So the body constantly being in a state of trying to heal has affected my immune system." Gwen also perceived constant pain as unhealthy. "I know it's not healthy to have constant pain. I know that's not good for your body. I know it causes wear on your neurons, and there's stress, and—so, and that causes other problems. I mean, I think I've been—since I'm aware of it that I'm not letting it get like, I'm tired. I'm stressed. I don't come home and then gorge eat, like I used to before I got it under control." For Gwen, the pain not only limits her body but also creates new problems to deal with. The limitations of pain had a huge impact on Philip's quality of life. "Everything. It's limited everything. Dreaming to do things or actually doing things. Or anything. You can have the will, but if your body can't do it. The pain keeps you from doing it. It don't matter how much will you've got. I've learned that over the last few years." He becomes quite discouraged, because there are so many things that he cannot do.

Nearly every participant expressed some way that their pain kept their body from doing everything they wanted their body to do. Luke talked about the huge life impact of losing his mobility due to the pain. "Because to loose mobility, ooo that's huge. That's just huge! Not to be able to use my legs and walk and stuff like that. That's probably what would scare me the most is if I couldn't be mobile. Because I want to be able to move." The conflict between wanting one's body to move and not being able to move one's body causes emotional stress. Cora described how she combats this, "My body with the pain is difficult at times, but I've learned to deal with it. Emotionally it's kind of stressful, but I try not to let that show. Umm, I try to be strong for my children. Physically, it doesn't stop me from doing the things as long as I'm able to work up the muscle in my back."

For Dorothy and Abby, the pain limited in ways and allowed in other ways.

They practiced body awareness to know when to stop before harming their bodies further. Dorothy wondered, “Well I think probably because like I can’t really jog any longer so I’m not getting in as much exercise. Course as you get older then you have a tendency to gain weight anyway so you know and that’s part of it is gaining the weight. So that’s kind of the effect it’s had on my body.” Abby asserted, “Yeah I have to space it [exercise] out. I can’t just go at it too hard. My body kind of says no.” The participants knew when to heed their bodies’ warnings.

Disfigurement Disfigurement regards an extreme form of body limitation. Jason talks about the impact of disfigurement on both himself and his father. “And of course that’s what happened to my dad. It started with a toe. And he lost a toe, then he lost a stub. They actually amputated my dad six different times, because the diabetes and it would not heal.” Other participants talked about hand and posture changes, as examples of disfigurement. For most participants, the body disfigurement itself did not have as much impact as the psychological toll of continual pain. Jason described how being an Apache man, he needs to stay whole until death. “We have to be whole members so that was really really hard for my dad. And it was really hard for us to also want to get it done, because we knew it had to be done because the gangrene was going. He didn’t want to and I understand that because in our nature we don’t believe in that. But it is what it is. I mean we have modern times now.” The disfigurement caused a loss of culture and discordance with beliefs. When faced with the choice between dying whole or being alive not whole, Jason would choose dying whole in accordance with his identity as an Apache man.

3.5 Causal Narratives for Chronic Pain

In this section, I explore what participants understand as the origin or causation of their chronic pain. The cause of most chronic illnesses cannot be fully elucidated without a consideration of both proximal and distal determinants in complex, multifactorial relationships. Proximal determinants refer to factors nearest to the illness such as a person’s particular physiology and health behaviors. Distal determinants refer to factors farther from the illness

that more broadly constrain experience such as a person's race, gender, and socioeconomic status.

My participants searched for their pain's causation until they found an origin point. They then started off the interview with this origin point—the accident, the stress, the abuse, the environment, or the disease that led to their pain. Even with an satisfactory explanation, participants wonder why am I the one in constant pain? Maynara asked about her pain,

Why would the Creator put pain on me? This is something we do to ourselves. Maybe inadvertently we do it to ourselves. The Creator would not put pain on me. Creator loves me. I know this. And I tell people all the time, my best friend is Creator. And I honestly in my heart absolutely believe that.

As many participants recount, they have been in pain for so long they cannot, like Rikki, remember what caused the pain initially. Rikki said, "But I don't know what precipitated it. I don't know what caused it, the initial." Other participants, like Cora, have a reason for all of their pain.

Well there's different kinds of pain that I've experienced. I have emotional pain that's caused by stress. And I have back pain that's caused by being too tall. And I have tissue damage from when I got shot when I was younger. When I was younger, I didn't experience it as much as I do now....So I started thinking, what if I have a heart attack and then my brain just got the best of me where it was making me emotionally sick and withdrawing from everybody and having more pain than I should have from the tissue damage and all that.

In this section, I begin with unchangeable causes of chronic pain: aging and genetics. I then talk about behavior and exposure related causes: accidents, injuries, occupations, environmental, athletics, and lifestyle. Next I discuss how other illnesses undergird the presence of pain: comorbidities. Finally I present the causes that I hypothesized would be most related to chronic pain for urban American Indians given historical trauma from colonization: abuse cycle, stress, alcohol, violence, and grief. I end by defining community pain and arguing for a cause and effect approach to all the potential and interrelated causes for chronic pain.

Aging Aging, according to participants, refers to mentally and physically wearing down. Getting older becomes an explanation for chronic pain for

many participants when time fails to quell the pain. In fact time may worsen the pain. Luke asserted that pain itself is aging. The aging process produces pain above all else. "Pain to me is aging. You feel old. You just feel old. That's the best word I can say. You just goodness gracious, my body is getting old." He described how the assaults on his body contribute to pain arising as he gets older. "The pain gets worse as you get older, and I'm not sure why. I think the age of the body and probably what I've put my body through, you know." Shanta thought about pain and aging as an almost accidental but guaranteed occurrence. "It's the same thing for accidents, because lots of times accidents cause pain, just living over half a century will create pain. Your body gets old; things happen; you can't live like a 20-year-old forever. Your muscles get stiff. There's things you can do to prolong it, make your body last a little longer, and those things I've been looking into a long time." For Shanta, there is no avoiding pain as one ages.

Carmen tried to avoid the association between increasing pain and getting older, because for her the thought of pain increasing with age causes stress, which contributes to more pain. "I think what does bother me about these things is the fact that they're happening. To me, they're signs that I'm getting older. It makes me think about the what-ifs, and what's gonna happen a few years, ten years, when I'm really old, in 10, 20 years. Is my body going to work? What am I gonna do?" Barrett called what Carmen tried to avoid a reality check as he used his pain to accept his own mortality. "But it makes me have a reality check. My body is breaking down and I'm getting older and I'm on the downside of life. That's just the reality. It's morbid, if you want to call it that. But it's reality. I told one of my good friends the other day, it's reality. It's just the way it is." Barrett used aging as a starting point for explaining why he has pain but proceeded to talk about other factors causing pain and what one does to treat this multifactorial illness.

Not really just that I think pain in and of itself is enigmatic of lots of things. It's not just this. I realize and understand, pain is not, you can't narrow it down to one item. It's many items. It's many causes. And then as you get older, pain becomes an issue. And becomes an issue in more and more parts of your body. And I know that I have not reached that peak of it. And I am not looking forward to that. But I also know there's not a whole lot I can do about it. There's no miracle cure out there. I wish there

were.

Genetics Participants defined genetics in the context of pain causation as inherited traits that make developing chronic pain conditions more likely. Alma asserted that autoimmune disorders run in her family. That genetic propensity provided the initial trigger for her chronic pain from rheumatoid arthritis, but her own ways of dealing with pain determine her day to day experience of her pain. “It runs in families. I’m sure there’s hereditary disorders. Autoimmune runs in our family. But I don’t blame that for the way I feel. I blame me for the way I feel. Because I’m responsible for my own well being and taking care of my own ailments.” Rikki revealed that she has a genetic marker for a devastating autoimmune chronic pain condition but does not know how her chronic pain and the genetic marker relate. “I have a genetic marker for ankylosing spondylitis, which is spinal arthritis but I have never shown, manifested. I have the marker, but I don’t show any disease. So I don’t know if that’s related or not.” The connection between genetics and the actual chronic pain experienced is often tenuous. For many participants, hearing pain complaints from others in their family triggered for them the possibility that their pain was inherited. But the genetics of pain remains just that—a possibility. For example, Ginger recalled her mother also experiencing pain. “Well my mother. I used to hear my mother complaining about the weather. Bones are aching, she says. So maybe I might have inherited it from her.”

Accident or Injury In contrast to genetics and aging, which are uncontrollable internal causes of chronic pain, every participant pointed to an aggravating or initiating event that precipitated all the rest of their pain. I call these aggravating or initiating events accidents or injuries. They are moments when someone does something that they should not be doing or when something out of their control happens to them. Even if the pain moves, like in Carmen’s case, an injury began the pain process. “I had a—it started with a torn meniscus that was behind your right knee.” But now Carmen’s pain is in her sacroiliac joint. For Willow and Verbena, the pain initiating event occurred in their childhood. Willow related with certainty, “Way back when I was 14, I was in a car accident and I bent my neck above the front of a cab of a truck, pick up truck. I know that’s when that started.” Verbena

described a disconnect between the severity of her accident some 30 years prior and her current pain burden. “I was in a wreck when I was 27. And it brought on fibromyalgia because of the whiplash. The wreck wasn’t severe.” Even the smallest accident can lead to chronic pain.

Ignoring pain from the accident or injury, like Tuck did, often contributes to the pain progressing. “I fell down at a trailer out in New Grove where I grew up at. And I was turning a couch into the trailer. Well I went down on concrete. And I got up and shook it off. Oh I’ll be alright. I wasn’t. It started getting worse and worse.” Gwen also tried to deny to herself that something had gone wrong after lifting something heavy.

I was planning to fly out to Florida to visit my brother, and I had a heavy computer bag. I go to put it in the overhead bin, and I was using mainly my left arm cause I’m left handed. I get this huge twinge in my arm, in the upper arm, in the shoulder, in the upper arm. I thought, Ooh. That hurt. I was able to get it in, but for the whole plane trip across country, my arm was really throbbing. Just a pain sensation. It ached big time.

Thinking back, both Tuck and Gwen decided that those injuries contributed to their chronic pain. Some participants, like Bailey, failed to seek out a definitive cause for their pain, fearing the many inconclusive tests. “It may be from an old car wreck injury, where that part of my back was actually hit,” postulated Bailey as her pain’s origin. “It didn’t do anything to the spine or anything, but it may have damaged. And I don’t know what it is. But I don’t want to do all the tests and stuff to try and figure it out.” Participants realize that a full diagnostic workup may still not reveal the full complexity of causation.

Occupational The accidents and injuries presented in the last paragraph are not related to participants’ occupations. In this section, I demonstrate how participants link their occupations to their chronic pain. Many participants worked in blue collar and labor-heavy jobs, where the work environment significantly increased risk of injury. Jason’s work exemplified a pain-inducing occupational environment. He said, “I’m in construction. I’ve been doing it for 35 years since I was young. Naturally I’ve incurred a lot of injuries with my type of work and my age. I have a lot of arthritis now so therefore I live with that.” Due to his occupational exposure, Jason

considered the source of his pain obvious. “Oh the pain that I have is just obvious. It’s through my years of my working the trade that I’m in and injuries that I’ve had....It’s just basically because of what I’ve done through the years. I know why I have my pain.” Terry also told of one initiating event—the source of his current physical pain—that occurred while he was a truck driver. “There was oil I didn’t see on the deck of the lift, and I come out the back end with the car engine and went off the back end of the truck with the car engine not far behind me.”

The occupational exposure leading to chronic pain for many participants occurred in the past, either because the participants have retired or been laid off, or because their pain burden makes it impossible for them to work. Fauna asserted that her pain is not as bad, despite her increasing age, as when she worked at a mattress factory. “It’s been quiet because, of course, I’m not doing all the lifting and what not that I did at work. They’d have us beating fiber comforters, to spread the fiber. That’s constantly this [demonstrates overhand beating motion with arm]. Sometimes this arm gets bad. Or, I get mad and take two of them to get the lumps outta this thing.” Cassia wanted to return to work after her job site injury, but her boss would not even consider a desk job for her. The loss of her job made the pain hurt even more. “Well I was a home health aide for a hospital and I got hurt real bad, lifting, caring for a real large tall woman all by myself at her home. It’s not good to put your knee up against a tall person to help them get up if you’re short like me I’m short.” Peony, a lawyer, blamed her own behaviors at work for contributing to her pain, not the work itself, in an interesting self-blame turn. “Cause I don’t really have a problem with my upper back any longer. And I’m sure it was because of the work that I did and the stress that we were under. I would inevitably create the problem in my neck and in my upper back.” Based on the jobs my participants worked, their risk of having chronic pain was often high, and therefore many participants articulated that their occupational environment contributed to their pain’s causation.

Athletics Instead of work-related injuries, many participants characterized their pain as arising from their athleticism. In particular participants spoke of playing sports in young adulthood with repeated injuries that were not allowed to heal as leading to constant pain. Barrett, for example, drew the link between childhood athleticism and current pain, “Well really it goes

back, it probably even goes back to grade school, because I was an athlete. I've been an athlete all my life." He goes on to describe the specific sports that contributed to what pains. "As I think about it the intense pain to body probably started in high school when I playing football and later wresting. You were taught to ignore pain if you wanted to make the various teams [i.e. freshman to varsity]." Rikki spoke of ignoring her injuries, "You know I don't even pay attention to things like that, cause you're just playing on adrenaline and you don't even notice you're hurt. And I had actually forgotten about it until I started hurting. Cause it's just part of the things that we did when we played soccer." Rikki never firmly asserted a cause of her chronic pain, contemplating genetics and athletics injuries as possibilities. Terry reported how athletics wore out his body. "And then my knees is from just taking a beating all my years. I was very athletic and I just wore myself out in my knees." Strider talked about current athletic injuries that he pushes through, causing re-injury. "I was just constantly getting new injuries. So I was always in pain for some reason or another. But more recently it's been the same pains constantly bugging me, and they never really tend to go away anymore. They are very persistent now....I'm very hard on my body physically through running and working out. So I think the stresses that I put on my body just keep them around." Though for other participants athletics caused injury which caused pain without any other factors, Luke linked his athleticism with his heritage with his diabetes and with his pain. "I've been told that I have degenerative arthritis, because of my football days. I have really really bad ankles that have just floating cartilage everywhere from the arthritis and again having diabetes and it's a vascular disease, it makes sense that your ligaments and everything arthritis is more prone to people with a Native American heritage, I guess. It's what I've been told." Luke asserted the multifactorial causation of his pain as: "Of football and my heritage and diabetes. So all of those mixed together as a cocktail is what has caused it."

Environmental Although accidents and injuries and athletics and occupational exposures precipitated a lot of participant's pain, some of the environmental exposures that lead to pain cannot be classified under the previous categories. Kelly, even when scheduling the interview, told me the cause of her chronic pain was her father's exposure to Agent Orange in Vietnam. The interview began with that exposure and moved to consider other

factors for why her legs were different lengths, causing her pain. “They think it has to do with being a child of Agent Orange. But then my dad said that they had lived in the mountains for so long and lived on the cliffsides that that was a trait in our family. I don’t know if it’s from one thing or the other.” Luke articulated that his broken family contributed to his chronic pain. “You know when your family breaks up and you know there’s divorce, I mean it effects people into their adulthood, because you lose the power of a mother and a father and their leadership and that family unit and love and all that kind of stuff.” Verbena also returned to her childhood when thinking about causation. “So there was a lot of issues that had to be resolved through the healing process for the pain. Which you think the past wouldn’t affect all that, but it does, because all of a sudden you’re having to confront oh why do I feel that way or why whatever. And it does come back from your childhood.” Both Luke and Verbena argued that the entire context of their childhood contributed to their pain not just one accident or injury when a child.

Lifestyle Participants’ lifestyles often predisposed them to chronic pain. For Alma, her diet linked to her pain.

I know that diet contributes a lot to pain. I mean we eat completely healthy. We don’t eat processed foods. We don’t eat fast foods. We eat organic healthy grass fed you name it. I mean I cook from scratch. Herbs. Everything is from scratch. We don’t eat crap. I won’t allow us too. I watch how omega 3s are going into our diet. How much sodium is going into our diet. It’s very important to me. And I learned that from watching what my mother suffered through. Had she a better diet, I think a lot of her ailments wouldn’t be so severe.

For Andrew, his physical lifestyle contributed to his pain. “I’ve been a very physical character since I was a very little kid. I’ve always been adventurous. Basically living on the edge. I used to climb trees in high areas. Not afraid of the heights. Like a little daredevil riding my bike down hills and you know, wiping out. So I’ve been dealing with pain since I was a little kid. Very like, serious pain.” Time compounded the assaults on Andrew’s body from his daredevil lifestyle and further elevated his pain. “Doctors warned me all the pain, all the broken bones that you’ll have, they’ll come at you later on in

life. You will feel aches and pains. You will have to live with that. So I've been dealing with that you know."

Comorbidities Another physical condition, such as diabetes, could also lead to the chronic pain. I call these causes of chronic pain comorbidities. Most participants received a comorbidity explanation for their pain from a physician. Philip had seen a physician but never received a clear causal explanation. "They've [the doctors] never really told me. They just told me it [my heart] was failing and then let me go...now with the heart problem that's everywhere so now the pain's everywhere." Cassia felt she heard the same response from the physicians every time and doesn't trust that they call all different kinds of pain the same thing—arthritis. "[The doctors] blame everything on arthritis. And sometimes I don't think it should. It's something else." Fauna also had doubts about her physicians calling her pain arthritis and then refused to dig deeper, because she at least had a diagnosis. "One doctor took x-rays. He said, 'Well, you got arthritis starting to form around the spine, in the lower back.' He said, 'That's probably the source of your pain.' Pretty much left it at that."

I believe the participants who provided a comorbidity cause of their chronic pain did so for the legitimacy of a diagnosis; I have pain, and it comes from somewhere identifiable. Alma struggled to get a diagnosis after her initial exposure to the viral process that turned on her rheumatoid arthritis.

When I was 14 years old, I was bitten by a wood tick. It turned into. It started out like the flu and then I went into like my body started getting really stiff and really painful....So through my entire life I've been dealing with in remission, out of remission. In remission, out of remission....And my last one, my inflammation levels were normal but I had all the pain. So now it's chronic undiagnosed pain because they can't tie it to the rheumatoid arthritis.

Rosaline, through her own research and through discussions with her physicians, determined her rheumatic fever as a toddler precipitated her fibromyalgia. "I had rheumatic fever as a child, when I was 18 months old, and they have found through studies that fibromyalgia patients are usually, mostly female, mostly females who have had rheumatic fever. What this involves or what triggers this to become fibromyalgia, I don't know and I don't think

they know.” Noah also contributed all of his pain to one medical condition—diabetes.

Pain, well I have diabetes and I have oh what you call it neuropathy in my legs. That is because of poor blood flow. That hurts. In different ways. I have to sit different ways. I have to be like this. Cause I have pretty poor blood flow. Cause of that I have an ulcer on the bottom of my foot so that’s what I’m dealing with now. There’s also diabetes and neuropathy in one of my toes. Other than that, my pain. I don’t feel that much pain because I don’t have that much feeling. It’s just all because of diabetes.

Despite a diagnosis from a physician or a disease condition known to cause chronic pain, most participants still wonder what, inside the nerves, causes good days and bad days with pain. Willow wondered, “There must be something in there I think maybe nerves under there somewhere something that’s causing the pain.”

Abuse Cycle In this section I present experiences of abuse that participants shared with me as contributing to their pain. Maynara’s abuse began as a child both from her mother and from other relatives. The only place she felt safe was at the foot of her Cherokee grandfather’s rocking chair listening to stories. The cycle of abuse trapped her until close to middle age with each marriage and relationship a detriment to both her mind and nerves. As such the abuse accumulated over time. She told me,

The sexual abuse was to the point one time I woke up and I was naked and his naked cousin was on top of me and I’m fighting him off and my ex-husband and Fuzzy’s girlfriend were trying to hold me down. But I kicked and fought and I finally got out of that. And I got out of that. But it was just the stress of dealing with it all the time was just. I think my nerve-endings finally just fried.

By the time we are talking, Maynara has escaped most of the abuse but still learns on a daily basis how to cope with her fried nerves. The day before our interview Maynara’s abusive brother had stopped by her house while she was out. Her son kept him from entering the house and alerted the neighborhood to watch out for Maynara’s brother. The stress of her brother finding her shook Maynara, and she remained tense about the situation the

entire interview. “I really do think the reason of fibromyalgia is when I was in pain as a kid or when I was getting abused by my mother, I had no one to go to. When I was married. And with my brother. I had no one to go to. When I was married to the different guys, I had no one to go to.” Ultimately Maynara contended that most pain arises from emotional factors and general imbalance—side effects of abuse.

Cause I really do think the source of most pain, unless it is a physical trauma like an injury, is emotionally related. It’s just like in the native, they talk about balance being physically, mentally, spiritually, and emotionally balanced. If you’re out of balance, you get screwed up. So most would say if you’re emotionally and spiritually out of balance, of course you’re going to be physically out of balance. The majority of pain is from that. Car wrecks that’s another story.

Maynara did, however, separate pain from the factors discussed so far in this section—internal, unchangeable factors and external, unpredictable factors—as different both in quality and in causation from pain due to abuse.

Cheryl portrayed a multifactorial picture of her pain causation with combat experience, being native, and an abuse cycle all contributing to her pain. Yet she asserted that the abuse overrode the other factors in determining her pain. “But I think the abusive husband was much worse than the Marine Corps.” Cheryl also contemplated how identity and abuse interweave to contribute to her pain in ways she has yet to perceive. “Yeah being native and having an abuse cycle my whole life, I’m sure that affected me in many ways that I’m not even aware of.” As she becomes more skilled and knowledgeable in coping with her pain, she hopes to perceive more of the connections between the accumulated trauma of abuse and the cultural trauma of being native. She faulted poor lessons in love for continuing her abuse cycle.

Well I had a pretty rough and I think a lot of native women can you know say this with pretty much confidence. I mean we are some of the most abused people out there. And I don’t know why that is...and you look back and my dad was abusive so that’s what love looked like. I mean you put yourself through these things and you don’t even know you’re doing it.

Before she realized her pain’s depth, Cheryl had undergone physical and emotional assaults that rendered her pain deeply buried and resistant to

healing. Fern hid the abuse she received from others, who noticed anyways, and further enhanced her pain by blaming her for the violence. “And that violence is one of those things that you try to hide and then you find out later on in life that everybody knows. Everybody knew. Why didn’t someone do something? And the ones that did know still blamed it on me. I had to be doing something wrong.”

Bailey and Azure shared one aggravating incident in their cycles of abuse that initiated the pain they continue to feel. Bailey noted the disconnect between having nothing physically wrong yet having pain.

Oh what I finally got over was a pain in my abdomen area. But I was in a relationship when I was about 20, 21, my daughter’s age, and he hit me there and it took a long time. It took probably 20 years for that pain to go away. Because there was. I had every test done. There was nothing wrong with my stomach, my intestines. So I just figured it was more emotional pain. But it took decades to get over it.

Azure described a time in her life when verbal abuse from her boyfriend aggravated her lupus flares on a daily basis.

When I was in the relationship with my ex-partner, when I got sick and was no longer basically working and having the money come in that he wanted, he said he didn’t want to be with a sick person anymore. He was calling me worthless and all that and there was tons of stress and pressure there. When he left, my flares decreased 80%. And my doctors even noticed. My pain med consumption was down.

Removing the abuse enabled her to remove pharmaceutical treatment as well, because she addressed the root cause of her flares.

Keira thought about the wounding from abuse metaphorically as a seed planted in one’s body that germinates into chronic pain. Continued abuse nourishes the germinating pain. “You know when you say, I feel like I’ve been run over by a Mack truck, that’s the kind of pain my body is in...constant. And I think that comes from all the junk, the abuse, all the beatings. It came from that. I don’t want to draw on everything came from the emotional. But basically it did. That was the seed that was planted there.”

Stress Many participants linked stress to pain with both positive and negative outcomes. Iggy realized she could foster positivity around her in

order to relieve her pain from stress. “Anything negative. Come on. That’s going to jeopardize my body in general is not good.” Carmen, who works a high stress job, noticed that her pain worsened when she tensed up unconsciously at work. Carmen expressed, “I do know that if I’m really busy—if I’m working on something really hard or whatever, I clench—I’ll clench my jaws. I think I tense my muscle. Right now, as we’re talking, I realize I’m tensing that leg.” Tension caused her pain. For Abby, quickly and quietly stress could trigger her pain. “You know they said it [RA] can be an emotional or physical stress that can set it off. It’s there, you just don’t ever know what’s going to start it.”

Finances are a common source of stress. Shanta told how stress from her job, from thoughts that grip her, and ultimately from poverty create pain.

I think stress creates pain, cuz sometimes I’ll be up, stressing over something...I stay up later, so then I’m stressed, and then my neck hurts more. I gotta deal with that too on top of the stress. They feed into each other. You have to do relaxation stuff...Just worrying about stuff, money. Poverty is bad. Being poor isn’t exactly fun.

Cora, too, realized a precipitous moment for pain aggravation when her husband lost his job. “The emotional pain just started a few years ago when my husband was laid off of work, and I was struggling financially to pay everything.”

Trying to be superwoman, as some of the woman participants called themselves, also causes stress, which brings on pain. I discuss the concept of superwoman more in the identity section of Chapter Four. Maynara characterized all of her different identities, which build on each other much as her stress builds from enacting those identities and her pain builds from the stress. “Well then I finally get me a job and I’m going to U of L. I’m putting myself through school and it was just stress after stress after stress. Cause I was mommy, daddy, chauffeur, housekeeper, student, worker, anything that had to be done.” In retrospect, Rosaline established stress as a major trigger of her pain, even stronger than the comorbid rheumatic fever.

But when I think back now, I think it was stress that brought a lot of this on, because of trying to be super-woman. Seriously that’s what it was. I seemed to think that I could do everything, and I couldn’t. I found out the hard way. The fibromyalgia was

probably a combination of the stress and the rheumatic fever when I was a child. But I think the stress actually triggered it.

Beyond the participants quoted in this section, nearly all participants noted some way that stress initiates or aggravates their pain.

Alcohol Many participants went to great lengths to portray their sober lifestyle, which I expand on in Chapter Five. Iggy and Roscoe, however, opened up about how alcohol contributed to their life in general and their pain specifically. For them, lowered inhibitions due to alcohol and other poor decisions made when drunk led to injuries that now cause constant pain. Iggy began our interview making a long story short. Alcohol played a major roll in the accident that generated her chronic pain.

Anyway make a long story short so there's this big wall about this tall and I scaled it. I wanted to just jump on it. I did it before and nothing happened. This time I couldn't get up it, couldn't jump over it. It was pretty tall, but I had did it before so when I came down my whole knee went like that. And ahhh and I fell over. Fire station is across the street so I don't know who I was with but go get help. I'm like ahh. They just put a brace in it. So I never went back and had it taken care of, you know. I probably pulled some ligaments or something of that manner that needed to possibly, if I had done things differently, went to seek some medical to see what was really wrong with it maybe I could have avoided all this bone on bone that I have right now.

Beyond one aggravating accident, Iggy contended that her lifestyle in general kept the pain from the accident from healing, shifting acute pain to chronic pain.

During the years, I didn't live the best lifestyle either. I mean alcoholic, addict, you know, stuff like that for a very long time. Didn't take care of myself. Sure that has a lot to do with it. And then I mean running here, running there, not knowing I was really injured. I'm just doing crazy stuff....The first time I probably didn't feel it, I was so out of it. Plus when you're under, how do you feel it so you're damaging even further doing. Like I said, crazy stuff. So who's to say. I didn't feel nothing.

Alcohol abuse, itself, came from a need that both Iggy and Roscoe felt to dull their existing pains. Both Iggy and Roscoe spent much of their childhood away from their birth families, away from their reservation community,

and in terrible foster situations. They spoke of using alcohol to numb themselves. Iggy illustrated the relationship between alcohol and pain through the metaphor of fog. She cannot see.

Cause I was drunk, taking my pain away, and I'm acting a fool, going to jump on a wall, get up there, to do god knows what...So you know your eyes open up and you can see things through the window now. I couldn't see before, it was just too much fog, you know, and the brain is damaged. You're just fucked up.

Roscoe set up a progression from pain due to grief, stressful life events, and historical trauma, questions I asked on the survey, to drinking to his current pains from injuries acquired while drinking.

[The drinking] not for my pain but just for escaping life probably. I mean shoot now I realize it I wasn't dealing with a lot of things in life. The pain I don't think there would have been any pain if there hadn't been any drinking....But as far as pain, the pains come from drinking cause drinking came from all the questions before [ie questions about historical trauma, grief, and stressful life events on the survey]. And nowadays I kind of deal with that. I've dealt with being adopted. Whatever a lot of things.

Violence Historical trauma, gang involvement, alcohol-induced fights, and physical abuse increase the possibility of pain. Iggy suggested a more challenging root cause of chronic pain—the historical and continued poor treatment of American Indians.

I'm not that friggin smart, but I'll tell you lady, yes you can, because that's where it started, that's where it originated from, and that's why it's so messed up now. That's why. The genocide against us....I don't like to talk about it, because it hurts me. It pisses me off. Mainly it pisses me off. But I could cry about it, because it really bothers me so bad....Has it ever ended? Goes to infinity. Keeps going and going. We're still getting screwed.

Iggy brought up historical trauma and then quickly changed the subject, though her agitation remained. The painful wounding festered. Barrett also connected historical trauma with his physical pain. “Because both the Native Americans and the Afro-Americans have gone through so much, historically, that I would say it probably increases the possibility of pain. And increase the various physical elements.”

Roscoe set up a dichotomy between his drunk self who gets injured due to the violence he induces and his sober self who rarely gets hurt.

Well most of it is from fighting and things like that back in the day you know....I think it all stems from that mostly. Like my lower back. I didn't put it in there. I got hit with a car jack. It went into my bones and all. I just. I didn't really do nothing. I had it cleaned out and stuff. They couldn't sew it....See I don't hurt myself much when I'm sober. It's just when I'm drinking.

Despite pain arising from her gang involvement, Cora remained thankful that, though a painful life, she is alive. "I was in a gang when I was younger so it was really, I got stabbed and shot and ran/hit by a car all in the same year so it was like really terrible. I'm still here, thank goodness." The presence of normative violence generates gratitude and diminishes hope for an unimaginably better quality of life.

Iggy linked her life choices and her ancestors' experiences with emotional pain but continued to argue that her physical pain comes from an accident and has nothing to do with her alcoholism or her Ho Chunk identity.

You know, being an addict alcoholic, you don't take care of yourself. You know what I mean. It's generational trauma, you know. Because I've struggled a lot with my own demons and I'm taking these courses and I'm learning so much about my friggin self. So you know, as far as culture. Alcoholics, Native American Indians are famous....they love their whiskey. Been like that since the Europeans came here. We won't get. There's not enough time in the day to talk about that. You know being taken away at a young age to foster care for many years. Running away. Yeah, I want to go back home. I want mom. You know my mom's a full blood American Indian, Ho Chunk. That's upsetting. But I mean, I don't think that has anything to do with my knee.

Grief

From the blog "Painfully Optimistic": In dealing with grief from your chronic pain though, it can be difficult to deal with at the best of times. There aren't any ceremonies that you go to in dealing with your emotions for the physical pain you feel. You have no bereavement leave to help you adjust to not being able to carry out daily tasks. There are still some people out there that think chronic pain is still not even real pain that 'it's still all

in your head'. Lots of times because of this people dealing with chronic pain miss lots of the thoughts, feelings, and actions that are all part of dealing with grief (<http://painfullyoptimistic.com/archives/1476>).

Few participants trusted me enough to talk about their grief. Terry mentioned his wife's death and the daily emotional pain of that. Shanta told me about her daughter's death and re-appearance that gave her strength to cope. She cried when thinking about it. Roscoe disconnected from his own pain experience to define the grief that enters into group sessions he has with other recovering alcoholics. He related:

If you're spiritually bankrupt that's what causes grief, that's what causes all of this. Why do we cry about losing somebody, because they touched us some way. It's not sad that their physical being is dead. It's the things you shared or whatever, the emotions, the different things. That's what you're grieving. You hear songs you think of them. It brings something. I think a lot of it is you need a lot of healing in your spirit. And I'm not talking religion because I'm not a church person or nothing. But I think you can pray anytime.

Like in the previous section, Roscoe sets up a causal chain; spiritual bankruptcy causes grief and grief causes pain.

The most common reason for emotional pains that participants mentioned was loss of a significant person in their lives, though few participants connected their grief with physical manifestations of pain. Terry, a truck driver whose pain began when an engine fell on him, provided a definition for all types of pain:

There are two kinds of pain, I look at it, physical pain and mental pain. Physical pain from your body and mental is what you're thinking, what you're going, what you're been through. A lot of trauma you go through it's a pain burden on you anyway. I lost a fifteen year old son to the streets of Chicago and it's still on my mind. And that's pain itself just thinking about it everyday. And I lost my wife after 35 years of marriage. I watched her from a healthy woman go into the hospital and a year later comes out into hospice. I lived in the hospital for a whole year and a half. That's pain. Mental. Things that. Trauma. Not only to me and I watched them going through pain and it was pain on me. Lotta stress.

Both the physical pain and mental pain, according to Terry contribute to a high pain burden. Roscoe also asserted how grief underlies his pain. “I think to me it’s all connected so I mean my grief is pain. This is just something that my body’s got to go through.”

For Rikki, the pain burden did not manifest physically. “Well I lost my parents. I lost my friends. You know that spiritually, you know that hurts. But I can’t correlate them [physical and emotional pain].” Andrew argued that the reasons for his emotional pain are the loss of romantic relationship and the loss of friends too young.

The only emotional pain that I would say I have to deal with would be like partner, partner pains. The separation of you know a break up or like the loss of a friend. I haven’t lost a friend since 2001, which is over ten years. So that’s been a long time since I’ve really had that emotional pain like that. A loss of a friend who’s only 25 and went way too soon, before his time. That would be like a very strong pain in my life.

Dorothy also provided loss as the reason for her emotional pain but expanded that out to encompass change in general as a reason for her emotional pains. “Emotionally, yeah going through divorce. Going through relationship break ups. Going through changes which I don’t like a lot of change....So that healing part, the pain of that has been uplifted.”

Though Andrew finds that emotional pain quells with time, Terry asserted that the grief of his wife’s death will be with him until the day he dies.

You can’t never let it go. Think about it. It’s always there. I can’t block it out. It’s just there and I try to work around it and find something different. I’m at home laying in bed and I think of all that stuff and I just get up out there and find something to keep me occupied, because I just let it sit there and dwell on it. So I’m still not over my wife’s death, and it’s still hard on me. I think about it everyday. You know. That pain will never go away. That will be with me to the day I cross over.

Alma cannot overcome the pain from her mother’s passing a few years previous. Her mother’s end of life was extremely painful and difficult for the whole family. Alma and Terry carry grief as a pain burden.

Community Pain A final reason participants cited for their chronic pain was that the entire native community is in pain, because, for example,

some people live too much in the past, are more focused on prior generation's pain, and are afraid to make the leap toward rising above the past and healing themselves. Maynara counseled not to wallow in pain or embrace anger that infiltrates a community and continues to cause pain.

I think a lot of the pain in the [native] community is because of anger....It's not anger because of pain. It's pain because of anger....It's just like with my fibromyalgia. When I get upset, I go through pain. And I think there's a lot. And they talk about historical trauma. It's cause they need to move on. Don't waller in the pain.

Cassia wondered if certain types of pain occur in the native community now because contact with white people brought the ailments. "I don't think they had arthritis in them days [pre-contact]. Maybe it's a white man's disease. We didn't have arthritis. We didn't even have a cold. We didn't have venereal disease. I think maybe it comes from all that communicable diseases all this pain we're having." Carmen described her family's pain and how she carried those stories with her deep inside, feeling their pain along with her own.

My mother would tell me stories about when she was a little girl and the pain that she went through with issues....You take on that pain, actually. You're hearing stories. You feel sorry for—you feel sorry for your mother going through those things....As they've heard their parents' stories and their parents' stories, is it all stored in and brought down? Could very well be. Or like you said, too—that's why I asked back earlier saying with cell memory, if there's something else there. I do believe that. I think there's some—if I can feel recognition towards a soul mate or there's something that just penetrates you that stays with you. There's just some things that don't go away.

Cell memory preserves community pain, generating simultaneously new pain and pain carried forward in each generation.

Cause and Effect I argue that the above causes have effects, resulting in chronic pain both alone and in combination. In this research the effect is chronic pain and the cause may or may not be identifiable. Unlike I hypothesized, the cause according to participants is not always related to colonization's consequences. Rikki asserted, "I think there's a cause and a reaction. But sometimes like with the hip, I can't think of a cause." It is

easier to track the effect when the cause is known and more difficult to work backward from the effect—pain—to a cause or causes. Shanta described a cyclic process of injury and re-injury that over time became more and more difficult to heal.

Well, when you damage something, and it takes a long time to heal, or sometimes it doesn't heal if you're over a certain age. It just won't heal, or if it does it heals really, really slowly, so you just gotta put up with it 'til it heals and hope for the best. If you over do it, and you re-damage yourself, you re-injure your injury, then it's gonna take longer to heal. It's just like if you break a leg and you keep standing on it. It's never gonna heal. You gotta let it sit and do its thing. Nature will heal it if you let it. People don't let it. That's what makes pain last.

The cause and effect may generate another effect and another, compounding pain until some intervention disrupts the cycle. Though he recognizes the cause and effect pattern, Philip remarked that he does not consider the question of why he has chronic pain. Just like someone is tall, he is someone with chronic pain.

You have to find your truth or your peace so to me I don't think it really is a question of why. It comes with it. It's something you've got to deal with. Life is the way life is, whether you're born short or tall, you're going to have to live your life and so. Some are pain. Some are just different things. You know so it takes time. I forget when it's hurting real bad. And so that's kind of how I kind of deal with it.

There is no cause. There is no effect. Some things just are—like pain.

3.6 Meaning of Pain

In this section I characterize the meaning of pain in participants' lifeworlds. Knowing what pain is, how to understand pain within the body, and where pain comes from all contribute to the meaning made from the constant affliction of chronic pain. I begin with disbelief and move to acceptance of pain as necessary. In between I demonstrate how deeply and broadly pain penetrates. Chapter Four expounds further pain's penetration throughout participants' lives. Feelings of isolation and despair do arise from pain but on

a continuum of good and bad days with pain. Eventually the pain absorbs completely into daily life—a meaning of pain in and of itself. Ultimately, participants establish meanings for pain that allow them to live with the pain. Chapter Five more comprehensively examines how to live with pain.

Child’s Eyes Seeing with child’s eyes means for participants perceiving the world with innocence, awe, and wonder. It also concerns the surprise devastation of the realization that pain will not go away. Carmen said, “It was disbelief. It’s not going away.” Pain, when new, ravages with a cacophony of nearly-rhetorical questions, unusual sensations, and destroyed beliefs. Verbena described how she transitioned from pain as new to pain as making sense in her life as much as pain can make sense. “It’s one thing if it’s a gradual change, but when it’s a drastic change, night and day, it’s too much to take in and you have to have...a good support system or and/or, if you can have both it’s really good, or you have to have really strong beliefs. You have to really know that everything happens for a reason, if that makes sense.” Roscoe, when asked to draw a picture of his pain, created a child’s eye. A tear falls from the eye and in the tear are symbols of cultural loss: a buffalo, a tepee, and fire (Figure 3.12). The child’s eye cries from cultural loss explained Roscoe. In contrast Kelly defined the child’s eyes as a way for happiness despite pain. “Because you have to think there are so many people out there who have it so much worse. And they choose to be happy. They are happy, because they look at things with a child’s eyes. They don’t look and say, I want this or. No, because you do the best with what you got.”

Hidden Hiding the pain functions for participants as a way to deal with the pain. Bailey explained, “Because you got to realize it’s [pain is] always going to be there. Nobody’s free from it. And uh it’s just how you handle it. So I’ve seen people where they can’t handle it. And it’s not good.” Participants hide the pain through movement, through denial, through refusing to pity oneself, and through remembering that pain will not kill you. Strider hid his pain through movement. “Mostly it’s just kind of annoying....As long as I’m doing something, I usually don’t think about them. It’s when I stop that they bug me the most.” Terry also forced himself to get up and fight the pain instead of letting the pain overwhelm him and put him back to bed. “I don’t want to just sit there and pity myself, because I’m in pain. I’m the



Figure 3.12: Pain as a Tear Encompassing All that was Lost by Roscoe

kind of person I got to keep moving. If I let it beat me up, I'll be in the bed all day." Peony denied her pain, refusing to give the pain meaning, because meaning can give the pain power.

I think we can kind of. I think, depending on what kind of pain it is, we can kind of leave that behind us. But sometimes when you ignore it, it only makes the matter worse....If you kind of dwell on it, I think you can manifest it. I think you can manifest the pain, maybe that's why a lot of times we just ignore it. If it gets to the point where we can't ignore it, if it's still nagging at us and we can't ignore it. That's when we have to do something else.

Rosaline took comfort in knowing that the pain will not kill her. "I have found out with the fibromyalgia; it is a disease; if God came and said pick a disease, you have to have one. You might as well pick it. Because it's not life threatening. It's not crippling. And if you choose to control it, you can control it rather than letting it control you. So I just block out the pain."

Despite efforts to hide the pain, many participants conceptualize the pain as bone deep and therefore embedded far into their lives. The usual methods

of pain treatment rarely penetrate bone deep. In a sense the pain remains hidden by its depth. Kelly thought of her pain as normal, a status quo, while growing up.

But growing up it was like, I was in pain but I didn't know why. I thought it was normal. I didn't know other people didn't suffer. I never really thought of it as suffering, because I seen everything in life with like awe. Ummm. And then. I mean, I took. I mean I thought it was normal to break bones so easy and to have that stuff happen. I didn't know that it wasn't.

The pain did more than afflict Kelly's bones, it became a normal part of her identity. For Cora, the pain resided deep in her body. Her brain may dig up the pain, but if she can keep her brain from dwelling, then the pain recedes deep again. "That's a jagged edge from when it starts. It goes up and down, up and down, until I alleviate myself from my brain. My brain it stops. My biggest problem, I think, is my brain because it doesn't stop." For all participants who spoke in this section, pain is something to block out and hide in order to prevent pain taking ahold of you.

Good Days and Bad Days Nearly every participant divided their pain experience into good days and bad days much like Charmaz, 1991 theorized. They structured their conceptualization and meaning-making of pain off this dichotomy of ways to experience pain. Bailey defined good days and bad days. "Ok good days I can do pretty much what I want to do. Bad days, I actually had to take off a day of work about three weeks ago and that rarely happens, because of the pain." For other participants, including Bailey, good days involve movement, while bad days mean very little happens. Willow drew progressively larger bursts of pain for her pain image (Figure 3.13). The largest burst of pain results in a bad day, and the smallest, a much more tolerable day.

Alma characterized good times with pain—her remission periods—as functional and energetic times. She cannot move when out of remission.

Well during the remission periods I function more. Like I have the energy to get up and do things. When it's out of remission, I literally just want to curl up in a ball on the couch and cry and cry and cry....There's no other way. You're just stuck in pain in a ball.

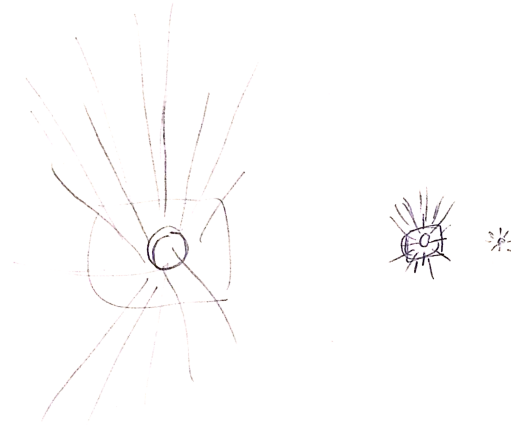


Figure 3.13: Progressively Larger Bursts of Pain by Willow

Verbena described how she separates pain into good and bad days, usually metaphorical imagery (Figure 3.14).

A good day is like ropes. It's like being tied up in ropes maybe like that ropes. It's like ropes all over your body being pulled at different times. That's a good day. And this is the face that normally goes with the good day....That's a bad day. You will bite anybody's head off just, because they said hello to you that's why the mouth. Sharp teeth. Piranhas. Piranhas. That's how you feel.

Each morning, Verbena assessed whether the day was a knots or piranhas day. Her assessment of the pain involved consideration of everything else discussed in this chapter—causation, description, knowledge, typology, and meaning. Without this assessment, the pain controlled her life.

If you don't acknowledge the good moments, then that means you're too wrapped up in the pain itself if that makes sense. And the more you let the pain wrap you up, the more it controls. The more it controls your life. The more it controls what you can do or not do. How you talk to people or just your whole outlook really? And it really is an outlook issue. It's an emotional issue.

The ability to assess pain demands that participants use all the resources described in this chapter.

Living with, Coexisting, and Moving On For all participants, it became clear, at some moment in their pain story, that the pain was not

Good day



Bad day



Figure 3.14: Pain Knots as Good Day and Pain Piranhas as Bad Day by Verbena

going away. They might still hope for a cure, but on a day to day basis, they must coexist with the pain. Marcella separated out feeling the pain from pain stopping her activities. “I feel it, but it doesn’t stop me from doing all the things I do.” Andrew asserted that the accumulation of pain allowed him to deal better with the pain. “Pain on top of pain. Which is exercising the muscle, which is already traumatized as could be, you know. And so I’ve become very accustomed to dealing with pain in that sort of manner.” He actually expected the pain. “The pain actually becomes like an every day event for you, like you’re expecting it. It’s like getting up, time to make the donuts. It’s like get up, time to feel the pain again. And you just have to go through.” Another way to think of living with pain would be to think of moving through pain to a place of greater peace. I talk more about psychological peace in 4.

Gus mourned the loss of his physicality due to pain. Therefore coexisting

with the pain required a shift in his physical ability that demanded resources from his emotional and spiritual reserves. “And I can’t believe it. I mean when I was a mechanic, I was a physical person. And those are big machines. And now it’s kind of hard to do things physically, when I used to do things easily when I was physically fit.” Gwen has accepted her physical limits, asks for help when needed, and just pushes through when she has no other options.

I don’t mind asking people to help me carry this and that. At the same time, is this gonna be worse where I’m not gonna be able to lift a damn thing? It’s just like, I live by myself. I don’t have any children. I don’t have a man in my life. My cats can’t do it. They don’t have thumbs.

The shifts, not just physical, that pain demands can be very scary. Barrett noted how his entire lifestyle changed, but to keep it from changing too much, he sought out appropriate management of the pain. “Just the total lifestyle. Not to be able to have a decent lifestyle that’s scary. And it definitely makes you think about it. And that’s why I’m constantly searching for ways that I can manage.” For Fern, coexisting with pain works fine until she can no longer do the activities she loves most. “Probably I don’t know which would be worse, losing the use of my legs or my arms. At least with my arms, I could still sit and maybe do things. Or the pain being so bad that you can’t do anything. Because I’m very. I mean I quilt, I craft, I bead. A lot of things like that.” Living with pain accompanies the fear that some day one will be incapable of living with the pain. And then what?

Pain as Necessary or Not Though pain produces widespread affliction in bone, in blood, and in nerves, many participants come to understand their pain as necessary. Cassia argued that pain necessarily calls attention to an area that requires attention. “Pain is for when there is something you should have attention to that area. But not just to stay and get worse and get worse.” She qualified her argument, though, because pain should not continuously call attention to an area that has already healed physiologically. Tuck also flirted with the idea that pain may have a function, but, like Cassia, concluded that chronic pain outlives its functionality. “Pain is supposed to tell you when something is wrong. But my pain is almost all the time so I don’t know if there’s something down there agitating my nerves where it not

stay there constantly. Or what. But something has got to be wrong back there somewhere.” For Strider, pain clearly functioned to remind him that he is alive.

The way I see it, the two things that make you feel most alive are love and pain. Those are the two things that you feel internally so I don’t want to do something to take away from the most basic experience of life. So if you don’t have some sort of pain in your life, it’s hard to know the wonders of love.

He approached pain and love with a child’s eyes, with wonder, despite how deep or boiling the pain might be. Maynara conceptualized her pain as human not divine. “My Creator is all about love and nurturance and would not do bring pain on his creation. People create pain from their actions, by mistake, accident, or by choice.” In the physical world of humans, perhaps pain is necessary, according to the above participants. In the spirit world, pain does not exist.

3.7 Conclusion

In this chapter—The Chronic Pain Itself: Bone Deep, Fried Nerves—I presented a profile of pain. I began with the diagnosis of pain and the many ways pain is misunderstood. Then I shared typologies of pain (physical, emotional, and spiritual) as well as ways to conceptualize, visualize, and describe pain, moving more broadly to how pain impacts the body. The center of the chapter concerned causal understandings of pain as a bridge between conceptualizing pain and knowing pain well enough to live with pain and move on. I ended talking about the various meanings participants assign to pain. Participants found it very necessary for their own wellbeing to establish what the pain is, where it comes from, and what it means for their lives. In the next chapter, I expound more on the widespread impact of chronic pain in the participants’ lives.

Suffering: Like a Broken Toy

The Social, Psychological, and Cultural Impacts for American
Indians Suffering with Chronic Pain

Abstract

This chapter will explore the difficult conversations and the places of tension and conflict in the lived experience of chronic pain for urban American Indians. Specifically, the American Indian chronic pain sufferers I spoke with struggled with the multiplicative invisibility of both their chronic pain condition and their native identity. The invisibility led to passing as white in environments hostile to people of color. It also resulted in family disconnection, loneliness, and isolation. In order to survive these socially-mediated assaults, my participants kept their psyche at peace through stress management, cultural engagement, and non-negativity. They also called upon a warrior strength; their understanding that American Indians as peoples have always survived bolsters their individual strength to push through the pain and keep on living.

The participants talking about their pain echo a chronic pain physician when she says, “With pain, you must always talk about so many things at once, the social, the economic, the psychological—not just the sore knee or the bad back (M. Jackson, 2002 p45).” To comprehensively or even partially deal with an illness like chronic pain requires multiple points of reference and multiple enactments (Sweet, 2012). In this chapter, I present the many ways pain impacts on life through shifts in identity, psyche, social world, and cultural engagement. The suffering that proceeds from all the ways chronic pain impacts life is “ordinary, chronic and cruddy rather than catastrophic, crisis-laden and sublime (Povinelli, 2011 p132).” In order to survive these socially-mediated disruptions from chronic pain, my participants keep their psyche at peace through stress management, cultural engagement, and non-negativity. As Verbena sums up, “And that’s the whole thing...living with it.”

4.1 Statistical Image of Experiences with Grief, Trauma, and Violence

The following analyses come from participants completing the Stressful Life Events Questionnaire, Historical Loss Scale, and Texas Revised Inventory of Grief (Table 4.1). The trauma demonstrated in Table 4.1 both proceeded and followed the chronic pain. Participants on average experienced 4.8 of the 12 stressful life events I asked about. The most common events were verbal and physical abuse as well as witnessing the killing of another person. Over half of the participants experienced physical and verbal abuse. The least common events were being in a dangerous situation, having a weapon used against them, being in a life-threatening accident, and feeling helpless.

On average participants thought monthly about various losses associated with historical trauma. They thought most often about cultural loss and loss of respect for elders, especially by the younger generations. They thought least often about boarding schools and forced relocation. Forty-four percent of participants were currently experiencing grief. For some this grief was for the historical losses, for others it was for personal losses of friends and family, and for others it was the loss of functionality associated with having chronic pain. Over half struggle with acceptance of grief, emotional responses to

Table 4.1: Descriptive Statistics Profile of Stressful Life Events, Historical Trauma, and Grief

	N	Min	Max	Mean	Std. Deviation	Interpretation
Stressful Life Events Questionnaire						
illness_trauma	39	0	1	0.41	0.498	41% life-threatening illness
accident_trauma	40	0	1	0.3	0.464	30% life-threatening accident
force_trauma	39	0	1	0.28	0.456	28% force used against them
deathwitness_trauma	39	0	1	0.44	0.502	44% witnessed death
miscarriage_trauma	25	0	1	0.44	0.507	44% miscarriage
sexforced_trauma	38	0	1	0.39	0.495	39% sexual abuse
childabuse_trauma	40	0	1	0.35	0.483	35% child abuse
physabuse_trauma	40	0	1	0.5	0.506	50% physical abuse
verbabuse_trauma	40	0	1	0.57	0.501	57% verbal abuse
gunthreat_trauma	39	0	1	0.31	0.468	31% threatened with weapon
witnesskilling_trauma	40	0	1	0.5	0.506	50% witnessed killing
danger_trauma	40	0	1	0.23	0.423	23% other dangerous situation
helpless_trauma	39	0	1	0.31	0.468	31% helpless situation
TTE_totaltraumaticevents	40	0	12	4.8	3.421	4.8 out of 12 traumatic events
Historical Loss Scale						
land_loss	38	1	9	4.16	2.15	monthly think of land loss
lang_loss	39	1	9	3.69	1.935	weekly to monthly think of language loss
spirit_loss	39	1	9	3.77	2.288	weekly to monthly think of spiritual loss
boarding_schools	38	1	9	4.74	2.049	monthly to yearly think of boarding schools
relocation	39	1	9	5	2.34	yearly think of relocation
respect_loss	38	1	9	4.11	2.299	monthly think of respect loss
trust_loss	39	1	9	3.85	2.195	weekly to monthly think of trust loss
culture_loss	39	1	9	3.28	1.932	weekly think of culture loss
alcoholism	39	1	9	3.38	1.914	weekly think of alcoholism
elders_loss	39	1	6	3.31	1.657	weekly think of elders loss
people_loss	39	1	9	3.95	2.077	monthly think of early death loss
tradition_loss	39	1	9	3.18	1.848	weekly think of traditions lost
Composite	39	1	8	3.8761	1.57542	about monthly think of historical traumas
Texas Revised Inventory of Grief						
grief	36	0	1	0.44	0.504	44% currently grieving
nonacceptance_grief	40	0	14	7.57	3.529	half struggle with acceptance of grief
thoughts_grief	40	0	22	14.98	4.627	68% struggle with thoughts of grief
emotionalresponse_grief	40	0	18	11.75	3.992	65% have emotional response to grief
already_grieved	40	0	5	2.93	1.269	true and false already grieved
functionwell_grief	37	0	5	3.3	1.412	true and false function as well after grief
pain_grief	39	1	5	2.59	1.251	true and false have pain from grief
pastbehaviors_grief	39	1.5	4.13	3.1673	0.63024	true and false past behaviors influenced by grief
presentfeelings_grief	38	1	4	2.1338	0.8473	mostly false present feelings influenced by grief
disbelief_grief	39	1	4.67	2.5897	1.11728	mostly false disbelief over grief

grief, and continued thoughts of grief. They are neutral regarding whether

or not they function as well now as they did before the grief, whether or not they experience pain from the grief, and whether or not they have finished grieving. Regardless of current grief, the majority of participants struggled to accept grief and had strong emotional reactions to grief.

Regarding these data, I asked: 1) Is a lower grief composite score associated with less maximum intensity of pain and less pain sites? 2) Are less violent and traumatic events in life associated with lower pain maximum intensity, and fewer pain sites as well as a more limited description of pain? and 3) Finally does a lower historical trauma composite score associate with a more positive and bearable pain profile? In answer to question one, thoughts of grief and continued pain from grief related to a higher pain intensity. The number of violent and traumatic events in life did not have an association with pain intensity, in response to question two. For question three, thinking more often about historical losses, especially loss of respect for elders and loss of culture, is associated with a higher pain intensity.

Those with more stressful life events do not rate their present pain as more intense or their health as poorer. This holds true for the most common stressful life events—physical abuse and verbal abuse. Those who think more often about historical losses for American Indians do rate their current pain as more intense than those who think less often about historical losses (Chi-square: 4.829, $p:0.028$), but self-rated health has no bearing on frequency of thinking about historical losses. The most thought about historical losses (loss of respect for elders and loss of culture) show a weak relationship with current pain intensity (respectively, Chi-Square: 3.3; $p:0.069$ and Chi-Square: 7.519; $p:0.006$). Those who feel that ‘even now I am in pain for what I lost’ have a higher current pain intensity (Chi-square: 8.087; $p:0.004$), but again self-rated health does not have an effect. Inability to accept the grief does not relate to either self-rated health or present pain intensity. Those who continue to have thoughts of grief do have a higher current pain intensity (Chi-Square: 5.293; $p:0.021$). Less significantly those with a persistent emotional response to grief also have higher current pain intensity (Chi-Square: 2.934; $p:0.087$). More significantly those with a persistent emotional response to grief rate their health as poorer (Chi-Square: 6.667; $p:0.01$).

In this paragraph I discuss other correlations of interest in building a profile of trauma, grief, and violence relating to chronic pain. For the complete correlation table, see Appendix F. Those who are younger are more likely

to have witnessed the death of a close family member or friend ($r: -0.355$; $p < 0.05$). They also have higher current pain intensity ($r: -0.359$; $p < 0.05$), higher worst pain intensity ($r: -0.385$, $p < 0.05$), higher emotional response to grief ($r: -0.316$; $p < 0.05$), and they think more often about the loss of family and friends due to early death ($r: -0.373$; $p < 0.05$). Women are more likely to have experienced sexual abuse ($r: 0.360$; $p < 0.05$), physical abuse ($r: 0.327$; $p < 0.05$), and verbal abuse ($r: 0.320$; $p < 0.05$). Those with more education are more likely to have felt helpless in a situation ($r: -0.413$; $p < 0.05$).

Those who have experienced one trauma are more likely to have experienced other traumas. For example those with a life-threatening illness are more likely to experience a gun threat, a helpless situation, sexual abuse, a dangerous situation, and the death of a close friend. Those who were sexually abused are more likely to have physical abuse, verbal abuse, and child abuse as well as feel helpless. In addition they are also more likely to think frequently about loss of self-respect, have difficulty accepting their grief, have a high emotional response to grief, and still feel in pain from grief. Those who were abused as children are more likely to think about loss of language, relocation, loss of self-respect, and loss of culture. Those who were verbally abused are more likely to have experienced physical, sexual, and child abuse too. They are also more likely to have been threatened with a weapon or felt threatened. In addition they think more frequently about every question on the historical loss scale ($r: 0.499$, $p < 0.01$). Finally they think more about grief and have a higher emotional response to grief. Therefore the more stressful life events experienced associates with more contemplation of historical loss and more grief in addition to a higher current pain intensity. Trauma, historical loss, and grief do shift the experience of pain in the moment and overall. In what follows, I will describe participants experience of chronic pain as it impacts on their identity, psychology, social world, and cultural—impacts that either precede or proceed from traumatic life experiences, historical loss, and grief.

4.2 Impact on Identity

Meghan O'Rourke in a 2015 *New Yorker* article 'What's Wrong with Me' writes, "The worst part of my fatigue, the one I couldn't explain to anyone—I

knew I'd seem crazy—was the loss of an intact sense of self....The chronically ill patient has to hold in mind two contradictory modes: insistence on the reality of her disease, and resistance to her own catastrophic fears.” Maynara provided her own interpretation for how the chronic pain can become the prime identity. “Sometimes that’s emotional too, because once your body heals the pain should go away. But a lot of people that becomes their identity. I had this car wreck and I got this back injury. I can’t work....In their head it does [hurt]. I don’t think it’s there. It’s in their head. That’s their identity.” The identities I am concerned with in this section are intersectional identities of race, gender, and illness experience. Thus in some ways, identity precedes the pain (race and gender), and yet the pain further transforms identity through the illness experience. Regarding the impact of chronic pain on identity, six themes emerged from the interview data: invisibility and secrecy, warrior identity, superwoman caretaker, mixed blood, future vision gone, and identity based endurance.

Invisibility and Secrecy When asked what invisibility and secrecy meant to the participants, I received the following responses. Invisibility and secrecy refers to subjects that are not discussed, because they are taboo or not ‘polite’. It also concerns things that go on that must be kept hidden for fear of shame. This includes unrecognized child abuse, rape, alcoholism, and spousal or partner abuse. An individual can be invisible or secret by keeping actions and beliefs hidden from others or manipulating things to appear different than they are. Even before the chronic pain diagnosis—a disabling illness without a visible disability—participants experienced the need for secrecy and invisibility. Carmen portrayed the invisibility of her identity. “Nobody ever told us we were Native American. Looking back, we see it was hidden. A lot of it due to discrimination.” Verbena frequently encountered other’s ignorance regarding her identity, which her family kept hidden. “We killed all the Indians, you can’t be Indian. Really? Somebody forgot to tell my family.” Verbena used humor as her weapon against the ignorance. Verbena also noted how she was more fair-skinned, less ‘native’ looking than her sister, which complicated others’ perceptions of her as a native woman.

Fern admitted how much of her life she did not and could not live the native life, because she had failed to ask questions of those in her family

with the passed-on wisdom. “I haven’t really been living the native life for very long. I always knew we were cause my grandmother would talk about it. But silly me, never ask enough questions, before she was already gone.” She also connected the hush hush in her family about being Native American with her quiet suffering due to restless legs syndrome (RLS).

Getting more into talking to people about it, because it’s kind of like one of those things that you don’t talk to people about unless people understand what you’re going to because they think she’s a little weird. There’s no way that can be true. And there’s so many doctors that feel the same way so you just don’t talk about it. It’s kind of like when my grandparents were growing up and not talking about being Native American. It wasn’t. It was something they kind of kept secret. I mean even on the census and stuff, they would put white because it would be held against them. They wouldn’t be able to hold land or own property or anything. So they didn’t talk about it. And it’s kind of the same way with the RLS. Because people just don’t get it. They just don’t get it.

Carmen and Fauna recounted the idea that pain itself can be invisible on bodies with a high pain tolerance. Carmen related, “I think as far as how it makes me feel, it would vary. I tend to have a high tolerance to pain, which is unfortunate because many times, I don’t feel things until they’re really bad.” Her high pain tolerance both enables increased coping and risks not perceiving an injury that needs to be addressed in a timely manner. Fauna told about her doctor’s perception of her pain tolerance, in a way silencing her own understanding but at the same time providing legitimacy to her strength. “I know my doctor says, ‘Well...you got a high threshold for pain.’” Neither woman associated a high pain tolerance with being American Indian and the stereotypes regarding native stoicism and toughness, though other participants did. In this way historical trauma silences, both through silenced native identity and silenced person with chronic pain identity. Healing, in contrast, gives voice.

Warrior to Survive I found that participants considered a warrior someone who stands her/his ground and abides by all laws, both the spiritual law and the law of the land. But a warrior also knows when to walk away, though not run away as a coward would. Those who are not warriors lose

themselves to society and have their morals and values compromised. When a warrior abides by both laws, she/he flourishes and maintains her/his moral fortitude. Embracing a warrior identity augmented many participants' existing strengths. Maynara shared what it means to be a warrior due to her chronic pain.

It's made me a strong person. I really do think that all this stuff has made me a very strong person. And no matter how much opposition and adversity, I can shove right through it. I can get focused. I'm like a warrior. I can shove 'em this way and shove 'em that way. And kick 'em aside. And plow right through them and get to the goal. I can. I can. It makes people crazy. Whatever you throw at me, I'm going to get around it. Oh that is sick.

Kelly said what many others also said, "It's strengthening to know that my family are warriors." She continued, referring to the Trail of Tears, "I think it makes me stronger. Because my ancestors. How far they walked. I mean really. You mean they made you walk all the way there and all the way up and all the way down." If Kelly's ancestors can walk all the way up and all the way down and endure the pain that arises, then Kelly can as well.

Cassia structures her sense of a self in a similar way to Kelly. She pulls from her identity as an American Indian to explain her own high pain tolerance. "I think that my nationality helps me be very strong about it. I don't show pain. I don't look like I'm in pain. I look strong, because I try to look strong. I don't want to be looking all bent over and pitiful like I can't, that I'm weak. So I put up a front that I'm...I try to stand as straight as I can and not to show my pain." Cassia later admits that society's stereotypes about American Indian stoicism and strength motivate her to not show pain. She wishes for a world where she could be strong or weak without judgment about the way her brown skin should cause her to react to pain. Because Cassia could not display a warrior image to the world she retreated into isolation.

Andrew, on the other hand, disconnected a bit from structuring his sense of self on ancestral actions. He imagined what his ancestors must have been like instead of embodying what his ancestors were like. "So like a broken arm or broken anything or stab wound or if they caught a virus, all those type of things, I imagine that were strong people...that they had strong immune systems. That their bodies were built for that like how animals are built

for the wild, you know how I mean.” His language suggests that while his ancestors were strong people, he is not as strong. Nevertheless he set up a comparison between his body and his ancestors’ bodies that allowed him to deal with his chronic pain so that it does not overwhelm him.

Edith characterized American Indian women, herself included, as stubborn. “I think it’s just stubbornness from you know. You’ll find a lot of Native American woman are stubborn. I can bear it.” Bailey suggested that the racism associated with having brown skin and being a native person fosters strength and stubbornness. “Like anybody with brown skin, you deal with that. But our folks were great. They said they are ignorant. They don’t know what they are talking about and it shouldn’t be affecting you. That’s no excuse. They were real strong in that.” Verbena described the silence required by her family so racism did not always wound them.

‘Cause see my grandma, my great-grandma, she was a full-blood and she grew up when a good...a dead Indian woman was worth twenty bucks. That’s what she would tell us. And when I was little, I even knew it when I was little we were native, and I was asked questions. She’d look at me and go honey you’d pass for white, just be white. And she’s look at my sister and go, I’m so sorry dear. ‘Cause she looks full blood. And she would look at her. I’m just sorry. You’re just going to have trouble your whole life you know. And that would hurt me even as a young child because I thought why. Why can’t we let people know we’re native?

Gus expounded upon the continual presence of racism that keeps American Indians prisoner on their land.

Our people on reservations are starving. And we aren’t. We don’t even have where it should be our government. And we ran our own lives like we’re supposed to be. And yet we’re still prisoners in our own country. That’s my opinion. Why are we still prisoners in our own country? They took away our land. They killed our people. But the Jews had a Holocaust going on almost constantly, crying about all the people that were killed. What about here? We were killed here.

For Gus, freedom and forgiveness would alleviate many social problems for American Indians.

The social problems that exist, in part, structure why Roscoe claimed that American Indian men, in particular, experience more pain. Roscoe also argued that physiologically American Indian men embody pain differently.

And one thing is I, with Indian men, I think we deal with a lot more pain. Indians period. I raised a grandson. He's been cracked in the nose. He's done all these things where you think the kid must be carrying on, and he doesn't even cry a lot or nothing. And I've never told him men don't cry and things like that. I just think something is in us that we tolerate a little more pain. And a lot of things I think in our body is different, because even. I've got friends who are paramedics and things and they say they pick up people diabetic that a normal person, white black whatever, would be in a coma already whereas a native. They're just so high but they are still moving around. So I think a lot of times, I'm just thinking there's something in our bodies that kind of balances out on that stuff. I mean.

One of the few who directly countered a racial connection to pain, Strider asserted, "I mean I'm Native American. I guess it's my race, but it's not who I am. Everybody is different." Therefore being a warrior or being a native person never fully structures who a person is. In Chapter Five, I discuss in more detail the ways that a warrior identity coupled with ancestral and ceremonial strength foster a survival mindset when confronted with pain that is not going away.

Superwoman Caretaker The woman participants that I spoke with characterized themselves as superwomen or women warriors. Being a superwoman or woman warrior is so central to Keira's conceptualization of her pain that she drew the woman warrior as her image of pain (Figure 4.1). The woman warrior in pain, that Keira drew, wears a pink clown collar—a color of happiness for the childhood she never had. She screams, her mouth black as a bottomless hole with her pain rising up from those depths. Nothing lives in her eyes except emptiness. She wears a single eagle feather for strengthening. Throughout our interview, Keira continued to darken the eyes and mouth of the woman warrior in pain. She commented, "Those don't get dark enough. The eyes they don't get dark enough inside. Little tiny holes I get to breathe through." "Ogitchidaakwe in our language means woman warrior," Keira explained, "And even though I've never been in the military service,



Figure 4.1: Ogitchidaakwe or Woman Warrior

I was given the title Ogitchidaakwe by a four level lodge woman, medicine woman....I would say I can't call myself that. But other people can say I am a strong woman after that cancer journey. But I was given that title so now I can introduce myself Ogitchidaakwe." Keira embraces her warrior woman identity after being given the name in a proper way. Yet, within herself, in the worst moments of suffering, Keira doubts her own ability to fight, to protect, and to overcome. In those moments, she justifies to herself, "They say the ones who are...the healers, not that I'm a medicine person, that's not what I mean. But spiritual. I'm a warrior. Are the ones who suffer the most. I don't get it, but it's true. Our medicine man for our tribe, who walks with his hands drawn and two canes."

In the context of pain tolerance, Peony supported the idea of women suffering more and therefore having greater tenacity regarding the pain. "I always have believed that women in general have a higher tolerance for pain than men do. Why we just have a higher level for pain tolerance? I don't know if it's just something that we are born with, being Native American, we're always tougher anyway. We're tough old birds. Don't know if that makes a huge difference or not." Rosaline agreed that being a native woman

really does make her tougher on a DNA level. “And I think most women are better than men, at ignoring pain. It’s just something that’s instilled in our DNA, really.” Abby took the discussion further, noting a personal feeling of responsibility and societal expectations for women as reasons for women enacting the superwoman.

I think we’re kind of expected, a lot of times to be tougher than what it is. You know my mom’s always telling me you don’t have much choice. You still have to take care of your kids and still get things done. I think there’s kind of an expectation that we’re going to handle it and keep going. And maybe it’s kind of a sign of weakness to acknowledge that it’s happening. So umm I’m not sure if that comes out of being native or just the family culture that I had. I think there’s that native women are expected to carry on quite a bit. Responsible for the family and the home.

Carrying the responsibility contributes to the pain instead of alleviating the pain. Though the woman warrior identity often precedes the pain, it also amplifies the pain.

With the expectation of toughness, responsibility, and protection central to their identity, Keira and Carmen experienced frustration when the pain overcame their ability to control it. Keira related, “As a strong female you know, it’s like control everything else, but I can’t control this stupid shoulder. Come on, give me a break. That’s frustrating too. The control factor.” Her shoulder acts as if separate from the rest of her body over which she has control. For Carmen, a hernia degraded her ego. “I think it also—the hernia for me also is—took a shot to my female—‘cause my ego, being an independent woman. Because part of what—I have a day job, but I’m also a singer and a band leader.” For Keira and Carmen, the amplification of pain came from their inability to maintain their tough, in-control, and independent identity.

Alma explained her own understanding of being a woman warrior as being a protector and caregiver.

Being a native woman, we are raised to be the providers and the caregivers. You know we live in matriarchal societies [Matriarchy is not in every American Indian tribe. Alma is Menominee.] so to me being well is important to the rest of my family, because somebody’s got to take care of them....I’ll be more concerned what’s going on with my boyfriend’s body than mine....I’m always like we

need to have positive vibes and positive energy, because positive energy makes you feel good, and I think that all comes from that native side wanting to be more natural about everything....The [native] women we cook for a hundred every night so I'm always trying to feed everybody good stuff. And make good recipes and send them out. And I just want to take care of you. You got to eat this to make you feel better this way.

Her body comes second, after she cares for the wellness of her loved ones. Alma eats after she prepares food for everyone else. She suggests to others how to care for themselves before she takes time and provides her body with the care it needs.

In order to maintain their ability to perform their sense of self, Native women come together for support. Cheryl described her social support.

And you know being part of the Women's Warrior Society. And having something to do with these other females who have dealt with the same thing I have dealt with. Not only military service, but you know, there's just so many abused native women out there. It's crazy. And having that group to kind of bounce off of when it gets bad, you know. And going to the different ceremonies and all helps a lot to. Because you can kind of shut everything else off.

In the sharing of experience, the sampled experience becomes less noxious to the individual body. Thus, through a shared identity of being Native women with chronic pain, the participants support each other and others like them in their families and communities.

Mixed Blood or Compromised Identity Because I interviewed American Indians who do not live on reservations, the participants all dealt with having their identity tested frequently. As I demonstrated in the invisibility section, participants and their families often passing as white for protection against ignorance. But for those, like Jason, who identify as more full-blood, having non-natives playing Indian was also contentious. Jason talked of his experience passing out literature on American Indians at powwows. "People come in there who have ancestors who are native, but they don't know anything. That's what I try to avoid. I want when my grandchildren to grow up not only can they be proud to say but I am native. I may not be full blood but I am native, and I do know traditional ways because it was taught to

me by my elder.” Though members of their family might reject their native identity, all participants I talked with embraced their indigeneity with pride. Cheryl described how her geographical context fostered a propensity to claim part Cherokee heritage, usually through a grandmother.

An Indiana weird thing. Really weird. And if I hear one more time, cause I do all this education and travel to all these events, you know, I’m a big powwow person. Not only do I do powwows, I do educational events and things like that. Love it. Kids are fantastic. They have the most intelligent and wonderful questions ever. You get the adults in there and my shoulders look like oh ahh. And it’s oh well my spirit animal is blah and my native name is blah and my great great somebody, I don’t know who it was, was part Cherokee. Part Cherokee, part Cherokee, part Cherokee. It’s all we hear, here in Indiana.

She confronted the ignorance, primarily through teaching children, who do not receive school-based education on the first occupants of the land they live on.

For some participants, like Luke, they found out they had native heritage later in life.

At that time I didn’t know that I had Native American heritage, because my dad hadn’t suffered his first heart attack and it wasn’t until after he had his second heart attack and his bypass surgery that he was kind of recovering from prostate cancer, you know, spending time with him because he was on the clock...maybe seven months to live that he told me about my heritage. So that is where it all kinda all started so then I got diagnosed with diabetes at age 40. Umm and at that time I knew my heritage and my background so that’s when things just started happening.

The conversation on heritage arose in a larger conversation about genetics and inherited disease for Luke and his father. The participants who learned about their heritage later in life realized what they have missed and grieve that loss, while those who were raised with their native identity compromise to live in this world like Jason explained.

So therefore I’m even compromising because I’m married, and I have to work in the white man’s world. I have to live this life to sustain, but at the same time that doesn’t bring happiness to my spirituality or myself with the Creator....I want to be more

spiritual. I want to be more like my grandfather was but due to modern time, I have to you know uh kind of just uh bite the bullet on some things and compromise and make the best of both worlds.

Whether mixed or full blood, being a native person in the spaces where I interviewed people, meant negotiating identity. Finally, Azure described what it means to be mixed blood. “And my experience personally being as removed as I am. Not urban and not white. And being a kind of walk between there.”

Future Vision Gone While the previous sections in impact on identity concern components of identity established well before the pain, these last two sections regard pain’s unmistakable damage to identity that requires endurance to heal. For Philip, Luke, and Abby, the realization that the pain will remain in their body and in their life for the rest of their life diminishes their dreams for the future. Before the pain, the future might have included workplace success and physical prowess. After the pain, the future may only include sufficient pain relief to have more good days than bad days. Abby described what occurs using the metaphor of a chalkboard.

So you have this vision of your future ahead of you and then when I got sick and I realized there were things that were taken from me. So the life that I had pictured for myself was no more. It’s like somebody came in. I had my future all mapped out on a chalkboard and they just erased all of it. And it was like I had to start all over and it was a different life. And it was a different me. So when that happened, I think I really had to mourn that loss.

Philip characterized the loss he mourns as hidden on days without pain but back with a vengeance on days with pain.

And I have a hard time sleeping sometimes because of it, because the anxiety of what if this is my last day, do I waste this day? So that’s a fear I kind of have. Did I do that person right? Was I best the father, brother, uncle? Did I? If this was my last day type of thinking. Every once in awhile I’ll have a couple of good days together and I’ll start thinking about the future. Then the pain brings it back to reality.

Luke mourned the loss of his body image. “And I think just your concept of yourself, which is tough, you know. I still kind of consider myself a young attitude of mindset type of person, you know. I’m pretty outgoing, I’m pretty energetic, pretty excited about life but yet, you know, body image turning from being an athlete slim and trim and turning into a pear, you know. That’s hard.” Loss of body image, loss of self-perception as able-bodied, loss of parenting, loss of career advancement, loss of athleticism, loss of a former self, all these losses may and do arise when a pain sufferer realizes their pain will not dissipate completely from their bodies. And when hopelessly confronted with overwhelming loss, Gus reminded himself that “I may be old, but I can still fight.”

Identity Based Endurance Identity and strength interact at every level in the way participants conceptualize who they are before pain, who they are with pain, and how they become someone better through the pain. Morgan argued that her empathy increased from her own struggles with pain.

And maybe the way I am has turned me into the type of person that I need to be and not who I could have been without the pain. So I think it helps with compassion. I think it helps with empathy. I am very empathetic. You know I feel bad for people going through things similar to me or anything real bad. It doesn’t have to be an ailment. I think having this creates a better understanding that you’re not always so self-induced. Maybe me having this ailment has allowed me to do the things that I’ve done and maybe that’s helped other people in their life or so I’d like to think. Whereas maybe I’d be a different person if I didn’t have the pain.

Shanta characterized maintaining who she is despite the pain as a matter of life and death.

I believe that it is something you just endure. You just go through it. You just move on. You don’t give up over one little thing. Otherwise, you just lay right down and die, and people would walk on you and forget about you. You’re not even there. You have to keep on going and keep doing what you do, the way you can do it. You find different ways of defining what you can do and defining yourself and your own capabilities as you age. Redefine your abilities. You don’t consider your disabilities so much, because if you did—there again you’re gonna get depressed, soon you’re gonna think, ‘Oh, poor old me.’

Shanta gave attention to her strengths and found innovative ways to overcome her weaknesses.

In conclusion, pain's impact on identity both precedes and follows the pain itself. Just as my participants' native identities have been ignored both within their families and within their communities, so also is their status as a chronic pain sufferer ignored. They appear white, they must be white. They appear healthy, they must be without pain. So in both situations of racial identification and illness identification, participants must compromise their identity. Recalling how native peoples in general and specifically women have dealt with the micro and macro insults of colonization provides participants with strength to compromise and mourn the losses associated with the decisions from the compromises.

4.3 Psychological Impact

Pain reminds of humanity, of corporality, and of the mundane. In this section on the psychological impact of pain, I begin by talking about the negative psychological impact of pain. According to my participants, pain in the body leaves one psychologically broken in the mind. As a result, the person suffering with pain avoids interactions or forces themselves into numbness in order to deal with interactions. The continual assaults from pain and its side effects maintain the brokenness, causing frustration. In order to find psychological peace, my participants steer clear of negativity and strive for realness instead of holding back, bottling up, and re-fracturing the brokenness every day.

Psychologically Broken Azure defined psychological brokenness as being like a broken toy. The broken toy cannot function. The feeling of being broken occurs both psychologically and physically, according to Azure. It is a feeling of not being whole, not being complete, being damaged, being wrong, or being incorrect in some essential way. Azure, Cheryl, and Verbena are three women who have been in pain for much of their adult lives. The experiential wisdom of many years with illness allows them to face their pain with courage. Yet they all noted moments in their pain story where their psyches broke and remained broken until after intensive healing. For

Azure this moment occurred early on before her diagnosis with lupus, when she was working fast food to make money that allowed her to maintain her relationship with an abusive boyfriend. “By then I was kind of psychologically broken by what I was going through. I was going to work and coming home and taking about six Advil chased by a couple shots of booze just to cope, fighting taking pain meds, because I didn’t want a mask, you know. I wanted to know what was wrong with me.” Feeling less broken, for Azure, came when she received a diagnosis of lupus. At least she could call her pain something that others would recognize.

Neither Cheryl nor Verbena received a diagnosis for their pain. Both mourn the loss of what they could do before the undiagnosed pain. Verbena related,

In the beginning it was going to do something I had always done and realizing I couldn’t do it. I tried to commit suicide a couple times just because I thought what kind of life is this?! I’ve always been an active person. I used to rollerskate. I danced at the powwow. I danced anyway. That was always a big part of my life. I used to run, swim. I mean I was always a very active person. I grew up in the country and worked with cattle and stuff. And then all of a sudden.

A once active toy, with the pain Verbena was broken. No one wants to play with a broken toy so they are usually discarded, added to the heaps of plastic slowly breaking down in landfills. As Verbena said, sometimes the toy itself discards itself through suicide. A handful of other participants (Cassia, Kelly, and Azure) also contemplated and attempted suicide, like Verbena, early on in their pain experiences. As they became better equipped to cope with the pain, their suicidal ideations decreased. Cheryl observed how her ways of dealing with her pain kept her from doing the things that keep her psychologically whole. “Yeah I deal with and it stops me from doing what I love to do. When it does, then your mind kinda cycles as to not wanting to live anymore.” Both Cheryl and Verbena (and Cassia, Kelly, and Azure) wonder if no life is better than a non-functioning life.

Cheryl and Verbena also mourned how the pain changed their mind. Cheryl described:

Because constant pain it works on your mind. It can make you irritable and it can make you snappy. And you know sometimes you forget and you might snap at one of your family members or

something like that. And so. For me the biggest thing is it makes me feel old. It makes me feel like an old person. And I'm not quite used to that, because they didn't teach us anything about how you handle aging. I don't think we do that in our society.

Likewise Verbena went through anger management classes just to deal with the pain-aggravated mood changes. She says, "I mean it really made me aggressive, because the pain was so intense." Thus the pain makes them feel as if their mind is uncontrollable.

Avoidance and Numbness For most participants, the bad days with pain involved taking an analgesic and retreating from the world. The absolute worst pain seemed easier to deal with alone, sleeping, or trying any method of mentally traveling away from the body in pain. Bailey depicted the psychological and physical irritation of pain.

I think it's like irritating so. I can't think of any drawings for it. But it is irritating. And then if I'm not feeling well, I'd just rather not be around people. What do you call that when you don't want to be around anybody? Just rather be alone....It's not sadness. It kind of drains your happiness. It's kind of like trying not to feel anything. I'd say it's like irritating, can't concentrate and I'd rather be alone so you're just kind of going through the motions and getting the work done, not really outreaching to anyone.

The overwhelming experience of not reaching out has lead Kelly, Maynara, and Shanta to push themselves to reach out despite the urge to retreat inward to a place of numbness. Kelly reassured herself that strength comes in reaching out, even if you ask for help completely numb and not entirely able to accept the response. "I just want to be able to give somebody else some hope that if you want it bad enough, you reach your hand out, and if you ask for help, that means you have strength not that you are weak." Shanta saw herself as an advocate for others despite her desire to maintain pain's silent hold on her. "Sometimes I feel I can feel everything around me crying [pause], waiting for me to open my mouth and say the right thing to make people listen." Maynara compared herself to those who use drugs of any sort to avoid life and foster numbness in mind and body.

I see people and I'm like that has got to be one miserable ass experience in life. How can you live a life where you have no

happiness? All you want is pity. That's got to be miserable. I feel sorry for them. Not sorry enough to go buy drugs and give 'em to 'em. But I feel sorry for them.

Though every participant conveyed moments like Bailey where the pain's psychological and physical irritation kept them from doing something, they also all portrayed remarkable resilience—a resilience of mind over matter. Iggy defined how she puts mind over matter to use in her life. “It's like mind over matter for me cause I know I have to do something and I don't want to go out and I don't want to do it, but I have to force myself to go out and do it. And I'm not happy when I have to do that. It doesn't make my life easy. But who else is going to do it. I only have me!” Therefore while avoidance of interactions and retreats into numbness tempt participants in this research, most participants push themselves through the temptation in order to maintain social interactions and escape the pain in other ways.

Continual Assaults In one moment of pain, participants may succeed at thwarting the temptation to be numb, but the pain continues to hurt physically and psychologically, and the outside world continues to deny the existence of the participants' pain and therefore deny compassion. The continual assaults include hearing that you are a lesser person all the time and knowing the pain will not let up. The consequence is that it is hard to feel whole and accepted. Verbena conveyed the continual assaults metaphorically. “I tell people all the time, you're on my last nerve ending. And I've only got a half of one so get off of it.” Like many participants, Andrew and Philip feared the consequences of continual assaults. Andrew realized he will have his pain everyday without a hope of miracle cure.

So yeah that is scary for me, you know, to have to be in pain everyday. That there's nothing you can do. There's no pill you can take. There's no amount of morphine that they shoot you up with. That you're going to have to live with that pain for the rest of your life. That is a scary thought. Yeah that's what scares me about my pain.

Philip depicted more of the psychological consequences of the fear that pain will continue. “I guess you try to keep upbeat but I'm always bothered....I can be irritable easy and sometimes it's mood swings, because the pain it's just constant. If I don't keep an upbeat, I just lay in bed. You know it

would keep me down.” Some days Philip succumbed to the pain keeping him down. Other days he fought. Cassia experienced one consequence of pain’s continual assaults; she was fired from her job after a work-related injury left her in chronic pain. Her employer was not willing to provide a desk job for her. “I started crying when he said you couldn’t work no more....You felt like you were just thrown out.” The feeling of being thrown out leads participants, like in the last section, to retreat into themselves.

Frustration Another result of the continual assaults from pain on mind and body is frustration. The frustration often results from an inability to predict the future. Especially frustrating for participants is when bad days sneak up when they least expect it. Likewise frustrating is to see other people give in to pain and abuse. Abby expressed in detail how physical pain arouses emotional pain, requiring her to confront the pain both emotionally and physically.

I think when I’m really hurting or I feel like I didn’t get something done, because I got too tired then I kind of get discouraged and so I feel like I kind of give into those emotions that add to the pain. So if I can kind of change direction on my thinking that it’ll help me to umm just live better in spite of the pain. Once I start feeling better, the pain doesn’t seem as bad. It kind of. I always feel like it puts it in its place. You’re not going to rule me today. In spite of you, I can still have a good day.

Despite her frustration, Abby maintained the hope that she can experience more good days than bad days. Cassia defined a good day and a bad day. “Well a good day is when you’re in a good mood, because your pain ain’t so bad. And bad weather is usually a bad day with the weather. And if you’re in pain, the outlook is not good. You’re grumpy. You don’t like nothing. Everything bothers you. Good day I would say is when you can get up and do your daily things.” The bad days that come out of nowhere cause the greatest frustration for participants.

The frustration from pain becomes particularly detrimental in the context of relationships. Alma talked how fights between her boyfriend and herself increase when they are both in pain. “We have no reason to argue. Yet we find when we’re not feeling well and the pain, we do. That’s like. And that causes emotional pains.” In this way the pain has emotional consequences.

Willow discussed how her husband and she deal with bad days with pain—avoidance. “It made me not be a good person to be around, especially when it’s really bothering. I hang by myself and angry at my husband for something that’s not. Well I know I shouldn’t. But he knows. He goes away, cause he knows it’s my knee.” I interviewed both Alma and her boyfriend, and Willow and her husband, and both couples confirmed the physical to emotional pain transfer that occurred in their relationships. Morgan, in her close work relationships, has come to a mutual understanding that enables forgiveness for emotional outbursts due to pain. “They kinda understand, you know, if I was snappy, it wasn’t because they did something wrong; it was because I was in pain.”

Despite the frustration, participants constantly remind themselves the way Bailey does: “I’m not as bad as some people.” Morgan also counteracted her frustration by counting her blessings and maintaining her hope that the pain isn’t worse.

As I’ve gotten older I realize that there a lot of people out there that can do less than me. That aren’t able to do certain things due to being confined to a wheelchair, confined to their home. There are a lot of other people that in worst conditions than I am. I think that helps get through a lot of it, you know cause knock on wood. Things could always be worse.

Such an outlook represents one aspect of non-negativity that participants needed to psychologically cope with the pain.

Non-negativity The above sections detail some of the negative psychological effects from pain. Now I shift to talking about dealing with the pain in a psychologically positive way. The pain itself will not produce a positive psychological impact, but working through the pain can enable psychological peace. Not being negative is a primary tool participants used for engaging positively with the pain. Carmen separated her pain with a negative psychological impact from her pain that affected her less psychologically. “I’d wince when I first get out of my chair, but it doesn’t make me angry. This kind of pain—it doesn’t make—it doesn’t get me down. I think the torn meniscus affected me a little more, emotionally.” Carmen described her process of shutting out negativity in order to maintain her functioning.

It's almost like a—I just could feel it—when you go through some horrific times, there's a strength that just comes from I don't know where. None of it hit horrific times, either, but in things—I produced a few things, charity shows and stuff for charity or this or that. It takes that same kind of leadership, in a sense, that you have. You have to close out all the negativity, all the what-ifs, all the doubts. You have to just keep going so that everything happens.

Just as Iggy employed mind over matter to confront pain's irritation, Terry used mind over matter to guard himself against the negativity. "Just put it out of my mind somehow. I'll think of something else. Keep my mind occupied on doing something." The mind occupied on something else lessened how much pain overwhelmed Terry.

Psychological Peace Psychological peace transpires in the moments when participants do not feel mentally and emotionally attacked by others or their pain. Stress management may produce psychological peace. Stress management and the resultant psychological peace also compels the feeling that one can cope with what's happening. Iggy argued that selflessness, humility, and a positive attitude despite the pain will render the pain more bearable. "I think everyone should have a positive attitude in life, you know what I mean. You have a negative attitude, it's not going to make things any better. A positive attitude, at least you're happy and you're not thinking about pain. You know, maybe try to help somebody else." If a positive attitude alone did not lead to psychological peace, then participants practiced a stress management technique. Alma fostered psychological peace through cooking. "Because honestly going in the kitchen and cooking even when I feel like crap makes me feel better. Makes me feel better like emotionally, mentally, spiritually and those things boost. They help when you're in physical pain. If your mind is in a good place your body feels better." Verbena generated her psychological peace through humor. "And you've got to find the humor in it. You've got to. Cause otherwise it will beat you down. Just beat you down. So those are some of the nasty lessons. But you got to find your inner core and your inner peace. Then the rest of it just kind of. Breathe. Breathe. That's where the meditation came in." The alternative to humor for Verbena was pain beating her to death. "If you don't find the humor in the emotional crap, 'cause life is always going to throw something

at you. Bills, bosses, people, jerks, you know. Life is going to throw something at you. Don't take it personal." Both cooking and humor serve as stress management techniques. Ultimately psychological peace comes with the acceptance of pain as a consciousness in one's life. Bailey asserted, "I just kind of live with it. I live with it. I just learn to live with it." Pain is present. Be strong. Possess peace.

Becoming Real Though I asked many participants if they perceived any benefit from their chronic pain, only one participant described how pain actually produced emotional maturity and peace in him. Roscoe related:

I think a lot of any of the losses, the pains with my kids, the different things, I think a lot has just made me stronger. You know not like. For a long time it was the kind of thing that a stronger thing around my heart where I never felt. Cause I didn't until I sobered up. And then after that I didn't even know how to deal with emotions. I told them I said, 'Man, I don't what's going on. I feel all these.' They're like: 'Man, dude, you're becoming real.'

Pain made Roscoe real. When previously he gave in to brokenness, avoidance, numbness, frustration, and negativity, Roscoe, through pain, developed a deeper understanding of emotions themselves and his own responses to them. Strider also argued that knowing pain meant he could know love, because love and pain are the two most compelling human emotions. For Maynara, the experience of pain included the reminder that she was alive. "But you know you're alive. As long as you got pain, you're still alive. That's one thing, I'm not afraid. I'm not afraid to die, because I won't be hurting anymore. I don't know what's over there, but I know it will be a good thing." Pain wreaks psychological havoc, destroying perseverance, changing moods, and severing relationships. Yet psychological peace may arise despite the pain if one acknowledges pain as life-sustaining like Roscoe, Strider, and Maynara.

4.4 Social Impact

In this section, I provide examples of the social impact from chronic pain, focusing on the relationship between failures of the body—the pain itself—and

failures in the participants' social worlds. I describe first what the participants portray as a hopeless vision of pain and then what they portray as a space of peace, endurance, and home. In relationship to others, the pain is often ignored or addressed in a way that the participants cannot control. For them this leads to feelings of losing freedom, being a prisoner, and loneliness. Those with pain caught in an abuse cycle eventually will not take the abuse anymore. Pain also aggravates existing financial burdens. Despite these negative social impacts from the chronic pain, participants remember their children and grandchildren, taking measures to ensure they do not suffer. Finally, participants seek a place that feels like home where the negative social impacts cannot infiltrate.

Pain Ignored Within most relationships, participants find their pain ignored. The healthcare provider they see about the pain and I, as the interviewer asking about their pain, likely receive the most information about their pain. Others they encounter may perceive the disability from pain as something fake, causing the participants to feel the constant need to defend themselves. Others might not care enough to ask about the challenges of chronic pain. A rare few do care to know the story of one's pain. Azure recognized that some care and some do not. Nevertheless she tended to keep quiet about her pain. "So the story of actually living with chronic pain, some people want to hear it, some people don't. You know. I have a friend who's what's wrong with you today? It's oh, but the lupus will attack various things and it'll be something different so I've learned that I can't talk to that friend about my illness at all." Philip's family ignored his pain. As one of the younger family members, he is supposed to be healthy. Therefore his pain disappoints his family, who trusted in him to out-live them.

I'm not quite sure, but it makes you question God...if that's what you're asking. When I was in the hospital to be as young as I am for these to happen and continue to happen, it makes you question. It makes you wonder why things happen. Why things are the way they are. Friendships. Cause I was in there by myself. I come from a big family, but I was in there by myself. And a lot of them didn't believe, because I'm one of the younger ones of my family. They didn't want to believe. They still don't believe that I could be as hurt as I am.

Like for Philip, disbelief undergirds much of the pain ignored.

The theme pain ignored encompasses not only reactions like Philip received from his family and Azure received from her friends, but also the reluctance of those in pain to talk about their pain due to how they perceive the reactions. Shanta, Cora, Strider, and Barrett rarely talked about their pain with other people. Shanta would enter a conversation about pain only to provide others sympathy for their pain. “This is not something I usually talk about even. Usually I don’t talk about it unless somebody else is saying it, and then I just talk about it to sympathize with them.” Cora, in general, would not share her personal problems with others and talking about her pain fell under her *modus operandi* of silence. “But I don’t really like telling people my personal problems. So it was kind of difficult for me.” Strider thought that talking about something, especially pain, had no benefit for his pain so he kept quiet. “I don’t care to spend time talking about pointless things. Like if I hurt my ankle, I don’t see a point in sitting with my friend and talking about how my ankle hurts. It’s not going to change anything. It’s not going to make the ankle pain go away.” Barrett finds it difficult to trust that others will not judge him inappropriately due to his pain so he also rarely shares his personal problems.

I’m a little leery about telling people too much, because people have a tendency to misread and misjudge everything. They think they know you and they don’t know you. Or they take what stuff you said and take off with it. So I really don’t say much to a whole lot of people about anything anymore.

To counter pain ignored, participants like Abby educated those who needed to know about her limitations.

And now you know there’s people when they are aware of it, they think of it when I can’t get things done. There’s people here in the church that know I sometimes can’t get it done, because of it. But people aren’t always that understanding, because if you look like you’re healthy, you know, then they don’t think you are sick or anything’s wrong...I try to educate people about it. But I don’t know how you teach them understanding. You know that part of it is just...something they have to learn.

Very few participants behave like Andrew, talking about their pain regardless of the situation. “I’m constantly complaining about it, of course. It hurts. It hurts to be me. Yeah. I just, I try not to vent too much to other people.

Some people they get sick of it, they're like ahh I don't want to hear about it. We already know you're an old man. So yeah I do talk about it." The reaction to his venting that Andrew described is another reason why most other participants remain quiet about their pain.

No Control The reluctance of participants to share pain with others stems in part from their inability to control actions by others with respect to their pain. Cora depicted how even her close-knit family would react poorly to her pain, because the pain disrupted their striving to be a big happy family.

Other than that, my aunt, my mom's sisters and brothers, we hardly talk because we live in the city and everybody works and stuff like that. So the only time we do get together is around birthday parties and that. And then we try to be one big happy family like how the general society is, but it doesn't always happen like that. But we don't bring up the issues and stuff.

To prevent reactions that Cora cannot control, she does not bring up her pain.

Despite having little control over others' reactions, participants find many ways to foster a supportive environment around them. In this way the theme of no control regarding the social impact of pain also includes the theme of little ways to control. Azure described her eclectic support system that improved when she freed herself from an abusive relationship. "It's really kind of an eclectic mix of people as a support system around me. I have a therapist. I have a psychiatrist. I have a team of doctors. It's taken me a few years, but I am finally at a place now where I feel like I have a good support system. Up until basically my partner left, I did not have that. He kept me very isolated." Kelly related how many people do understand and support her. "My mom. I have a ton of friends. My neighbors. And I have lupus too. And one of my neighbors has lupus. So there's people who understand. I have a lot of support." Andrew, too, in his workplace knew many others with pain so they could all sympathize. "Everybody's got pain. I know that every guy I work with, they all got their own pains and they ain't got time to hear about yours. So you leave that at the door too, kind of."

For those, like Verbena, less successful at stumbling upon or creating a strong support system, intentional choices need to be made about healthy

relationships and negative relationships, eliminating the negative. Verbena illustrated, “I narrowed down the people I was around, where I went, things like that. I had to really simplify my life until I could really get a grip on all that.” Verbena brought up another point of no control—her own inability to control how her body will react to the pain. Therefore no control refers to how those in pain cannot control how others will react to them, how those in pain cannot control how their own body will react to their pain, and how those in pain buffer the reactions of others with a good support system—an element of control.

Losing Freedom, Prisoner, and Loneliness The loss of freedom, feeling prisoner in one’s body, and the resultant loneliness accompany chronic pain for many participants. They describe this social isolation as being reclusive, disconnecting from family, and isolating from the world. They feel like nobody really understands their pain so why bother. Or when someone does ask for their story, they construe the curiosity as the other person wanting to be reminded how lucky they are to not have pain. Days with the highest pain level aggravate freedom-loss, feeling prisoner, and being lonely. The participants rarely chose these isolating feelings; rather, they come as an unavoidable side effect. Kelly would love to work. “Oh my gosh, I miss work so bad. I mean I do. I had started working when I was 14. And it’s just something that I love to do.” Cheryl continues to work despite her pain, but that reduces her quality of life, because she is in survival mode.

Well when you’re a single mother of three, you don’t have a whole lot of time to worry about. It’s just a matter of surviving the day, trying to get some rest and surviving the day. And some of the worse times were when I knew something was wrong, and I couldn’t get any help. And ummm you know in the beginning of my career, it was totally computer work. So I’d have ten twelve hours a day in one position that was doing nothing but aggravating it. Go home, try to get out of the pain cycle and then come back to it the next day. And I lived like that for years.

Her pain cycle keeps her prisoner.

The thought of being alone scared Fauna and Dorothy more than the pain. Fauna noted, “I think the pain don’t scare me as much as the thought of if he [her brother whom she lives with] passes before me. I don’t like this idea of being alone. I’ve always been with people.” Dorothy told of an event that

made her realize how much she needs to live with someone else. “So I went across the street to say, I was choking and I didn’t want to be in the house by myself. But to be by myself. But I don’t mind being alone in the house. But if I die, I don’t want to be by myself if I can help it.” For Cassia, in contrast, being alone is the only way she deals with pain. She rarely sees her children and grandchildren, because the pain is too great to deal with interactions, even positive ones. “It used to hurt but now I’m in so much pain that I don’t want to see anybody.” Cora, on the other hand, looks at her children in order to motivate her to keep on. “I guess just looking at my children and knowing that I have some things that I need to take care of, whereas I can’t think of me being in pain. I know that they’ll need me so I have to do something to get rid of it. I think of my children as a healing source also for some reason.” Her children caused her freedom to be lost in a sense, but they are also her healing sources.

Philip and Verbena both encountered the unwillingness of their friends and family to continue support after their chronic pain diagnoses disabled them. Verbena, with tears dripping down her cheeks, recounted, “You think you have friends and then your friends ain’t even there. I think that was the hardest part. The money you can deal with. Eventually you’ll figure it out. But to not be able to do the things that you enjoy doing. To not have people understand. To have people looking at you like you’re nuts. That kind of stuff. It was hard. I’m sorry. I still get emotional over it.” The isolation comes both from friends leaving and from her own body denying her the ability to do things she loves, like rollerskating. Philip described how nothing is the same now that he is sick and in pain daily. “I guess it devastated everything. It tore down everything. I mean four years ago I was someone. I was brown. I thought I had a lot of friends and family. Four years later, I’m sitting here with my kids still, but everybody else is gone. Everything else has changed.” Chronic pain infiltrates into every aspect of a person’s life.

Despite loneliness in the hear and now, some participants find comfort in their connection to the land and ancestors. Shanta pictured everything and everyone that looks out for her.

Usually I can do something. It would be a rare incident if I couldn’t do something. Then I might freak out, but that hasn’t happened, thank God. That has not happened. I believe possibly

the reason why that hasn't happened is because of my ancestors, and the people that have gone on before. My herbs. My trees look out after me too.

Abuse Cycle When I returned her interview transcript with the theme 'abuse cycle' listed as central to her interview, one participant responded, "That's a biggie". She went on to describe how she got used to being abused. An encounter with a new abuser became normal. An encounter with someone who was not abusing her felt abnormal. Iggy spent most of her childhood transferred between foster homes, removed from her family. She ran away from the foster homes as a teenager and began living on the streets with the wrong crowd. "What was I doing all that for during these years?" questioned Iggy. She then answered her question: "Because of being taken away and the life, not having a family structure and all that. It didn't make you crazy or what. Trying to be different. I didn't try to make sense of it. I just know the kind of life that I really wanted." It took years of not having the kind of life she wanted, because she was stuck in an abuse cycle and fighting however she could, even ineffectively, before Iggy broke the abuse cycle. Maynara's abuse cycle began in her childhood as well.

I would still have some arthritis stuff, but I was so used to dealing with it, because when I was a little kid and I had these problems with my knees and my father wasn't around, my mother say, she'd slap me and say I'll give you something to cry about. So I learned to choke it down. So when I was a teenager, I just didn't say anything. I just choked it down.

She learned a non-confrontational silence as a result of her abuse. Her abuse cycle continued through multiple marriages and relationships. Now Maynara even posts on Facebook when she succeeds at eliminating an unhealthy relationship from her life. She wants to teach others that you can escape.

Not Taking It Anymore Though there is no escape from the chronic pain, eventually the participants who were abused refused to take any more abuse. Shanta, Kelly, and Verbena all related how free they are, having escaped an abuse cycle. Kelly argued that pain does not stop her. In short, she will not take the pain just as she did not take the abuse from her husband. "I've always been in pain. It's just always been a part of my life. I never

thought of having life any differently, if that makes any sense. Cause I never let it stop me.” Shanta depicted how her isolation enables her to heal. “I live alone now. I like it too because I can heal. If I have to sleep, I can sleep. I like my school. I like going to an online school where I don’t have to get up and go to class if I don’t feel good.” Verbena expressed her surprise when someone showed compassion instead of ignoring her pain and isolating her further.

So that was kind of hopeful if that’s a good way to put it. When somebody actually shows that compassion. To say there’s somebody and I can see they are in trouble. I might not know what to do, but I’m going to at least try to be supportive. That’s so infrequent nowadays. So everybody wants to judge everybody and it’s not just racial. It’s not just cultural. It’s whether you do something different, whether you bring in food stamps or you have to have help for a little while. Whatever, everybody’s judging everybody and it’s sickening.

The decision to not take it anymore frees the participants, because it provides room for hope to enter.

Financial Burden For many participants, financial struggles in their lives pre-date and post-date the chronic pain. Work causes and aggravates the pain, but work brings in much needed money. Instructions from healthcare providers assume the ability to afford a much healthier diet, surgeries, and medications. Fauna asserted, “Most of us don’t have a good income coming in so that plays a lot of part. The doctors want you to eat better blah blah blah. Well when you’re not in control.” Because of the need to work, they cannot take time away for rehabilitation like that necessary following joint replacement surgeries. Edith, who works as a line cook, is always on her feet. She probably needs a knee replacement. But finances limit her choice in that regards.

Well you know each time it gets worse, you’re doing more damage, cause that’s what causing the pain especially in my knees. Eventually maybe knee surgery. You kind of look down the road, even if you don’t want to. You can see, oh, this may be the way. You can’t stop it you know. You have to work. You have to be on your feet.

Chronic pain forced Verbena to quit her successful job and in turn changed her entire lifestyle.

And I said I'm really sick and tired of you sitting there implying it left and right, left and right. I said I would give anything to not have this. I said first of all, I'm not making any money right now. I used to make in a week, a thousand dollars a week just from working. Why would I want to do this? This is changing my whole lifestyle. I mean I had a pretty good lifestyle.

Gwen described how her coworkers might manipulate her chronic pain stories. She will not risk the potential financial consequences from that manipulation. But she described a coworker who did.

Well, with my coworkers, my close coworkers, ones I tend to talk to all the time, they're very solicitous. Wow. We're sorry....The other coworkers, they really don't know too much more about the pain. There's also a lack of empathy, because we had a teacher two years ago claim that she hurt her arms, both of them, when she had to move her furniture from one classroom to another. Went out on Workman's Comp. Now she's no longer even teaching, because of the so called arm problem that has traveled to her back, which has traveled to her neck. At the same time, we see her on Facebook going out and partying.

Finances represent an area of stress and manipulation for nearly all the participants.

Children Suffering In spite of the pain, participants still have to care for their children and grandchildren. While they suffer, they do everything possible to keep their children and grandchildren from likewise suffering even if they believe that pain is genetic or socially inherited. A better life for their children and grandchildren is their greatest wish. Verbena did not know until very late in her pregnancy that she was pregnant. During that time, she was on a lot of medication to control her pain. Her son displays autistic behaviors, and she blames herself.

So that's 18 weeks of medications in my body that they had no idea how it would affect the baby. A lot of the pills they had me on they said well you should abort him. But my son has a lot of issues. Sometimes I think it's my fault. So that's kind of a hard one. Dealing with that.

Verbena accepts the impact pain has on her life, but she resents that her pain also messed up her son's life. For Barrett, the shared experience of pain, both physical and emotional, between him and his mother provided a source of strength. "Oh she had tremendous pain. That's something I think I remember as a child. She complained about pain. Always not sure what it was but uhh...again, remember she and I were thrown under the bus by the entire family. So we had each other that was it." Verbena talked about moments she wanted to kill herself, but did not because of her son. Keira experiences pain because of her grandchildren and also makes many choices about educating others, because she does not want her grandchildren to suffer like she has.

I said 'Mishiike, Turtle, why do you want to cut your hair?' He said, 'Cause the kids they call me a girl.' Well he's beautiful. He is beautiful. And I have his scalp lock in my car. I carry it with me all the time. And he's never grown his hair long again. And he's in seventh grade. This causes me great pain in my stomach in my back in my soul and my heart.

Social Home Though much of the social impact of chronic pain described above is negative, chronic pain also motivates participants to seek a home—a safe place where they feel a sense of belonging and connectedness to their surroundings and a place that provides healing and overcomes pain's negative impacts. For Alma, this place was with her mother, who passed away in a horribly painful death a few years prior to our interview.

So that emotional sense of needing your mom and needing someone to comfort you, because like my boyfriend doesn't understand my pain and what I feel. To him he thinks like I'm just drama queen or whatever. And it's not that. And so like I get all emotional, because I really just want someone to understand and have some kind of compassion. And I don't have my mom. So it becomes like an emotional thing on top of it.

Alma mourns her loss of home and portrays her immense grief at losing that safe place and that person who understands.

When the pain overwhelms her, Keira retreats from her inner city ghetto living conditions to the woods and the water. At home in the woods by the water, she performs ceremony. At home she heals. At home she has others who nurture her—human and non-human.

So I went home and when I went home, I took semma. And I offered spiritual semma via telephone calls and emails in the right way. I offer semma to you, can you have a special lodge? And I didn't even get a return phone call. I said, you're my friends. We don't know what to say. So I think the lack of response for the help was they don't know what to say. I know what I need done. Just let me tell you what to do. Have a lodge. Get the heat up. Give me some woman to take care of me, to pat me down. Bring in the fresh cedar. I need water. I need the cedar water. I need the healing water. Take me to the lake. Take me out in the water. I lose my balance so easily now. Go out into the water with me and just let me stand. Let me do ceremony, and if I lose my balance, fall and go under. Grab me. Help me up. I'll tell you what to do.

Pain primarily results in lost relationships and lessened freedom for participants, yet participants display immense power to refuse abuse and isolation and to find the places and spaces where they can be at home.

4.5 Impact on Culture

In her wandering story, Carmen moved from a silent and unknown Native American identity through a tragic loss and mourning that called her back to her Catholic upbringing to an invitation into a Sundance ceremony, where at last she felt home.

I've always had an affinity towards the Native Americans and their way of life. I've always—since I can remember, as a kid, just—I preferred prairies. I just understood horses, animals. It just seems to be a part of me....A clan had taken me under their wing and helped me through this 'cause I had just recently—I had lost—that was my third husband, and he was my soul mate....A couple months later, all of a sudden, I've got this tumor....In order to survive, I had to stop grieving. I knew that if I continued to grieve, that it—that would not be good. I think, in looking back, yeah. I do believe that—it's like something inside drives you. Something inside calls you. There's this—I don't know how to explain it. It's like a core. It's the middle of your being. You just know, and you connect, and there's strength. I was born and raised Catholic, and so when anything happens, the, my first, my gut reaction's grab the rosary and pray. When that happened with the kidney, I knew I had to dig deeper. I knew that just,

that there, I needed to connect with God much deeper. I feel I was led to the Native Americans that helped me. They made me a part of their Sundance ceremony.

I include this excerpt, because the progression from a silenced identity to pain that drives a deeper connection to discovering her place in a Native American ceremony relates with what many participants said about pain's impact on identity, psychology, social world, and culture.

In this section, I elaborate on numerous ways that chronic pain impacts on culture. Most participants strive to live in a native way. I begin exploring what living in a native way means for my participants and then present how participants utilize the native way to cope with their chronic pain. In part due to recruitment bias, since I found many participants at powwows, a common way of coping with culture occurs through engaging in powwows, dancing in the circle, and seeking the healing of particular songs and dances. I further delineate the specific practices of culture-based healing in the next chapter. After illustrating how culture positively affects the pain by providing coping techniques, I describe some of the troubling realities of being an American Indian. Brown skin racism and the avoidance technique of passing as white represent barriers to practicing culture in ways that may assist with pain alleviation. I describe another coping mechanism in which participants hear spirits and reconnect with ancestors for healing, especially from emotional pains. I also portray how silent endurance is a way chronic pain impacts culture and vice versa. Finally, I recount participants' concerns regarding future generations, especially the trials awaiting them.

Native Way The native way or red road, according to participants, encompasses spiritual engagement, not being white, a place for peace, and relationality. After elaborating on each of these components, I provide a summary of how pain motivates participants to continue living the native way. I end with a counterpoint where traditional way is compared with what many native people's perform as a native way of living. Roscoe told how the Indian way allows him constant reminders of his spirituality through ceremony, in particular the Wiping of Tears ceremony following a loss. In the ceremony cedar and tobacco carry prayers to Creator to diminish spiritual negativity.

I never would have done that if I wasn't sober. All them things

now is completely different, dealing with. It is what it is. Death is death. But there's a lot of things in Indian Way that we have for taking care of them things if we utilize it...Like my people [Lakota], we have Wiping of the Tears. After so long you can go and they will. It's kind of like the spiritual way, ok that's enough. We're ending it. I've cried for them and now it's time to move on.

Later in the interview, Roscoe connected the Wiping of Tears ceremony back to his pain, noting the challenge of moving on from mourning, because the chronic pain remains.

Cheryl and Cassia found it difficult to describe the native way to me, as a white woman. Cheryl conveyed an inner and outer world. In her inner world, she lives in a very traditional native way, and thus her pain receives alleviation. In her outer world, she integrates into the white world, which aggravates her pain. She integrates into the white world in order to maintain her standard of living.

I don't know cause I'm not white so I can't compare it. I can't compare to how other people deal with it. I consider myself very traditional native. I mean I live out here in the white world, and I have to do things in the white world to keep my standard of living where I like it.

Cassia wandered from difficulty answering the survey questions to reminiscing about pre-contact to wishing away her pain just as she wishes away whites for the health of native peoples.

It must be hard for Native Americans to do surveys like this because we have to think about our day when there was no whites. But since there is whites and we've all got maybe white in us so I have to think and now this day what would make me happy. Of course to have your health back. No pain. That's the main thing. Not have pain kill you, practically ruin your life. That's it. What I would want most. No pain.

Like Cheryl, in the white world, Cassia finds it difficult to enact a native way of being. White hegemony intervenes too strongly.

Despite the challenges, Verbena and Gus compromised in order to find peace with their native way of living—a blended native and white way. Verbena discovered that cultural engagement brought her peace that she could

not find in most of her non-native interactions. “So that was one of the big steps, is realizing you have to be at peace with the walk you are walking, and the more I got into the native culture, the more at peace I became.” For Gus, his peace comes from his beliefs—beliefs that he argued are critical to living a native way. “I’ll always believe in those things until I die. Because without those beliefs, you can’t be a real Indian.” Central to the peace found in walking a native way is the concept of relationality. Fauna defined relationality in one pithy sentence, “Cause in our culture, you’re my sister.” Even a white woman researcher can be related in a native way.

A native way for living helped many participants prevent the pain from festering and spreading. Keira exploited the pain to keep her in a prayerful state of mind.

I look at my pain as a reminder to stay more spirit-minded, to stay more in the mindset of reasonable thinking more than emotional thinking, because when I come to work or when I’m doing a presentation, I stay in that mindset. But even though I’m doing storytelling. And I’m sitting with you today, my hands they are screaming. My body is screaming in physical pain. But I just live with it. And I look at it as a reminder of ok, my fingertips at this very moment throb with every heart beat, but it’s reminding me, even though I’m in here with you, talking with you, I’m still in a mindset of prayerfulness. For my body the pain means endurance and keeping on in the midst. Doing the best that I can. My relationships suffer, because I am irritable and short tempered. I don’t reach out and spend time because of the pain I’m trying to deal with. I go to work and that is a way for me to escape.

When I asked Terry about pain and culture, he needed a minute to think. His answer was tentative.

Pain is pain. It’s just in some ethnic background people treat, have their pain different from others. You know they have certain ways they treat their pain and deal with the stress and you know there’s probably a different way of dealing with the stress. But I never really thought about it. You know when I really get stressed out, then I’ll go and sit in a sweat lodge. And deal with it that way. I’m sure every ethnic group’s got their way, how they deal, how they handle it. That’s what I was always taught.

Embedded in Terry’s answer is the native way he was brought up in—go sweat.

The native way as most of the participants live it is powerful and prayerful. But Maynara took time in her interview to describe a native way that is entirely detrimental—all about anger and blame.

There's a lot of it in the native community. There's one thing, the native community is all about anger and blame nowadays. Hopefully they will switch back to the old traditional ways. That's what I'm hoping for. But right now, since AIM [American Indian Movement] started up. Since Wounded Knee. They are so focused on...it's your fault. You are to blame. You make me do things. Anger...They even fight amongst themselves and that's not traditional way. That isn't. Yeah back in the day, they'd make raids on each other, but it was more like for sport. You know they didn't hurt each other. They'd go and they'd make a fool of their enemy. They didn't kill em. They might steal their horses. They didn't burn their house down.

The native way of peace does not destroy enemies, but lives with enemies in peaceful compromise and spiritual connection.

Coping with Culture Coping with culture provides strength for participants to get through the day to day things that aggravate their pain. Though referring to times past, Roscoe presented one coping technique—prayer—practiced by nearly all participants. “You know they say in the day, everything that we did was a prayer.” More than prayer, Roscoe connoted a prayerful way of living. An essential component of a prayerful way of living is respect as Bailey explained. “I think what helped us overcome stuff was that we were brought up to respect and be involved with our own culture and other cultures too. So I think that was the strength that helped get through some of this.” Rosaline further defined a native prayerful way of living.

A lot of the Christian religions don't want to accept that when somebody crosses over their soul can still be with you like the Native Americans do. I guess I shouldn't say Christian, because Native Americans are Christian too. It's just we look at it in a different way....But the Native American religion, our traditional religion was based on love and that Creator loved us and that's why he created this beautiful Mother Earth for us to live on. We didn't really have a concept of hell. It was the other side world but not hell. We knew there was good and evil. It was just a different concept. I think you carry. When you lose loved ones

you carry that emotional hurt with you, but you learn to live with it. To exist with it.

For Rosaline's pain, both emotional and physical, coping involves living with and existing with the pain. Living with implies pain inside one's body. Existing with removes the pain from the body to a consciousness that walks alongside.

Iggy, Abby, and Alma also detailed how chronic pain motivates their prayer and how their faith enables them to cope with the chronic pain. Iggy illustrates her prayer on good days and on bad days with the pain. "I think a lot of people that are in chronic pain, if they have any faith at all, like I do, I pray on it. Everyday I pray. Let me have a good day. Blah blah blah. He already knows my thoughts, but I make it a point to do that. I mean when it really gets bad, it's like oh God, what are you doing to me?" Abby wrangled her spirituality to assist in her fight against pain, also noting good day prayer reactions and bad day prayer reactions.

I think if I didn't have my spirituality, I couldn't handle it. It's a necessary part of what I have to deal with. And when the pain is a little bit tougher or I don't feel good that day, I rely on my spirituality to pull me back up and not to get discouraged and not to think it's always going to be that way. And to try to carry me through to the next good moment. So umm I think the pain in a way increased it, my spirituality, and helps me. It's a reminder. You know I need it constantly to help me to fight it.

Alma emphatically told of how spirituality helps her pull through pain.

Believe me having some spirituality has gotten me through emotional pain, mental pain, physical pain. It's pulled me through a lot. Believing that there's something out there higher than me that's going to help me get through everything, that's what gets you through it. I really like. I think I rely on it more, because of the stuff I've been through, but like I mean, negative impact on it, there has been none.

Spirituality, Alma argued, only positively impacts her pain. In addition to prayer, many participants coped through their culturally-salient crafts. Cheryl expressed how she escapes through her beadwork—a ritualistic practice.

Well I've always done a lot of beadwork. And I've enjoyed that very much and it kind of takes me away....You know I can do it for an hour or two and then it just gets to be too much. But yeah I do, I really miss that. I want to spend more time doing my crafts than at work and things like that. That's a quality of life issue, I think.

Unfortunately her pain prevents her from beading for too long. Fauna also talked about how immersion in beading keeps her focused on something else and not the pain, though her body still aches.

Now, for me, hobbies are a great thing. I love to do beading. I'm totally sometimes immersed in that. Yeah, body parts are aching, but I'm focused on that, rather than the pain. It helps you get through the day. Whatever you love to do. You love to knit. You love to sew. As long as it's not physically challenging you, to the point of aggravation of a problem, go for it.

Beading, like prayer, is a meditative process of escape. Ultimately both practices fix one on the inside, in the heart and soul, in order to fix the physical pain. Rikki elaborated, "I need to get my body in better shape, the inside, probably spiritually too, cause I know Native American I'm more prone to diabetes, high blood pressure, and cholesterol levels. So just if I want to be on this planet longer. My spirituality and my knowledge of culture, I have to get me fixed on this inside, cause I know."

Powwow Engagement Though many participants recognized that they could not dance at powwows the way they once danced, they are still compelled to enter the circle. The circle transports them to a place without pain—a happy place as Morgan suggested and/or hypnotic place as Jason explained. Morgan related:

I have not been able to. Of course I'm too old to now. But I had to quit fancy dancing when I was 19. And that sucks. Fancy dancing is fun. So I would tease all of the ladies. Well I'm going to old lady dance, cause you know we have other steps. So yeah that's kind of affected that part. When you're in the circle it's just a different feeling, especially when you've been raised like that. You don't think about yourself when you're in the circle. Maybe that's it. You're not directly thinking oh that hurts, oh. You're not directly thinking about yourself when you're in the circle. I don't really think about anything when I'm in the circle, but

you're not really supposed to I guess. If you do there's supposed to be good happy thoughts.

When present in the circle, the participants said they think about the community and about the ones honored in the song. So the pain recedes. Jason described this process as hypnotic. He is hyper present to the moment. It's the next day when pain returns.

Now this might sound weird to you, but certain songs that they would get into, it would touch the spirit and so even though I was in pain, it was almost hypnotic so it made it bearable or it allowed me to go ahead and continue to dance. But, believe you me, afterwards like when I came back to earth, so to say, the pain was very intense, because I kind of like drowned it out or hypnotically to go through with my obligation but afterwards yes. And the next day, oh yeah. A lot of pain. A lot of pain.

Jason and Morgan still danced through the pain and endured the resultant pain the next day. Cora cannot dance anymore and mourned this loss. "I wouldn't be able to dance, because of my back and all."

Verbena expressed what it means to be able to dance at a powwow—a good day—and what it means not to be able to dance at a powwow—not a good day but not a bad day.

And if I can dance at a powwow, it's a wonderful day! If I can't dance at a powwow, but I'm at a powwow, ok it's still a good day. Just not dancing. The blessing was being able to get off all the meds, because that was really messing with me.

Like Jason and Morgan, there are powwows where Verbena must dance and will, despite the consequences. "I guess I said I don't care if I can't walk for the next two weeks I have to dance. I have to be able to do that." For Verbena, powwows give life, even more than her crafts and prayers. "You can be alive and not be alive. I think I'm living cause I do go to my powwows. I do make my crafts."

Brown Skin Racism and Passing as White At powwows, participants are able to openly express their native identity. In contrast, the emotional impact of brown skin racism leads many participants to pass as white in most other situations. Cassia wondered why Native Americans are treated the worst, why the racism is simultaneously overtly violent and silently toxic.

But how it affects me emotionally is I pray a lot. And I try to see if there was a purpose to all that that happened....God made everybody the same. He made everybody different races. I don't know why Native Americans. This is not the answer to what you're asking about. But I don't know why we were picked to be the lowest people on earth. And treated the worst. Was it just greed and wanting our land that we had? That's what I think. But then they hate us. They hate us. Where we lived [the Dakotas] they just hated us.

Due to hatred of American Indians, many of the participants' families chose to raise their children without native teachings and culture. This served as a protective mechanism. Andrew recounted, "We weren't raised in our culture. My mother took us out of that element so we didn't get to be raised knowing that this is our culture, this is where we come from, this our people, this our way of life, this is our heritage. We were raised like another city kid." Gwen illustrated the transition from brown skin racism to passing as white to connecting back with her heritage.

When I was growing up, it wasn't really promoted like it is now. I mean, even as a kid, we didn't even have a tribal complex....Now we actually have drums. We actually talk about—we actually have a language that more people are aware of...I'm more aware of everything, and I use that strength. I see as my tribe and the things that we've gone through and that my ancestors had to do. I have a better—I don't know. I'm motivated because of that heritage. I feel like I have more strength than an average white person may have...It's the Native American side that I feel I draw more strength from and the spirituality of it that—if this is what God intended, well, then, this is what God intended. There's always a greater purpose in life for something.

Despite racist consequences, despite being hated, Gwen above all draws strength from her culture.

Hearing Spirits When I listed hearing spirits as a theme on one participant's returned interview transcript, they responded with "positive thing". I feel this demonstrates that mainstream culture is deaf to connections between the spirit world and the physical world. Hearing spirits represents one form of intertwining, one form of sensing, and one form of feeling. Dorothy noted,

But as a Navajo woman, that wasn't a big impact in that respect. Because I was off the reservation in Oklahoma here. But I understand the process of that Indian spirituality and how it intertwines. It always intertwines and for awhile it was hard for me even now. I would see things when I was little, but I never told my mom. And I would feel things. I'm more of a feeling type person. I sense things.

For Shanta, hearing and seeing her daughter again after she passed was the only way she found strength to grieve productively. Shanta's remaining daughter never heard from or saw her sister after her passing and tried numerous times to kill herself, because the grief overwhelmed her.

My daughter passed away in 2008, and she came to me after she passed away, shortly after she passed away, sat in my bed, and told me that she gets in cars with people and plays with the radio because she likes music...My daughter might have been in the car with us, not to mention my friend's wife was killed in an accident on that highway we had just turned off of years and years ago. Her spirit might have been there too for all I know. That's a Native belief. That's not a Christian belief. They don't believe that spirits are good.

Central to native culture, the closeness of the spiritual and physical worlds in the above sense also reflects the way that participants conceptualized their pain.

Silence In contrast to hearing spirits, sometimes the connection between the spirit and physical world occurs through silence. Cassia, Jason, and Maynara spoke of ways that elders, in particular, teach silent endurance—a particularly critical component of chronic pain management as well as the native way of life. Stereotypes abound regarding native stoicism and natives not feeling pain as much as others. Cassia and Jason nuanced the stereotypes with experiences from their own lives. Jason depicted how his father provided an example of how to live with pain.

That's hard for me, because also part of the native instillment from my father is to suck up the pain, live with it, endure it. And therefore I have done that through my years, and I do have a high pain tolerance so when I finally break down and say oh it hurts, it's a pretty serious pain. Even my doctors know that, because they trust me like they said with my medicines. They know I

don't abuse them. For me to take that is when I absolutely can't no longer bear it. But there again I think that was something that was instilled in my head. Live with it. Live with it.

Cassia thought about how her people in the past dealt with pain.

So my people are very strong. And how they dealt with pain was the same way I guess. To not show your pain....But back then we didn't have the medicine. But they had roots. They knew how to. I don't know how they handled pain like maybe they. They had arthritis and stuff. I think the old people just went off and died. Willed themselves to death.

The subtext emerges that Cassia would certainly will herself to death but has no example of how to do this since she lives in such a white place. Maynara argued the counterpoint, calling out those who do not silently endure their pain but scream out for pills instead and yet call themselves elders, leaders, and spiritual.

We're your elders. We're your leaders. What's the matter with you? And that's the reason that this so important to me in the native community, because they want respect. And they say they are trying to lead the people and help the people. No they're not. So many of them. I'm a spiritual leader. Give me pills. I'm a warrior. Give me pills. Oh well. It irritates the absolute pee out of me.

Future Generations To conclude this section on pain's impact on culture, I present what participants revealed about grandparents teaching grandchildren—both the grandparents of participants teaching them and the participants, as grandparents, teaching their grandchildren. In this way the strength from culture continues on and, hopefully, counteracts any inherited pains like those I described in the section on the social impact of pain. Peony argued that this process is absolutely important, noting how the teachings skipped her own generation.

My grandmother was from the generation where they would beat the Indian out of them. So they didn't do a lot of that....It kind of passed our generation and my children, because we weren't real active about taking them then. To the grandchildren, it's important. It's important for them to know.

Verbena's family also denied their indigeneity, but she felt it critical to raise her son native. "And I want him raised as a native with our culture. Because my family don't like the fact that I follow that part of our culture."

Though Peony and Verbena were denied learning about their native identity, both Jason and Maynara learned their values and other cultural knowledge from their grandparents. Jason wants to utilize his grandmother's wisdom in order to find natural cures for his pain.

My Gramma was a healer. She knew a lot of stuff. She used to have things written down and over the years that disappeared, which all the family would like to know what happened to that because she used to have a lot of. She used to grow her own herbs and teas and everything to heal with. Cause she was a healer.

Maynara recalled the safe space of her great grandfather's house, where her mother would not dare to abuse her.

His elderly friends, all in their 90s, and they'd sit around in the rocking chairs, and they were all Cherokee heritage. And they would tell stories. And they would. I think that's where I got my values from. Because my brother was younger, I don't think he remembers it. I remember sitting there in between the rocking chairs and they would hand me stuff or hand me candy. And they'd tell me about the story of the rabbit or the story of the this or the story of that. And I'd pick up these stories. And I learned my core values from my great grandfather and his friends.

Maynara's strength to finally escape the abuse cycle came from sitting at the foot of her great grandfather's rocking chair.

Fern argued for grandparents teaching grandchildren as a dictate for maintaining culture, noting the process' presence in both the bible and Native American history.

There's actually somewhere in the bible that says that grandparents will teach the grandchildren. Because the parents are busy. And I have found the same thing in Native American history, the parents are busy out hunting and fighting, about the day to day things. So with the grandparents they teach the grandchildren. And so that's how that works. It skips a generation and that's why. And so it's very important to me. I have three that we live right there. So it's important that I teach them, because if we don't teach them it'll get. It won't get taught. And as a grandparent, I take that responsibility very seriously. And they know

the uses of tobacco, and it's not smoking it. They know how to give thanks with tobacco, and when they want to ask someone something, they give them tobacco. They get it from me. And I let their parents know, if you ever find a little pouch in their pockets or something that's got tobacco in it, it's ok. It's nothing bad. The use of feathers and how you treat trees. Just different things like that.

She resonated with Peony and Verbena that grandparents teaching grandchildren is critically important.

I end with Verbena comically teaching me the lessons from her grandmother for living with pain.

These are the lessons my grandmothers teach. Roll with change, because everything's always changing. And learn what you can out of it. For the better. And that's I think really native culture. They were always going through changes cause they were nomadic. Can't control the weather. Can't control the universe. Got to adapt. Go woo! When you have a good moment. Don't forget that woo! Got to have some good moments. Don't let anybody touch you unless you're prepared for it, because then you might end up on your butt and go 'God, I'm down here again. Somebody help me up.'

4.6 Conclusion

In this chapter—Suffering: Like a Broken Toy—I discussed the immense and wide-reaching impact of chronic pain in participants' lives. I began talking about identity both preceding and amplifying the pain. Participants are firstly American Indians and with the chronic pain, they become American Indians with chronic pain—two identities that they conceptualized as invisible. In addition to these two identities, participants are women/men, married/single, and working/not working. I then described the ways that pain psychologically impacts participants. They conceptualized this impact as brokenness and tried to bring psychological peace and non-negativity into their lives to cope with the chronic pain. The identity and psychological impacts of chronic pain undergird the social impacts. Chronic pain enters like a third member into many of the participants' relationships for better and for worse. Finally, I relayed how chronic pain affected participants' abilities

to do cultural activities and how cultural activities enabled them to cope with the pain. In the final chapter, I present numerous self-care practices the participants used for dealing with the pain.

Surviving: Prayer First, Then Pills

American Indians with Chronic Pain Surviving and Thriving

*I'm a overcomer.
 I've been saved by grace.
 When the devil tries to influence me,
 I get right in his face,
 I've had my share of trials and errors
 and sometimes death seems near,
 but I am strong and I am free,
 and I won't give in to fear.
 A survivor?
 Yes I am that too,
 although times have been tough,
 through all my pain, my sorrows, my tears
 Creator help me out.
 Because without him,
 I ain't nothing.
 I have no power over sin,
 but because of the blood that was shed for me,
 I am victorious,
 and I can win.
 Because I am an overcomer,
 and I've been saved by grace
 and by his love, his strength, and his power
 I'm going to run this race.*

– Keira keeps this poem in her pocket

Abstract

In this chapter I will discuss the self-care that my participants practice for their chronic pain. I hypothesize that participants who engage in pluralistic healing practices that integrate biomedical, complementary or alternative or integrative, and indigenous approaches will have a lower pain score and report better coping than those who engage exclusively in healing practices from one approach alone. From the interviews arose dichotomies of good and bad days with pain, things that help pain and things that make pain worse, and pain with a physical etiology and with an emotional etiology. Despite the fragmentation of pain conceptualization, participants manage their pain with very integrated care. On average, participants utilize almost seven different healing practices, demonstrating the active role they take in caring for their chronic pain. When asked, all participants wish healing would result in the elimination of their pain, but upon reality check, they seek to function without further debility and to maintain their economic, spiritual, social, and physical wellness. This is care for surviving and thriving not care for cure.

The predominant and dominant biomedical system considers chronic pain sufferers deviant, while the sufferers struggle to enact a different way of pain-free being. This research provides evidence for continued progress toward rewarding integrated self-care that promotes wellness. Healing differs from curing but may involve curing. Curing concerns elimination of pain, while healing concerns freedom from colonization, according to the participants' interviews. The participants pick and choose as needed from biomedical and traditional care models for the good days with pain and the bad days with pain. The goal of bad days with pain is to survive based on immense individual, social, and ancestral strength. The goal of good days with pain is to thrive, which involves immense resilience, gratitude, and forgiveness. Participants resist pharmaceutical interventions, except on the worst days with pain, in contrast to the current opioid abuse epidemic.

5.1 Care Plan Profiles

The statistical analyses that provide a care plan profile arise from the hypothesis that participants who engage in both biomedical and traditional healing practices will have a lower pain score and report better coping than those who engage in either biomedical or traditional practices alone. The hypothesis calls for breaking down healing practices into three categories: biomedical alone, traditional alone, and both. Nearly every participant uses both biomedical and traditional healing practices. Therefore I cannot test my hypothesis. Instead I will demonstrate the relationships between diverse healing practices and the pain profile. Participants use a diverse array of healing practices with an average of 6.85 practices out of a total of 12 options. The most used healing practice is prayer and the least used is peyote. Eighty-five percent have gone to the clinic some time in their chronic pain experience and therefore have interacted with the biomedical care system. Table 5.1 and Figure 5.1 depict the healing practices used.

Appendix F contains the detailed correlation matrix. In what follows, I discuss relationships of most interest given the qualitative data analysis. Participants who are older are more likely to pray and go to the clinic and less likely to do a pipe ceremony. Younger participants are significantly more resilient than older participants ($r: -0.491, p < 0.01$). Gender does not play

Table 5.1: Descriptive Statistics for the Care Plan Profile

	N	Mean	Std. Deviation	Interpretation
age	40	54.03	13.174	
female	40	0.7	0.464	70% female
education_yrs	39	14.79	2.949	
resilience_avg	40	3.9625	0.32792	resilience mostly true
tx_biomedical	40	0.85	0.362	85% go to clinic
tx_sweatlodge	40	0.37	0.49	37% sweat lodge
tx_healingcircle	40	0.52	0.506	52% healing circles
tx_pipeceremony	40	0.55	0.504	55% pipe ceremonies
tx_prayer	39	0.97	0.16	97% pray
tx_relservice	40	0.6	0.496	60% go to church
tx_massageyoga	40	0.45	0.504	45% massage or yoga
tx_energy	40	0.25	0.439	25% energy healing or Reiki
tx_herbs	40	0.6	0.496	60% herbal medicines
tx_oils	40	0.35	0.483	35% essential oils
tx_walk	38	0.89	0.311	89% take a walk
tx_peyote	40	0.1	0.304	10% peyote
tx_shaman	39	0.41	0.498	41% shaman healing
healing_#ofdifferent	40	6.85	2.824	6.85 practices out of 12

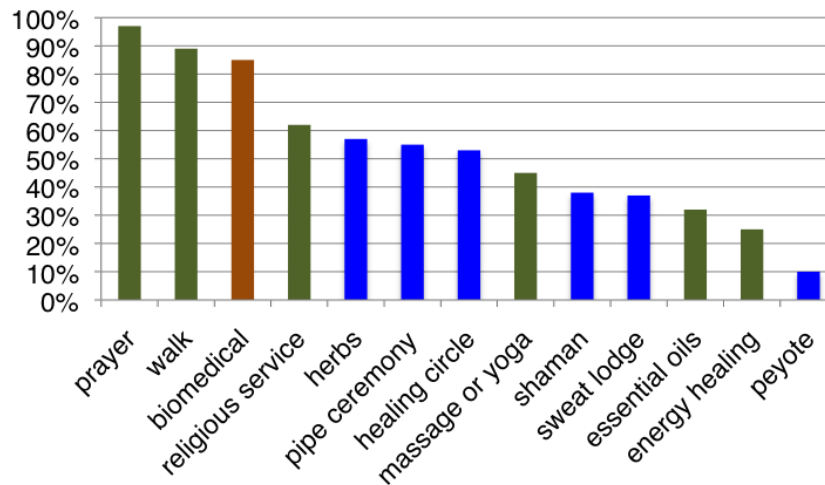


Figure 5.1: Bar Graph Depicting Frequency of Healing Practice Use

a role in healing practices used or resilience. Those who pray are also more likely to go to clinic and take a walk. Those who do one Indigenous healing practice are more likely to do others. For example those who participate in healing circles are more likely to attend sweats and pipe ceremonies, more likely to use herbal medicines and energy healing, and more likely to visit a

shaman for healing. Those who do pipe ceremonies think about historical losses more frequently. Those who give more sensory descriptors of their pain are also more likely to use essential oils. Those who give fewer evaluative descriptors of their pain are more likely to attend religious services. Those who give more evaluative descriptors are more likely to have a lot of stressful life events and pain from grief. Those who give more miscellaneous descriptors of their pain are more likely to have a lot of stressful life events and think more about historical losses. Those who report their worst pain as higher are more likely to do massage and herbal medicine. Those with stressful life events are more likely to use herbal medicine and have high resilience. Those with more resilience are better educated, younger, and have more stressful life events.

To establish the relationships between pain, historical trauma, grief, stressful life events, resilience, and healing practices, I carried out multiple binary logistic regressions. High present pain intensity and high worst pain intensity served as the dependent variables. Independent variables were high trauma, high stressful life events, pain from grief, resilience, and high healing practices. Due to low power from a small sample size, most of the regression analyses failed to elicit a significant result. Thinking more about historical losses significantly explains high present pain intensity regardless of number of healing practices (B: 1.457, p:0.036) or resilience (B: 1.482, p:0.034). In other words healing practices and resilience do not attenuate the relationship between historical trauma and pain intensity. Likewise resilience and healing practices do not lessen the strength of the relationship between being in pain from grief and present pain intensity (B: 2.178, p:0.006). In contrast resilience (B: 1.393, p:0.07) and healing practices (B: 1.26; p:0.097) do matter in the relationship between pain from grief and worst pain intensity. High resilience (B: 1.426, p:0.07) helps determine worst pain intensity but only when thinking about historical trauma and healing practices are also in the model. Finally, high resilience (B: 1.623, p:0.05) predicts high worst pain intensity when high healing practices and high stressful life events are also in the model. All these regression relationships are only marginally significant and not great predictors of causality. They do support the qualitative data that those who have been through more (higher grief, higher stressful life events, higher historical trauma) also show more resilience and call upon a greater diversity of healing practices.

5.2 Self Care

As Mehl-Madrona, 1997 asserts, “We all carry within our souls the capacity to heal ourselves (p17).” In this section, I discuss the self-care practices that participants call upon to heal themselves. Barrett imagined his chronic pain as an ogre (Figure 5.2) with a menacingly comical expression, as if enjoying the fight, punching him with closed fists. Many participants, as a way of dealing with the pain, consider the pain itself having a separate being and consciousness. The body with pain carries this separate, visible being.

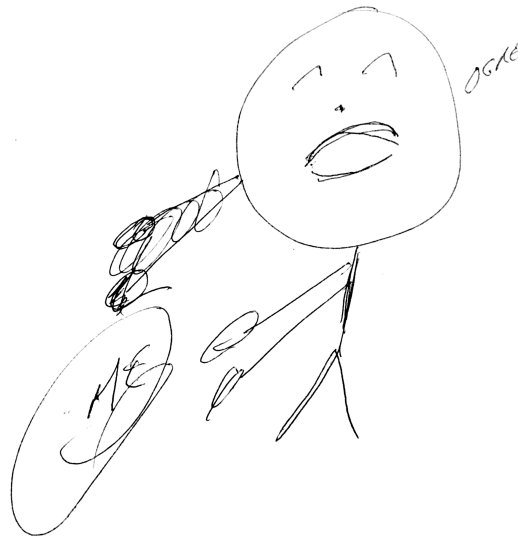


Figure 5.2: Pain Ogre drawn by Barrett

Kleinman & Geest, 2009 classify care into care with a light side and care with a dark side. In what follows, participants discuss self-care practices—dark and light. They battle the pain and nurture themselves. They do all this with a goal in mind. Maynara shared her goal: “Get it eased up for tomorrow. Either get it eased up today or let me go to sleep and sleep it off and be better tomorrow.”

Example Self-Care Practices The most common self-care practices fall into three interconnected categories: exercise, relaxation, and food. Establishing a consistent practice begins with digging for information. Rosaline reflected, “So then when I found out what it was and I really started trying to learn about it, then I realized that ok, if you get wore out, lay down and take

a break. There's no law that says you can't." For Rosaline, her diagnosis of fibromyalgia began a trial and error process of learning what works and what does not. After thirty years, she has established a broad collection of self-care that has reduced the fibromyalgia to a manageable nuisance. In fact Rosaline could not generate an image of her pain. It either has become that incorporated into her own being or that controlled that she barely reflects on it. She told me multiple times during the interview that fibromyalgia is one of the best diagnoses to receive, regarding its ease of management. Her lessons in self care for pain include: 1) Take a break, 2) Full body deep tissue massage; 3) Realize and uphold limits; 4) Stay active and do things you enjoy; 5) Get tons of illness knowledge; 6) Think of yourself as healthy; and 7) Play. Nearly every self-care practice discussed in what follows falls under one of Rosaline's seven lessons.

Carmen managed her constant fire-like pain in her hips with exercise.

I would largely say it went to gradual relief because of the exercises. It would come back. It never totally, totally went away. I think—well, I shouldn't say never because it did—last year, it was pretty much gone. I still would have to—still do my exercises. Not as much, though. You feel good, and you forget about it. It'd come back a couple times.

As Carmen mentioned, pain becomes part of life when felt, but on the good days when pain subsides into the background, it becomes much easier to forget the self-care that keeps that pain at bay.

Failing to actively manage the pain motivated Carmen for much more consistent management. Engaging the pain consistently might let it become like Rosaline's pain—a mere nuisance. Carmen talked about things that have helped her with pain since she was a kid.

Aside from the exercise, the—and the chiropractor, and there's—with the supplements, with the magnesium, zinc, and the high C—actually, breathing. If I take the time to just stretch out on the bed and do some controlled, deep breathing, that helps. Singing helps me. Believe it or not, that has always been—since I was a kid, I've—it's always helped me with that—with pain. I would sit and sing, and it seems to relieve a lot.

Shanta also integrated her exercise with play or activities that she loves in order for the pain's consciousness in her life to fade.

Most of the time I do stretches, and I always have done stretches all my life. I have stretches for different things, exercising and dance, and I played basketball in high school....I just do stretches, yoga, and I used to use Eastern medicine some too, like Ayurvedic medicine—homeopathic, I mean.

A lot of experiential knowledge acquired about pain comes from understanding causation or at least what causes fluctuations in the pain. I discussed how participants conceptualize the cause and aggravating factors for their pain in Chapter Three. For example, the weather shifted Shanta's self-care practices immensely.

I usually don't feel the pain if I'm walking, if I'm exercising. I don't feel it so much. I feel it more if I'm sitting. On a cold—like today; it's a cold day. It's nasty. You open the door a little bit, and the whole house gets cold because of the humidity and the just biting cold. It takes a while to get warmed up again, and once you get warm—the whole time you're getting warm you have to stretch and try to move around.

The participants noted discongruence between knowing what they are supposed to do and what they can actually do in a given life context. Iggy, in her approximately 21 years with knee pain from missing a jump up on a wall while intoxicated, has acquired a lot of knowledge about what works for the pain. Nevertheless she attends school full-time and cannot give the pain as much time and attention as it demands. She said without apology,

I know what I'm supposed to do. Eat good, healthy, exercise, and lose the friggin weight. So yeah I've done. I wear a knee brace when I have to. I just joined the Y so I'm going to try to get exercise in the pool. And what else have I done as far as trying to do self-care? Well in the past or recently? Because in the past I'd go get street drugs. For myself now, I found really. I have been prescribed hydrocodone, but it's really low dosage. But if I'm in something, I'm taking one of those. I will take. I would prefer not to take anything at all. I really would. But if I'm feeling like ok, I can't do this. I'm going to take something.

In Iggy's case, balance takes on a new meaning. Balance refers not to a perfect blend of physical, emotional, and spiritual life but instead to a balance between avoiding past negative self-care practices—street drugs and alcohol—and needing to do something targeted about the pain—hydrocodone—so she

can function. As discussed later in this chapter, the majority of participants avoid prescription medications for daily management of pain. Yet they perform other practices ritualistically with the ritual attention needed to take a pill every six hours. Iggy takes baths as her ritual pause in the momentum of her crazy life.

Just like my hot baths. It's a ritual with me. And I do it. It's a ritual. I've got this big old fashioned bathtub, girl, and two people would fit. And it's just like ooh. I look forward to it. When I wake up in the morning, I run my bath, make my coffee, and then I'm out the door by 5:30, sometimes quarter to 6. It's crazy.

Alma regulated periods of remission and worsening pain from her rheumatoid arthritis primarily through food, supplemented with ritual relaxation practices and exercise. "I try to move around. And like I said hot showers. Or tiger balm. Or bear grease. Or healing salves. Just trying to stretch and move and be active enough where I can try to loosen up my joints." Everything Alma tried for self-care emerges from her understanding of her body.

If you're filling your body with garbage and caffeine and processed food and food that's not even real, your body's going to feel like crap, and how can you balance like you have a disease like rheumatoid arthritis? How can you feel better when your body feels like crap on the inside? I mean you expect your joints to feel good. You know one contributes to the other.

Like Iggy, Alma balanced what she takes into her body with her knowledge of how her body responds.

While the women in this section so far have many years of education, other participants had fewer resources for establishing the best self-care practices. Ginger, for example, found one thing that worked and continues that ritually. "So one day I was watching Dr. Oz, and Dr. Oz was telling people in the program....He said if people have arthritis and there's pain, you should just drink some ginger ale. So that's what I've been doing now, whenever I have pain, I just have a little ginger ale." Her experiential evidence maintains that this unexpected practice works.

Self-Reliant Self-Care Self-reliance occurred for participants as an early lesson in attending to chronic pain. The self-reliance learned early in enduring chronic pain in part explains the silence between physician and patient about self-care practices. Terry, a former truck driver whose pain began when an engine fell on him, related, “This kind of pain the doctor can’t fix it. I got to do it on my own. Think about it. Pain and suffering in my head about everything. Something I got to do on my own. Can’t depend on nobody else but myself.” Terry’s fierce independence provides strength for getting through pain alone.

Self-reliance also generates inner attention that may close one off from others. For Cora, whose pain was triggered by being shot, silence about her pain to others allowed her to generate greater self-reliance.

Like I said, I don’t like to talk to people personally. I don’t like them to judge me. And I don’t want no doctor sitting there telling me how I’m supposed to feel. Or you’re this way, so you need to take this medicine. It’ll make you feel better. You know. I kind of figured out that if I talk myself down from it then it eventually goes away. If I move. If I keep myself active, it doesn’t bother me.

Alma, Terry’s daughter, found, in contrast to Cora, that while she relies on herself for her own pain care, others also rely on her for care. “So everyone turns to me. I’m like the encyclopedia of cures in food.” Therefore Alma’s self-reliance generated respect from others.

Self-reliance grows. For Andrew, the death of a very close friend, motivated him to take better care of himself. “I had just kind of wanted to do better, like take care of myself, eat healthier, and just appreciate the people that are around me more often. You know, because you never know when you’re going to go.” In addition watching the pain his friend endured in the dying process led Andrew to find added strength for dealing with his occupational and athletics-related pain. “Well yeah for me, that’s how I deal with it. But expecting it is mainly like I know it’s going to be there so I have to brace myself for it. Kind of like someone who bites on a stick when they are getting their arm pulled back in the socket. You know what’s coming.” He also turned inward. Self-reliance arose from his strength of mind.

A broken something was just another way of dealing with pain. I’ve just come accustomed to it and learned how to, I don’t know,

like deal in my mind. Of how to get rid of that pain in the moment. Like go someplace else and not feel that. So that's how I've been. That's how my pain story is.

Andrew relied on escaping to handle his pain—a practice that draws only upon his own resources and not those of others or the healthcare system.

Maynara categorized self-reliant self-care as 'old fashioned kind of care'. Her successful self-reliant self-care attracted others to her for care, sometimes dark care. She reflected:

Basically traditional old fashioned kind of care. I'll take the over the counter pain medicines or just anything stress relief. I've got little things in the house, you turn them on and they make bird noises at night. They got lights that flash and bird noises. Crickets. Rain drops. Anything to do stress relief. Scented candles. Just anything. Soft blankets.

The little things she does, she would never report to a physician, but they are the critical components of her capacity to survive and thrive with the chronic pain.

Escape to Home as Self-Care Home is a sanctuary where even the simplest and quietest self-care practices take greater effect than away from home. As I discussed in Chapter Four, the participants I interviewed live in diaspora, away from their tribal homelands and reservations. For many, their families left the southeast prior to forced removal and assimilated to protect the generations to come. The participants in Chicago talk about Chicago 'being Indian Country too'. Nevertheless home in the interviews often referred to a rural sanctuary on more sacred land than where participants transited on a daily basis. Keira, in particular escaped to woods and water, literally in central Michigan, and figuratively, in her mind.

But I lived there and I had found that place without that mockery, without that abuse, without those past memories. It was fresh. It was clean. And it was welcoming. And I had a sense of belonging. And I can go home there yet today if I'm in a whole lot of pain or something, I'll tell my children, I need to go home. 'Mommy, why don't you go home? Go to the water. Go home.' And yeah, I know. It's a physical place. But it may contain, even though it's a physical place, it contains all those other things also...all four aspects. So that's the place and that's when I was without much pain.

For Keira, home—the place—uplifted her physically, emotionally, spiritually, and socially. It is also a place where her pain subsides.

In her mind, Keira also escapes like Andrew did in the last section. She refers to going home in her mind as disassociating:

And [I] have learned how to dissociate, how to go somewhere else. Umm and that's how to this day I still deal with a pain. A lot...I escape, run away. I had my closet that I would run to. My tree that I would run to. There was a little creek down the road, underneath the culvert, I would run to. Physically to escape. But then if I couldn't do that, because there were also childhood issues...abuse, sexual abuse. Umm then I knew how to dissociate mentally also and emotionally to go somewhere. So I still use those techniques. I use those techniques now, mixed with my flute and drum. And I use those...tools to help me dissociate in a good way. Though I still dissociate in a bad way sometimes. Middle of the conversation, you know, I'll go right there. I'll be right there. I'll be flying with those birds, swimming with those fish. I can go there and still be here talking with you even though I'm galloping in the open prairie with those horses right now. And that's how I personally deal with pain.

Abby lived in her grandparents' home in Oklahoma—a place with memories, energies, and spirits. Though always in a special place, Abby still needed to go a bit further to escape and deal with her pain. “We've got this old bench that belonged to my uncle and it's falling apart, but I like to sit on that bench and just be quiet for awhile and just listen. For me that's kind of what I do to deal with it.” Quiet and solitude characterize home, because in quiet and solitude one may dissociate like Keira and disengage the body to perform its own healing. Maynara escaped through beauty. Home is a beautiful place.

If I see something that's stressing me out, I'll walk away from it. Go work in the garden. Go mess with the flowers. Go hang out with the little neighbor kids. Pet the dog. Get in your soul. Do beadwork. Anything beautiful. Get some beauty in your life. Get off of it. And that seems to work better than anything. It really does.

Home is the space that expands the soul, and with an expanded soul, pain no longer had room to occupy the participants' bodies.

Dark Care or Release of Crap Self-care At moments, the stresses and burdens of life take over and fuel pain's evil consciousness, inflaming the pain feeling itself. 'I'm not doing what I need to do' preoccupies many participants, like Cheryl, who worked full time as an engineer in a physical job that she loves but also that aggravates her pain. Often participants must decide between care practices that maintain their financial and social life and care practices that alleviate their pain. I think that this conundrum is what Kleinman & Geest, 2009 refer to when they describe dark care. Cheryl shared:

I'm not really doing things I should be doing but treating myself. I'd rather not treat myself on a regular basis. I mean it's pretty much nightly. There are some nights I don't have to. Like last night I was really blessed. But other times, like when the storms come in or anything else, I'm looking at the barometer going OK where's the ice pack cause it's about to get bad. It would be nice to stop the pain cycle. And if there's a certain residual or certain level I gotta deal with that's great. But when it starts spiraling and then after that you're dealing with a hangover from the pain and feeling crappy and all that.

Abby noted how stress and fatigue aggravate the pain and reflect a failure of good self-care or an overpowering from the rest of life. "It just picks its spot and then from that I also get fatigue and that kind of comes and goes. It does not depend on my level of activity. So I have to kind of watch my stress levels to try to keep ahead of it." The moments where dark care infiltrates require an offensive with good care practices. For Cheryl alleviation came through ceremony. "And there's one particular group and one particular elder and a certain healing ceremony that does help. And I think a lot of that is just releasing the emotional and mental crap that I'm dealing with. More than physical. But it certainly alleviates it."

Flexibility and Humor as Self-care Though escaping to a home space and releasing built-up negativity are essential and effective self-care practices, most participants asserted that above all laughter keeps them alive. Even in the most invigoratingly difficult moments with pain, pain, like the face drawn by Luke below in Figure 5.3, can be cross-eyed, mockingly angry—in short, humorous. The participants spoke of laughing at their physical pain versus not laughing at grief or loss.



Figure 5.3: A Cross-Eyed and Angry Face of Pain

Participants asserted that they needed to laugh at pain. Verbena, after years of being consumed with anger about the car accident that left in her chronic pain, found it essential to tell me about the need to laugh at your own pain. “You got to keep some kind of flexibility in all that craziness because it will lock you up.” The alternative to flexibility and humor is to not function. Alma sought out laughter to hold her pain at bay.

Laughter is the best medicine. It seems like when I’m in pain and someone can make me laugh, like hardcore, it really. I think a lot of pain is mental. If you are feeling well in your mind you can overcome the physical pain even when it’s bad. So to me finding like the spiritual and mental uplifting makes a difference in my pain levels. Because if I’m happy and I’m in pain, pain doesn’t seem so bad. If I’m not and I’m feeling down and I’m in pain, it seems like it’s much worse. So like to me the whole laughter is medicine, I believe that 110%.

The days where they were happy, though in pain, with spiritual and mental uplifting, were days participants celebrated.

Maynara emphasized the critical role of celebration in ensuring laughter is the 110% best medicine.

I have temporary. You know it’s not everyday, but when I’m feeling good, everybody knows I’m feeling good. I’ve got energy, and I want to do something. I want to go dig in the yard. I want to go walking. I want to do something. Go play with the kids. Anything. ‘Cause I’m celebrating. That’s a native thing too. Thankful for everything. And I’m thankful for when I’m feeling good.

Humor beget gratitude for Alma. Then gratitude beget flexibility. And another day would pass with the pain a little easier to manage.

Spiritual Engagement

From Joseph Rael, a Native American shaman: Some of the illnesses we carry here, we are carrying as a gift for folks on the other side of the cosmos. Grandfather's idea of healing is that illnesses never happen just because they happen. It's not just because we don't take care of our bodies or we don't eat properly. He thought it was connected to some larger purpose or condition. He believed that people die when they're supposed to die. He said, actually, we never really die. We drop these bodies, but we never die (Rael, 2003 p66).

The strength for healing may come from inside or outside. Many of the participants engaged with spirituality—Christian and traditional American Indian, especially. In the moments of greatest pain, they cried out to Creator and grasped at a fusion of spiritual practices for relief. Dorothy, a Navajo woman with pain that keeps her from running as her heart desire, spoke of moments when the longing in her soul was answered.

She goes, 'Here, I want you to have this. I usually have a hawk feather and cedar with it, but I want you to have this shell.' It was one of these shells you burn cedar in. I said, 'You must have read my heart, because I've been wanting one of those.'

Dorothy believed that many answers to soul longings come, because the spirit world integrates with the physical world. Some have the gift to see into the spirit world. Others are open to being touched by those in the spirit world. Dorothy's most intense grief came from the loss of her mother. Yet her mother's continued presence provided relief.

Even one time when I was on the trail. I go, 'Mom, my back's hurting, I don't know if I can make it.' And it seems like I saw her, the way her stride is. 'Come on you can do it, you're almost there.' But I know she's around. So a lot of the healing has been, because I know I can feel them and I know they are here.

In addition to traditional Navajo spiritual practices, Dorothy attends a Christian church and incorporated healing ceremonies, like laying on of the hands, that occur in that space. "But my back is my constant problem. That

will never go away. And I won't do surgery. I only do ibuprofen. Even at church when we have laying of hands, when we're doing that, I always put my hands on my back because that always helps too." Bailey also attended church for the reassurance offered. "Sometimes we'll go to a prayer service. That's mainly it. Prayer service where they lay hands on you or you know pray over you and stuff goes on like that. That's the more spiritual side that everything's going to be ok."

Jason was much more reluctant than Dorothy to reveal his own spiritual ways of coping with the pain even to his wife. Assuming a teaching role, as if I were one of his grandchildren, Jason told me of the following spiritual practices.

Well some things because it is my own spiritual way, but uh uh one of the main practices I can share is every morning at sunrise I wake, and I commune with my Great Father. I offer tobacco to the four directions and pray, and I ask for blessing. Or first off I give thanks for my health and my blessings that I have received. And I pretty much pray for my wife, my children, my grandchildren, my friends, family, or those who have maybe called me to pray for them or what not. I'm a firm believer that instead of praying for myself, I pray for others. The connection I have with my Creator the more I pray for others, my blessing comes.

Just as we can never know the extent and character of another's pain so also we cannot know how their soul stirs toward a higher power.

Some, like Dorothy and Jason, prayed daily—a ritual that if forgotten would leave them empty—feeling the rest of the day. Willow thought about her propensity to pray as learned from her mother. Of note, Willow responded with the following quote after I questioned her about how being a native woman influenced her pain experience. For the purposes of argument in this research, I have broken down culture, spirituality, and identity. As Willow reminded us, though, culture, identity, and spirituality intertangle in this struggle against pain.

Well I pray a lot for relief. I do every morning. And it helps....My mother, she prayed all the time also and that's probably where. She said that if you have anything that you need or you want fixed, you just pray. You pray, and he'll take care of it for you. So you know even from the time I was little, I remember her telling me that. So it just kind of stuck with me.

Carmen prayed more as an after thought brought on by the intensity of pain. “Definitely if I have pain, I will—that will definitely make me—I make a beeline for the spirituality. If I’m in deep pain, oh, yeah. It’s all of a sudden, I remember, ‘Oh, yeah, maybe I should pray.’” In moments of intense agony, Carmen sought out prayer. Pray has power and nearly all the participants mold prayer’s power to their own healing needs. Dorothy spoke of prayer’s power, comfort, and healing: “So prayer is a very strong element in my life, because I know what it does. But I can. It’s like a comforting feeling that comes over me, when we were there. That’s the best way, it’s like someone was hugging you. That’s the best way to describe it.”

Goals of Self-Care In this section, I discussed self-reliant self-care practices that those in pain use on a daily basis for managing their pain. Food, exercise, relaxation, escaping, releasing, humor, and spirituality all enable those in pain to achieve or at least work toward achieving their ultimate goal with respect to pain. For Tuck this goal is: “I want to be pain free. Plain and simple I want to be pain free. I want to go out and do things like what I used to be able to do.” Very few of those I spoke with felt that being pain free was a reasonable goal. Instead they set a goal like Bailey: “I just kind of monitor it in my mind. It’s like ok this happened about three years ago where it was really painful. And it’s always there, it hasn’t gone away. But it’s just managing it.” Das, 2015 writes that everyone seeks relief from illness, “I think that it is at the heart of illness entailed in the very ontology of disease that one suffering from illness desires treatment and cure, or at least a relief from the suffering that illness brings (p208).” In the next section, I discuss healing practices that require engagement with others for relief.

5.3 Healing Practices

To care for others is to make a claim; it is to make a small theoretical gesture. To care is to embody an argument about what a good life is and how such a good life comes into being. Thus the *arts* of caring for others always emerge from and are a reflection on broader historical material conditions and institutional arrangements (Povinelli, 2011 p160).

Healing practices, both biomedical and traditional care, incorporate in

pluralistic, messy, and complicated ways. For participants, healing is not the elimination of pain but sufficient relief from pain to do the things they love doing without worsening pain. They pursue stabilizing healing instead of curative healing. In this section, I characterize hybrid healing practices for my participants. I begin with the challenges of accessing traditional healers in urban spaces and note home-based practices, ceremonies, and natural remedies that provide relief when a traditional healer is not accessible. I then discuss the overwhelming resistance to analgesic medications, especially narcotics or opioids with a brief counterpoint from those who take narcotics chronically in order to function. Despite resistance to analgesic medication, as the statistical analyses above demonstrate, the majority of participants seek out or have sought out clinic-based treatment for their pain. I report clinical healing practices. Finally, I provide some data on failed relief and on successful relief through external healing practices.

Access to Traditional Healing Gus, Maynara, Gwen, Andrew, and Barrett all asserted that Medicine People or Traditional Healers are not available in urban spaces, including Chicago, Indiana, and Tulsa. Gus, a Chicago resident, identified a reason for the lack of access.

Medicine men, real Medicine Men, do not travel. They stay home. Sometimes you'll run across people claim they are medicine men. Then what are they doing in the city. Medicine Men don't travel. You should understand that. Real Medicine Men stay home. Treat people.

Andrew, another Chicago resident, identified another reason—economics.

Traditional medicine men they provide healing for free. There's no payment that's supposed to be accepted. So sometimes you got to find the right one. It's through people that you know, family sometimes, a friend, you know. So it's not like you just go there searching and like we can't google them. You have to really look. Like get on the reservation, talk to people, and ask them about healers.

Word of mouth and personal connections may lead participants to a traditional healer but only if they begin looking in reservation spaces.

Maynara, from rural Indiana, noted, like many participants when asked about using a traditional healer, that she would but there is no availability.

“I think I would [go to a traditional healer]. But I live in Orange County Indiana. It’s. It’s nowhere. It’s wonderful. I love it to pieces, but you don’t have all these things available.” Tribal access to traditional healers exists if you return to the current tribal spaces such as reservations. Gwen, who lives in California with tribal headquarters in central Indiana, related that going home she would have access to a Medicine Man, but she feels less strongly than Maynara that she would seek out healing.

I know, in my own tribe, they have a medicine man. Unless I’ve worked with that person and seen—know them personally, I don’t think I would trust them just because I—there’s still the skeptic in me. I’ve heard of laying on hands. I’ve heard it worked, but unless I actually see it for myself, I’m gonna believe it’s false.

Despite the certainty of poor access to traditional healers, some participants, like Barrett, hold out hope that when they need healing, they will encounter a healer so they put themselves in situations for meeting healers. “One reason I always go to these powwows, I’m always looking for new things. Maybe someone has some ideas of something. And you never know who you’re going to meet there. And if I find a person, then I would pursuit the traditional native healing.”

An Alternative: Traditional Healing at Home Despite poor access to Traditional Healers or Medicine People, Willow and Morgan both have access to a traditional healing practitioner. Willow lives in Tulsa, where despite the urban setting, one can find a traditional healer. Even with relatively more access than in Chicago or Indiana, Willow reported that their original healer passed away and finding a new one was quite difficult. “We do go to see a doctor, a Native American doctor, and he has given us. Which it really works. It really does. It’s tobacco and you wet it and he says to like, say this is your knee, get the tobacco and go out from the knee.” This Native American doctor provided Willow with the means to continue healing at home through tobacco. Morgan works for her tribe, and her tribe has a traditional healer. She related that the power from meeting with a traditional healer from the same tribe and local to the area is the power to call upon and understand history in healing the pain.

When you go and speak with a spiritual leader and you know you seek out that traditional healing, a lot of that has your history

attached to it, the history of your nation, the history of your own family attached to it, and I think that helps a little bit.

Peony does not have a traditional healer that she sees in person, instead she calls upon ancestors and medicine people to assist her as she performs healing.

And it's good to be able to call in ancestors and medicine people before me to come and help. A lot of times. I think what I learned through the whole thing is that I'm the one who gets in my own way. A lot of times I have to step outside my ego and let that go and let that go in order for all of this to work.

The ingenuity to overcome poor access to traditional healing knows no bounds with the participants. For Azure, her knowledge of traditional healing passed down through her family. With that gift she is never alone in her pursuit of healing.

I was raised in a medicine tradition, sometimes when you are taught to see things that sometimes other people don't see or even believe can be seen or perceived. People look at you a little weird, especially if people don't understand a shamanic tradition.

While both necessity and inherited gifts enabled traditional healing at home for many participants, other participants struggled to maintain traditional healing practices at home, because they distrusted community healing activities. Cheryl lives in Bloomington Indiana and suspects many in her local native community of 'playing Indian'. To avoid the frustration needed to educate those without understanding, Cheryl tried to maintain her traditional practices at home.

And they get together and decide to make their own Sun Dance. And you've got locals going down there who aren't educated enough to know that that's not what we did, you know. And it's a really frustrating situation. So I just steer clear of that kind of thing, and try to do my own thing as much as I can.

Rikki must also maintain her practices at home, because she has no access to an elder for healing. "Maybe it is spiritually there. I don't know. I'd rather try that [cedaring, smoking people off] than use the drugs. But I've never asked for the drugs either. I've never had it so bad to where I'm looking for that kind of [relief]." Her success at healing with cedaring and smoking

people off allowed her to avoid analgesics for her pain. Morgan described her own success with healing from traditional practices, including an increasingly popular practice from the complementary and alternative medicine purview—reiki. “I think it did emotionally. I don’t think it fixed my pain, but I think it eased my mind a little bit about the pain. But I don’t. It’s not like I had a reiki treatment and then I had no pain. It was still there. I just think I felt better about it.” As discussed in the goals for self-care, healing does not mean elimination of the physical pain source and sensation. Healing more often concerns an eased mind and emotional calm that permits more successful coping with and thriving despite the pain.

Ceremony While it can ease pain, most participants do not believe ceremony miraculously rids them of pain. This aligns with their understanding of the pain’s causation as primarily physical and not emotional or spiritual. Alma discussed her willingness to participate in healing ceremonies, but her reluctance to ascribe a ceremony specifically to her pain. “We’ve gone through a lot of healing ceremonies, but to me those are more for mental, emotional, spiritual health, which like I said if you are well there, you feel well in other places, but I’ve never like gone through a ceremony specifically for my pain or any of that.” Peony also remarked about pain alleviation that results from the resonances in the energy healings she performs. “Because there just isn’t pain. I always find that usually that happens, it’s after I’ve worked with the energy healings and stuff. I guess it’s just the energy, the residual energy in my body that helps.”

As a contrast to Alma and Peony, who acknowledge the mental, emotional, and spiritual alleviation in ceremonies, Kelly and Dorothy heartily believed that cures for pain arise from ceremonies. For Kelly, her ability to function throughout a day with her pain demands that she give away some of her pain to Creator.

I think spiritual enlightenment. Native American ceremonies. I think spiritual enlightenment eases pain more than any medication. I’m not going to lie. It does. You can be in pain and when you absorb that pain, you can let it go...I give everything I have to Creator. I give all my pain to Creator. I give all my problems and my woes to Him. And it lifts my pain. It lifts all of my burdens. Lay them down.

Dorothy, as portrayed earlier in this chapter, embraced a connection between the spirit world and the physical world. When she fell down during a parade, this spiritual openness allowed her to be OK. “I always land on my bad knee. I landed on concrete. And everybody goes are you ok, you ok? This Navajo man said just touch the earth and then touch your knee and you should be ok. And I said OK.” A miraculous healing resulted because of her faith.

The ceremonies most commonly used by participants are sweat lodges, communal cleanses, energy healings, and dancing in the powwow circle. Others primarily attend Christian churches such as Luke. Luke shared:

I’m a very strong Christian so we put a lot of our faith in the power of God and Jesus. And that you know it’s up to him to heal and stuff like that. Our faith is that in Christ, by his stripes, by his punishment we are healed. And we just have to be patient. And then sometimes we’re allowed to go through suffering so it mimics what he went through. Not that it’s intentional but that we are more dependent on him.

Jason, recognized as a spiritual leader in his local native community, organizes sweat lodges, integrating his herbal knowledge from his grandmother, as depicted earlier. “I’ll get a sweat lodge going. Are you familiar with that? That’s good for several kinds of ailments from arthritis to back pain to asthma. You know we use that a lot for a lot healing. Of course we’ll burn different herbs and spices in there for whatever the ailment might be.”

Though spiritual leaders like Jason organized sweat lodges, others, like Cheryl, are less trusting of the ceremonial resources and therefore power.

It just depends with my native background, we’re really particular about who we sweat with and who we let touch us. And I have so few resources in that area, it’s really difficult to even reach out and get that type of treatment. Because I won’t go to just any sweat lodge.

Her justified unwillingness to trust, however, leads Cheryl toward desperation about how to alleviate her pain. Fern also felt conflicted about ceremony. She wants to go to ceremonies performed in the right way and yet worries her own condition—the cause of her pain—will keep her from fully partaking.

The whole idea is not to eat, not to sleep, not to drink and no meds. It’s all a cleansing thing. That’s my only issue with that. Even though I’m going for it. I’m trying to find something that

will help me naturally. Plants I can chew on or things that help with that situation. Cause even spiritually, trying to sit and meditate or pray or whatever, if you got to get up, you got to get up, but when you're doing the setting out ceremony you're in kind of a small place under a tarp.

There are less involved ways for participants to participate in ceremony without dedicating themselves to a sweat or cleanse. Dorothy attended powwows to hear the gourd songs and uplift her spirit. "I just wanted to hear the music, because I sing at the drum with the women singers, and the gourd songs always uplifted me. They are like prayers to me. And so I just wanted to hear the songs." Ultimately, ceremony functions for healing of mind and spirit and therefore participants used ceremony in conjunction with the self-care remedies described above and the clinic-based treatments described below. Carmen summarized, "I've always leaned that way, towards natural medicine—actually, the blending of two. I've always been spiritual...I don't believe in strictly alternative medicine. I think you need both, but I do know that you need—you do need both."

Natural Remedies Many participants sought out natural remedies as a way to chemically manage the pain without introducing pharmaceuticals into their bodies. Teas, spices in cooking, and essential oils in baths accounted for the extent of natural remedies incorporated. Jason and Shanta had developed extensive knowledge of natural remedies, which they shared. Jason's grandmother was a traditional healer, and he recalled spending time in her garden, watching her prepare healing concoctions. The aggravation of his pain with age had led him to reopen the knowledge he received from his grandmother and put it to use in his own healing.

It seems like every year and year the arthritis is really getting, the pain is getting worse. 'Cause I won't take nothing for it....Now I lately, lately have been trying to go back to my own roots and herbs. And just have started taking certain teas and roots that do help with inflammation and stuff and that has been helping....[My doctor] thinks it's a good idea for me to get on our native diets and stuff because of course before the white man came, we didn't have diabetes, blood pressure and what not.

Shanta studies ecology and environmental social justice. Her love of Mother Earth motivated her to learn as much as she could about all of Mother Earth's

gifts, especially those found on her one acre secluded, wooded property. She provided an example:

I use sage, and it gets rid of—brings down the inflammation and takes the pain away, and it's gone the next day. I just put a leaf of sage in my mouth, and that's all I need. I don't even talk about it, because I'm afraid that the government will put a ban on growing sage, if they find out it works and people are using it.

As Shanta eluded to, the effectiveness of natural remedies is cause to worry about regulation. The community of those who know, therefore, teaches quietly and in private spaces.

No Pills The medicines that most participants reject are healthcare provider prescribed narcotics, anti-inflammatories, and acetaminophen. Before launching into the reasons behind an almost universal rejection of pharmaceuticals, in this sample, Fauna related that medicine carries many meanings. Therefore when I refer to prescribed medicines, I will use the term pills or pharmaceuticals.

When they hear the word medicine, they assume something that's either injected or taken orally. There's all kinds of medicine. There's a medicine that you carry, that you can share with people, that help with different healing, healing of mind, spirit, whatever. Or just talking to somebody and sharing with them.

Therefore, according to Fauna, all of the practices portrayed in this chapter qualify as medicines in one sense or another.

Participants rejecting pain pills primarily derives from personal reactions to the pills, including desire to maintain a sober life, fear of dependency, inability to swallow pills, uncomfortable or life-changing side effects, and familial rejection of pills. Cheryl characterized the urge from both the pain in her body and from healthcare providers to use pain pills as a slippery slope. She saw taking pain pills as disrupting an otherwise sober life where she functions at a high level, despite her pain.

Not only that, but, you know, I've lived a sober life all together. I mean I don't drink. I don't do anything. And I'd like to keep it that way. And I felt that you know it's kind of a slippery slope. And really didn't get a whole lot of relief from it anyway. I pulled myself off of everything they had me on. And if I wasn't stronger,

I could be laid up on disability right now, probably, just because of the medication. Not just because of the pain. Umm so I put a stop to that.

In her fierce stubbornness, she dealt with the pain on her own—chemical free. Keira also mentioned the slippery slope of dependency. “So I don’t like pain pills; I don’t want to be dependent. All those natural things. So I try to use, and I do a lot of research myself, with different types of medicines. When I say medicines, I’m speaking of natural medicines of our people.” She believes that natural native medicines have fewer habit-forming properties and therefore lead to less dependency.

Basing his judgment regarding dependency on a personal experience of needing more and more pain pills for relief, Jason said:

If today I’m hurting and I take one pain pill. If tomorrow I’m hurting, I live with the pain, because tomorrow if I take that pill it’s like my body gets used to it and then it doesn’t do me no good. I have to keep increasing it. So therefore because I don’t want to increase the dosage and this is something I do myself...because I wait until the absolute highest pain that I can’t tolerate and believe it or not when I take that pain pill your average person might be like woo, you know, they are in lala land. In reality it just kind of tones it down, but I’m still in pain. So believe it or not even with the strong pills, it’s not taking my pain away. It’s not taking care of the problem it just helps me bear with it a little bit.

He also remarked on how individuals respond differently to pain pills. Andrew, for instance, cannot swallow pills, which limits the availability of analgesia. “But other than that it was just massive rehabilitation. It was like that’s the treatment. A pill, like I said, unless it’s in liquid form or you’re shooting it into me, I’m not trying to swallow a pill. And umm so I would just have to deal with it.” The external motivation keeps Andrew far from the slippery slope of dependency.

Like Cheryl mentioned, side effects from pain pills are often perceived as worse than the pain itself. Terry described feelings of restlessness with the pills without any pain relief. “And swallow pain medicines. I try not to take as much as they give me but sometimes they don’t even knock me out, they just subside my pain, and I just lay there feeling restless. They give me the highest dose, but I don’t like taking it. I hate taking pills.” Gwen mentioned

how she cannot perform her work tasks if she takes the pills prescribed to ease her pain. Thankfully her need for pain relief increases on the weekends, when she does more physical labor around her house.

Then again, I don't like—they give me a muscle relaxer that the doctor wanted me to take. Well, hell, it knocks me out. Then it takes me up to like 10 or 12 in the afternoon to get—stop from being so groggy from it. I don't want that. I can't teach like that. I don't take it unless I really need it. That's usually only on the weekends.

Both Strider and Rosaline suggested that the economics of pharmaceutical manufacturing makes them wary of taking pain pills. Strider said:

I don't take any pills of any kind. Like I won't take Advil and I know things like ibuprofen, anti-inflammatories. They aren't bad for you but I just try to stay away from putting anything in my body. As far as the, not medical industry but the uh whole industry around pills and medication, I try to stay away from all of that. And I don't like anything that dulls feeling so even something as simple as icy-hot, I don't really care for.

Strider preserved his body, living a sober life like Cheryl as well as distrusting the industry around medicine and pills. Rosaline began rejecting pills due to their side effects and broadens to a macrosociological concern that explains why pills beget side effects and then beget the need to take more pills.

But I would rather do that than drugs, because I don't like the side effects from drugs. Something that causes that many side effects, I don't think can offset what benefit they think it does to you. I think it's just a way for the drug companies to stay in business. That's just my opinion.

Cora presented a more micro reason for her distrust of pills. “But I refuse to take any kind of drugs that the doctor try to give me for pain. I don't know why, it's just, it's just the way I am. I was made that way, 'cause my mom is not like that. My mom takes. If she's sick or anything, has a headache, she'll pop pills and stuff like that. But not me.” She simply doesn't like pain pills. Likewise Bailey looked at how her pain has changed with her body changing and sought alternatives to pain pills. “I don't want to take muscle relaxants. I don't want to take aspirins and stuff. So what I'm doing now is trying to

get on muscle strengthening. Cause my age. My muscles are like spongy, and I don't like that."

Daring to reject pills while integrated into the healthcare system for treatment has consequences. Verbena emphasized what occurs with pharmaceutical pain management when part of the healthcare system. After her car accident, she remained in a hospital or rehabilitation facility for months. During that time shelves and shelves of pills sustained her. "And I was on so many medications and that was hard, because I've never been a medicine type person. I try to heal naturally or eat healthy." It took immense courage for her wean herself off the pills that seemed so vital to her thriving. Likewise, when confronted with a breast cancer diagnosis, it took courage for Keira to refuse chemotherapy and pursue healing in her own, more spiritual, and culturally-salient way.

I refuse all treatment. Even chemo. So I go to a second opinion. And the same thing, I refuse treatment. So then they recommend I go for psychiatric testing, because then they are concerned if I am suicidal. Oh whatever. Because I won't let them murder. I'm suicidal, because I won't let you murder me. And that's how I look at that. Because I've been there, done that. And when I had congestive heart failure and almost died. With the chemo you want me to die again.

The reaction of providers to Keira's refusal of treatment denotes a larger concern about the unusual response of the population I sampled to analgesic treatment. Not dulling pain with pharmaceuticals is counter-cultural and begs more unpacking of why.

Beyond negative personal reactions to pills, participants identified two more reasons why they reject prescription pills for managing their pain. The first reason manifested from their observations of the many others in their communities, both local and native, hooked on pain pills. The second reason derived from a deeply-held understanding that pain pills dull sensations at the neural level without addressing the root injuries generating the pain. Maynara remarked about the current pill-popping culture. "People now, it's like. In order do survive you have to have air, you have to have water, you have to food, and you have to have pills." The desperation for pain relief has infiltrated every aspect of life so deeply that pills become a bare necessity. For Alma, her observations of drug dependence in her community aligned

with her personal poor reactions to pills, leading her to use a traditional native remedy instead—bear grease.

Because you know those medications, becoming dependent on these pills, you feel the physical effects of it when you don't take it and those feel worse than the pain. You know and these dependencies can become out of control for a lot of people I've seen it. And I don't want to get to that point. So I really try to look at things from a healthier all natural perspective and treat myself that way. And although my boyfriend says the bear grease doesn't work. I think that works great. That's better than Tiger balm, which Tiger balm is really good. We use Tiger balm and biofreeze and all that stuff for our joints when they are really bad. But I think bear grease does it too.

Instead of relying heavily on a traditional native balm to avoid the drug dependency Jason has witnessed, he cited his own spiritual connectedness as his source of strength for enduring the pain without dulling the pain. "I know of other people unfortunately and many natives, they just get on it and it escalates to a drug problem. Unfortunately. I try personally to avoid that. And I think my success in that is that I'm in tune with my spirituality so I think that helps me."

In addition to concerns about escalating pain pill usage, Jason also noted that the pills fail to resolve the root cause of the pain.

The pill doesn't really solve the problem; the pill just helps deal with it for a little bit. Some of the herbs and stuff will solve the problem, but unfortunately it's a long haul. It's not ok take a drink and you're good. No. You have to get it in your system. It has to be through your system unfortunately.

He suggested, instead of pills, a more systemic natural remedy born of the wisdom of generations, including his own grandmother's knowledge of herbs and spices. Morgan repeated Jason's attention to the need to treat for the long haul. If chronically using pain pills leads to dependency that only dulls the pain less and less, without promising pain free living, then some deeper, more holistic remedy or combination of remedies functions better as a permanent fix for the pain.

I won't ever ever ever go to a pain management specialist again. I don't want to be filled up with pain pills. I just want to feel

better....You know the medicine is a temporary fix. And I'm not looking for a temporary fix. I'm looking for the long haul so I'd rather not be pain free for a few years and then have other issues to worry about or deal with the pain and not be on the medicine and not have to deal with the side effects. If I can manage it that way, that's better in my mind then having to take that stuff.

Alma worried about pain pills only masking the pain, reflecting the inadequate answers she has received about the true cause of her pain. "So they are giving me medicine to mask the pain, and there hasn't been any real treatment for the pain. Like they haven't prescribed therapy. They haven't even prescribed like an MRI or x-rays or anything. It seems like they are just medicating the issue, and there's no real treatment." In contrast, the traumatic life impact of accepting that their chronic pain may have no real treatment leads a handful of the participants I interviewed to desire pain pills with a resounding yes.

Yes to Pills Despite an overwhelming resistance to analgesics, especially opioids, most participants characterized a good day as a day they could accomplish everything they wanted and a bad day as a day they needed to take at least an over-the-counter pain medicine just to get out of bed in the morning. Dorothy explicitly characterized the bad day: "The bad day is when I take ibuprofen. I don't like to take pills. But I have to take 800mg of ibuprofen, I'm in trouble. But sometimes I have to. Like there's times when I do have to pre-take it, because I'm going to be doing." Barrett gauged the intensity of his pain over the course of a week based on how often he needed to take an anti-inflammatory. "If its warm and active, it tends to subside especially if I've taken medicines and put the hypo-gel Arniflora Arnica Gel rub in, maybe taken a painkiller. If it gets too bad, I'll take a painkiller. Fortunately I haven't taken one in the past two or three days, but I'm still taking my anti-inflammatory." By invoking the weather's effect on his pain, Barrett also took away some of his personal responsibility for needing the analgesics. He was that reluctant to take something. Willow also shared how awful the pain must be to motivate her to take pills for pain. "But I don't like to take anything for it. I only do it, when I can't stand it."

Many of the participants, like Terry, have experimented with removing analgesics from their pain regimen.

I hate being drugged up. To be normal. If I. I tried one month I didn't take nothing for it and it was just unbearable. I couldn't even. I went back and they just keep every three months or four months I get steroids, and I'm fine. I get shots in my knees every three months. And it makes it so I can survive or walk. I don't want to be in a wheelchair. I don't want to go that far.

The result is unbearable. Rikki talked about how with increasing pain in the past few years, her need for over-the-counter pain pills has increased. "I guess just the last few years, I've noticed that it hurts a lot more where I might take an over the counter for it. But I try not to take much. But I try to do it with heat and just stretching." Kelly also reflected on the unwanted necessity of medication. "I sit there and I see people who are like pill poppers ,and I'm like what, why would you really want to take that? No! This keeps me alive, and I'm trying to find herb to replace it." She would rather use a natural remedy and has already begun to eliminate some of her medications by switching her dietary choices. Others took medications for chronic conditions like hypertension and diabetes but not for chronic pain, for fear of dependency and addiction as described above.

A handful of participants, though, like Cassia, both needed the pharmaceutical management of their pain like Terry and Kelly and wanted it. For Cassia, the availability of narcotics becomes a matter of life and death.

I'm on that pain medicine Percocet 5.35. But it could be stronger. Because I think if I was without pain medication. I don't think I could. I don't know what I would do. Just be crying. I'd be. I wouldn't be nice to anybody. Yeah if they took my pain medication away, I might try to kill myself.

For Luke, as well, the pain goes away with narcotics.

Again if you take the meds, then it dulls it and it takes it away. I'm on hydrocodone. So it takes it away. But then it wears off and you know. Doctors worry really a lot about it getting addicted, which for me, I don't feel any addiction to it. I just take because I have to take it. Recently we now have to go in and be tested every four months.

Luke perceived that he is not addicted, though he depends on the hydrocodone for taking the pain away. The differentiation between addiction and dependency sways with a delicate balance. Most participants chose never to enter the balance and, those who do enter, do so out of complete necessity.

Clinic-Based Treatment In this section I describe the various but limited encounters participants have with the healthcare system specifically for their chronic pain. Most participants initially saw a healthcare provider for the incident that precipitated their pain. But, as has become clear from their reluctance for pharmaceutical management, few participants continue to manage their chronic pain in partnership with a healthcare provider. About 70% of participants receive yearly physicals, but chronic pain usually remains out of the exam room conversation.

Even those who see a healthcare provider regularly have qualms about the quality of care. Cora, for instance, renewed her prescriptions for chronic illness medication (not pain pills) through a healthcare provider every few months, but her healing comes through her self-care practice of journaling. “So I do go to the doctors every few months for that medicine. But my healing source is my journal.” Others, like Barrett, have exhausted nearly every diagnostic resource, done extensive individual research, and still ended up with primarily natural remedies for pain. “I go to the doctor, have x rays done, MRIs done...I’ve read boatloads of materials about pain and what are some of the natural things you can do.” When questioned about what she does for pain, Edith begins by mentioning that she goes to the doctor. But like Cora and Barrett, her self-care practices provide more relief than the provider. “Like I said I’ve gone to the doctor. That’s mainly it. Take an aspirin. Do the ice packs or the heating pads or alternate them.” Kelly saw numerous healthcare specialties in order to fully manage the range of her chronic pain symptoms. “I started getting chiropractic, osteopathic, and orthopedic care at 8 years old.”

Fauna, Iggy, and Cheryl told a common story about having exhausted the healthcare system’s resources up until the point of surgery. They are understandably wary of surgery. Fauna argued, “You can’t run in for surgery for everything because there’s certain drawbacks, I found, with the—even with the knee replacement.” For Iggy, the current constraints of life kept her from getting surgery despite the presumed need. “My Nation is. They gave me money to get a knee replacement. I’m in school. I can’t do it right now. I’ve got to get this stupid degree, and then when I’m done, I’ll do it.” Cheryl had given up hope that the medical community could provide her any relief, as alluded to in previous sections.

I've exhausted the medical community. I mean they don't even want to see me anymore. They really don't. The only thing they say is, 'Oh, your next step is surgery.' But when you look at the type of injury that I have in comparison to the surgery available, I'm looking at less than the quality of life that I have now, probably. And it's just not going to take that risk.

Distrust, in part, stimulates participants' reluctance to seek out clinic-based treatment. Gus judged the Indian Health Service (IHS) clinic in Chicago—one of 11 urban IHS clinics—as incompetent and untrustworthy. “And first of all, we have no such thing as Indian Health. They're supposed to be in the urban part. But I don't trust them. I don't believe in them. And they don't have nobody anyway.” Philip perceived his primary care treatment as haphazard and therefore harmful. Instead he manages his own pain.

Since they are not specialists, I think that they are up and down with the pills, the dosage, how much to give me so it's not steady. So I've been doing my own experiments at home to see how much will help me have a good day or kick my days up....Then the doctors when they looked at it said it's for any kind of heart disease, and so that's why I'm kind of confused on it, because I get a couple of different answers from the different specialists, from the different doctors. So there's nothing consistent so I just figure if I die, I'm just another person that dies to them. But for me it's a little bit more important so I kind of have to adjust it.

Cheryl likewise considered the treatments offered by her primary care physicians as detrimental to her ability to work.

My primary care physician, you know, the only thing he'll do is either shots just to numb the whole area out where I can't feel it, which I know still hurts, not a good thing, because I could injure myself further by further working and stressing it out.

As I explained in Chapter 3 when examining causal beliefs regarding chronic pain, participants think in a biomedical way about their pain for the legitimacy it instills. Participants do not, however, find biomedical treatments legitimate for addressing the depth of their suffering and enacting functional healing.

Failed and Enacted Relief The above care practices both enact pain relief and fail to relieve pain. Participants found that the simplest solutions are often the most effective. Terry experienced this with her clinic-based treatment. “But the more they did treatment wise, the more aggravated it were.” Likewise Cheryl, who above talked about her need to just manage it on her own, said, “I’ve been suffering with chronic pain for, I don’t know, ten years plus and can’t get any relief from it through any kind of doctors or pain management clinics or anything like that.” Despite her stalwart efforts to manage her pain, her work, and her life successfully, Cheryl still begged to know some possibility for pain relief. Barrett simplified his request: “Just relief of the pain. Not. I mean I know it’s not going to be 100% relief, but just relief the pain enough where I feel like I can function. Because when the pain get’s so debilitating that I can’t function, I’m like OK I need to do something different.”

Verbena and Fauna considered the ultimate healing something mental and spiritual. Verbena remarked:

It’s like they think there’s going to be a pill that will cure it. And there’s no cure. I go to them your mind or your spirit...that’s the cure. And it’s not really going to cure. But you’re not going to let it keep you in bed. What kind of life is that?

Years in the healthcare system doing rehabilitation and years in bed barely functioning led Verbena to the insight that her mind and spirit should be the target of her healing not the pain itself. Fauna believes that through prayer, true prayer, in the community, healing will occur. It just might not be the healing one expects.

Not so much with my Native friends. If you’re looking at them and they don’t look right up to their perky selves, maybe we’ll get into it a little bit. They truly, if you follow traditional ways, you truly believe true prayer and participating in that circle, that some sorta healing’s gonna occur. Sometimes it isn’t always a physical healing, it’s some other type of healing, but it’s what the Creator knows you need, at that time.

Fauna asserted that Creator within your body knows how to heal.

5.3.1 Pain Takes Away Pain

In this section, I discuss what Jason said, “I don’t know why it is when one pain, when you’re having one pain, it seems like it takes away from the other pain.” For Carmen, other illnesses function as a distraction from her pain. “It’s like when something else has come up to make me feel sick or whatever, those—it’s like they’re—like they [the chronic pains] never existed. Then the minute everything else is okay, boom, we’re back.” Edith noted a multi-month cycle for her pain. “It’ll come and go. I mean it’ll come and stay for a couple months and then it’ll ease off maybe again.” She visualized this cyclic pain by drawing three distinctive images for her pain (Figure 5.4). When she has pain in her foot, she has less pain elsewhere, for example.

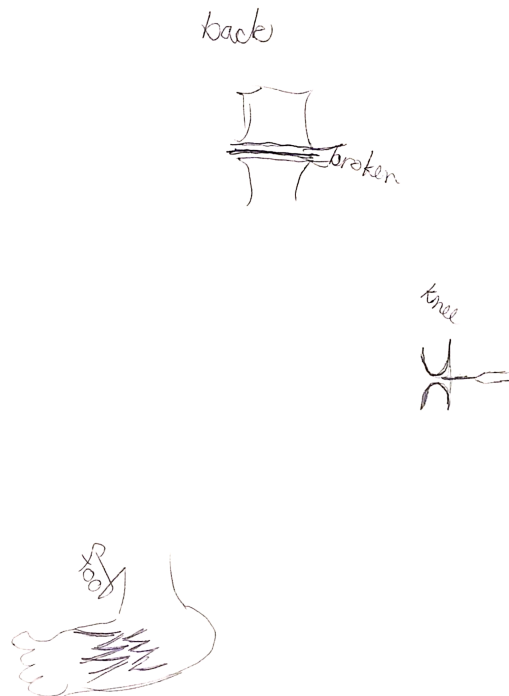


Figure 5.4: Pain in One Spot, No Pain in Another by Edith

In months when pain is less, participants must pay attention to what they do in order to keep the pain at bay. Bailey spoke about her attention to her every movement. “Because in the back of my mind, you can’t do this you can’t do that. You got to watch how you bend over. You got to watch how you pick stuff up. You can’t lift anything over really about ten pounds. So it’s just being aware of what you can and can’t do.” Other times participants,

like Iggy, are at a loss for how they actually have pain and then sometimes don't. "Even the doctor when I had my MRIs done, I don't know how you're walking. I said I don't even know how I'm dealing with the pain. It's just your body adapts to that. And it's been so long. But yeah there's times when I'm in a lot of pain. It just hurts so bad, you know, and I don't take anything for it." Rosaline intentionalized how she manages her pain to avoid aggravation. Mind over matter, she called it.

And you have to do the mind over matter with this. And just totally. And I've had three doctors tell me that I handle this disease better than anybody they've ever treated. And I said, 'That's because I don't listen to you people, because you people don't know what you're doing with this disease.' But I've also, my GP has said, 'Now look one of these days you're going to get in trouble, because you're going to be in pain and you're not going to pay any attention to it.'

Rosaline demonstrated that pain taking away pain can have consequences.

At times external assistance is required for reducing the pain enough. For Luke, the assistance comes from medications. "So you're aware of it. I mean there's pain all the time, the pain never goes away. It's just the pain medicine helps you just to be able to sleep. It just dulls it, you know. But it's always there. It's always in your mind. It never leaves." Carmen believed that losing weight would help ease up her pain.

Basically—I don't know if they're connected, but they probably are since this is all—with hips and that whole side, with the exercise that I have to do for the legs and the hips and stuff. Of course, it would help, probably, too, if I dropped about 25 pounds and not put so much weight on my—well.

In this section, I presented numerous healing practices that participants use to cope with the pain. I next talk about the strength that participants draw upon that helps them to survive and thrive with their chronic pain.

5.4 Survivance Regardless of Cure

Vizenor, 2008 defines survivance as, "Native survivance is an active sense of presence over absence, deracination, and oblivion; survivance is the continuance of stories, not a mere reaction (p1)." At the end of the stories

each participant told, I asked them a question for continuance. If you had three wishes to make you, your family, your community, and the world well, what would those three wishes be? Though the above care practices perform healing, they do not cure pain. Instead they foster endurance for coexisting with pain in wellness. Healing encompasses the transcendence of suffering. In this section I examine how participants think of their pain as shared and embedded in their families, communities, and tribes. Azure reminded that pain is deeply embedded in the native community, “I don’t think I have ever known anyone in the community that wasn’t in pain at some point or another. The elders are kind of always moving in a way that is not pain free or fluid.” The strength and power for participants to endure pain emerged from ancestral strength, ceremonial strength, individual strength, and social strength. I discuss each in the sections that follow. I end by elaborating on what one participant called ‘straightening things out’ or surviving.

Ancestral Strength Azure provided an extensive review of the ecology of pain in native communities and the necessary integrated care for healing.

Physically free or fluid. There is a lot of things that within the community might be linked to that. Alcoholism because alcohol does dull it. It really does both the psychological stress and the physical. Ummm. And within the community I’ve noticed that there are a lot of things that we don’t talk about. We don’t talk about child abuse. We don’t talk about rape. We don’t talk about spousal abuse. We don’t talk about the alcoholism. We don’t talk about the crime that is there. All of these things are painful to us. They are not good for our souls or our psyche. They are not good for our community, but we continue to perpetrate them, because we are just people trying to get along as best we can.

There are lot of things that have been heaped on us both as a people and individually with family histories that are very difficult to deal with. When your children don’t have enough to eat, you deal with this. And you may deal with this by going out and stealing. When you were abused by a partner or parent and you are ashamed by either yourself or your relatives about seeking psychological counseling and you can’t deal with it, you will turn to things like drugs or alcohol to numb...your...physical or psychological pain. You will get so frustrated in the world that you

might physically or verbally lash out at your community around you, at your loved ones.

And this pain and this grief from not only your personal history but your cultural as well. I don't know if the two are linked. But to think that we as people are more than just physical beings. We cannot separate the spirit and the mind and the body. We are beings on all these levels. What affects one has to affect the other. And if we can carry the trait on a genetic level. She has her mother's eyes. Is it not maybe possible that she carries the pain of her mother's rape? She carries the pain of the people with her. And that growing up when you are informed about what has happened to your people and that this is a factor of grief.

And then you see it growing up. Made fun of or hurt or abused for your race. Or have your race swept under the rug because you can pass. Uhh. It's all incredibly difficult. So it's possible that the wounds of the spirit mask physically. And more integrated healing might help.

From Azure's rich perspective, I mark a few points as exceptionally noteworthy: First, her causal belief that silence and burying abuse leads to soul wounds; Second, the absolute difficulty of not lashing out despite the continuing effects of colonization; Third, the desperation for numbness that nearly all participants rejected in this study but that is so common; Fourth, pain and grief are cultural and inherited; and Fifth, because the wounds cut through every aspect of a person, the healing must sew up the wounds on every level.

Roscoe re-articulated Azure's points regarding silence, colonization's continuation, and hope for a healing movement.

You know you got to speak up too. A lot of these Indians, some of our own worst things is because we don't say nothing. Ok yes we're supposed to overlook things, but hey if something's wrong what the heck, say something....I think to get over a lot of grief and a lot of different things that has been done. Yeah it's been done, but we need to speak up and take ownership of what is ours. So I mean yeah I wish we all still had our land. I wish but it ain't. Look at society through it, who's always been here? Us. Native American People. How many different forms have they tried to commit genocide? How many? Well we're continuous here. There's a reason. You talk to tribes all over the country. I talk to natives. And they all believe we're keepers of the earth.

So there's a reason we're here. We're not just going to go. And I think by keeping connection to our traditions yet still moving with our society, we can move through all them things. All them things that happened to us. You hear about tribes buying land back and stuff. I mean come on we can't just sit here and keep.

Roscoe added the powerful statement that his people are continuous—the keepers of the earth—adaptable and in that way, remarkable at enduring.

Andrew and Cassia also expressed awe at the ancestral strength that fortifies their own strength. In a nostalgic study of the history of his ancestors, Andrew grasped that he must survive. “Being a Native American, imagine how my ancestors were back then, you know. They weren't crying over a broken ankle or a shattered knee or stab wound. They were like, we need to move on. We have to survive. So that's how I feel.” Cassia also comprehended continued suffering as an undeniable source of strength, but she nuanced what Azure, Roscoe, and Andrew said by arguing that ability to endure pain does not mean that ethically pain should not be treated.

Native Americans they just suffer so used to suffering. Yeah I think it's my nationality. I've had several doctors say it's your good genes or like that. Or your nativeness or something. You can't always tell....They act like just because I'm Indian, I'm supposed to go through anything....Yeah you could like: ‘Oh you're just an Indian, you can suffer.’ So that's why I think. You know we had to suffer all them years like that....They were scared all the time. We never had no courts to take up for us. Didn't have nobody to take up for you. Had no rights. I think that's part of why we don't really like to show our emotions....Yeah it's a pain. You try to cover it up.

Shanta and Carmen identified gifts from the ancestors and Mother Earth to them in their treatment of pain. For both women, the gifts present themselves in specific places. “In a certain area where I would stand,” Carmen tells, “as I stood by this one area, my ears would just buzz so loud. As I moved away, it was less. I was talking to one of the elders, and I told him that, and he says, ‘Well, where were you standing?’ I told him. He says, ‘That's where some of the people from the Trail of Tears were buried.’ I'm, ‘Well, I guess it's picking up some of the energy or something.’” Shanta contrasted Mother Earth's gifts with Christian beliefs:

You have different beliefs than Christians do, because people who are Christian, everything is like faith, and ‘God can do this,’

and ‘God can do that,’ and forget that you can do things for yourself, because Mother Earth gives you things to use to do things for yourself. That’s what Natives have that Christians don’t have. It’s tough when people say, ‘God helps those who help themselves.’ Right, but they don’t have it in their beliefs. They don’t preach it. We live it, and it’s every day. Mother Earth has grown a tree out in my yard that I can scrape a little bit of the inner bark, and I can get rid of a headache. Another one I can drink, make a tea from the root, and it’ll clear up my head a little bit, make my blood go faster, stop blood pressure problems.

Cure may arise, Shanta believes, from the gifts associated with being keepers of the earth.

Finally, elders still living now will one day become ancestors. Shanta knows that someday she will be one of the ancestors and that determines her actions in the present day.

What we do today—that’s something that gives a person strength, knowing that it’s for your children, and their children, and their children. Someday I’ll be one of them. Star people, one of the ancestors. I can look out from the other side, but not if I don’t do what I’m supposed to do on this side. I have my responsibilities to the people, to my children now and my fellow man, mankind, womankind, and just my family. Everybody. Not just other Native Americans, not just other indigenous people, not just other people that live in the woods or whatever, but everybody.

The ecology of enduring pain for the participants relied in part on strength derived from ancestors.

Ceremonial Strength Ceremony provides the participants with extra strength for healing. Rosaline, highly self-perceptive regarding her pain, quickly realized the times she needed enriched strength for fighting the pain. At those times, she finds a powwow to attend.

But there was a time when he would say, you need to find a powwow. You need a dose of red. That’s what he’d call it. It’s like when you walk on the grounds and you hear that drum or you hear the flute and you see the people dancing and it’s just. It makes your soul feel good! So that’s how you handle that.

Jason called upon his warrior strength to endure pain during Sun Dance and his pain now.

What, me personally when I gave flesh I was in a state of prayer. I didn't really feel it. When they pierced me and I was dancing there and everything, there again I was in a state of prayer so. I guess what can I say? I guess a hypnotic stage. So I mean it really wasn't painful but it was. And I guess because we learned to endure that too....We are Apache warriors so you know we've always learned to live with, keep it strong.

Pain may continue to exist, but ceremony created, for participants, more calm physical pain.

Because ancestral and ceremonial strength promote pain endurance, many participants kept their pain disconnected from their race. Iggy argued:

I don't think nationality has anything to do with pain. Pain is just pain. I mean it doesn't have a name on it. It doesn't have a color on it. I think it does have something to do with lifestyle. And had I not been drinking and doing what I did, I wouldn't been doing some stupid stuff, you know. And then it runs in my family, alcoholism and addiction.

Nevertheless most participants, at some moment in their pain story, talked about asking God or Creator or Mother Earth the question Fauna asked to keep her pain at bay: "I think that's what a lot of people that have chronic pain could learn. You need to have—and you shouldn't dwell on it because that can make you actually feel the pain more. Oh, my god, my back, or my shoulder's killing me. Hey, God, can you help me with this pain?"

Individual Strength Participants demonstrated remarkable individual strength to endure their pain. Bailey explained her reason for fortifying her own mind against the pain.

There's obviously no cure, because I probably would have found it by now. So it's just managing it. And not becoming bitter about it. I have no reason to become bitter about it. It can feel at times like if you let hurt like that, then you can get depressed and I don't want to go down that route so you've got to be constantly aware of your own mental and emotional stuff.

Alma developed her individual strength through her mother's lessons. "Like my mom used to say, Stand up, be tough, you don't need nobody, get through your own shit. And you're like honestly, maybe it's better that I don't have

people to whine too, because then I'd be a bigger crybaby.” Alma also increased her individual strength through the empowerment of knowledge.

So like educating myself is important. And learning everything. Like when something pops up in my family, someone's diagnosed with it, I'm on it. I read. I google. I want to know what all this is about. Because if it's hereditary and we're susceptible to it, I've got to prepare myself. It's almost to the point of being neurotic about it. But it's come in handy.

While ancestral strength and ceremonial strength generate preparedness for dealing with pain, individual strength requires preparedness to be strength.

For Verbena, the necessity of developing her individual strength came at crisis moments of life and death.

And I had to learn to do it for my own survival. Because, like I said, I did try to commit suicide a couple times. The thing that did make me keep on trying was after my son was born. I said well if you're going to do this you've got to be all in. Because you don't want anyone explaining to your son that you committed suicide.

All the years she has dealt with pain, Verbena has worked toward telling herself it's ok. It's ok not to take the pills, because of the side effects. It's ok to take a day off, because you need to rest. It's ok to isolate yourself, because you heal better alone.

You got to find the ability within yourself to say it's all ok. If you don't, you'll keep on taking them pills and they will fuck your body up and your mind, because when you're doped up on so many pills, you don't know if you're sitting or standing. You can't understand what somebody's saying to you. That's going something to your insides. And it's probably not good.

Through the years, Verbena has learned what works and what doesn't work. Without prompting, Verbena provided her thoughts on individual strength—being true to herself. Individual strength prevents pain whooping ass.

If other people could learn those things. Breathe. Find the humor. Identify the emotions. Got to be able to identify before you can deal with it. And don't take all them damn pills, because they will keep you from fighting. And you got to care and not care at the same time. You can't care about whether somebody

wants you to do something and you just can't, because you got to know where your limits are for your own self. You don't have to please everybody, but you at least got to be true to yourself. And then the fibromyalgia can't whoop your ass. It gives it a good try. You just got to be stronger than it.

Social Strength I separated social strength from ancestral strength, because it is less racially determined. Multiple participants remarked that a good support system was essential to their ability to endure the pain. Verbena tied together social strength and ancestral strength.

Now if you can get a good support system, it makes it a little easier. If you don't, then you got to be your own self support. Then you got to find the support system. You got to get to the end of the race. That's the whole thing. You got to fight to be there. Fight to be there. Cause it is a fight. It's a fight for the right to live. Which the Indians should be good at that because they've had to do it for so long.

Cheryl also talked about how social strength requires putting things into perspective, recognizing your gifts and rewarding yourself for dealing well with the pain.

I mean being a strong woman for God's sake. These women who have been through. I mean I was abused and told I was no good and everything else from the 60s. I can't imagine what it was like. I mean I was talking to a woman the other day and you know she was taken away from her mother. And her mother was almost shot. And she was handcuffed and put in the wagon in 1944. You know. And you just. People don't think. Get over it and that kind of deal. Well you know what, these people are still alive. They are still dealing with it. Gives me a little perspective. I mean I've dealt with some crap, but there are people out there with much worse than me.

The social support for participants could both deter their healing and foster their healing. For Verbena, even if the people she loved deterred her healing, they ultimately provided important support. "And I've been around death all my life, but the wreck really brought it home that you've got to really treasure those moments with the people that you really care about, even if they do piss you off sometimes." Marcella experienced shared social suffering with those around her, especially those in her church. "I think I

realized it, because when the weather changes that affects how I feel and how I move. And Oklahoma's weather is changing constantly. And we have a lot of people with arthritis in our congregation you know. So when it turns cold or damp, we have. We all suffer the same thing." For Marcella, it is a suffering together that allows her to keep on going.

Straightening Things Out and Surviving Maynara critically reminded, "But laughter is good medicine. That is the best medicine there is." Participants believe that there is no power in sitting there and crying, because no cure exists. The pain must be survived. Verbena questioned, "It's like they think there's going to be a pill that will cure it. And there's no cure. I go to them, 'Your mind or your spirit...that's the cure.' And it's not really going to cure. But you're not going to let it keep you in bed. What kind of life is that?" It is not a life any of the participants choose to live. A parallel question, though, is, what can straighten things out and motivate persistent endurance? For Maynara the answer for survival existed in love.

It's like our people, we were never prejudice. That's the reason you see these Cherokee. It's hard to find a full blood, hundred percent, Native American Cherokee, cause they took in the whites. They took in the blacks. They took in everybody, because we weren't prejudiced. You know we're loving people. Get back to being the loving people. Focus on love and respect. And I think that would straighten things out, I really do.

As if with a shrug of her shoulders, Cassia commented:

Our people just kind of survive. We're just used to trying to survive. We've never had. After Europeans came, our old way of life and happiness was taken away. That was the end of our world. And as far as and now we're getting just like everybody else. We're getting sick. Like I say it's just intermingling, blood, the food. We never ate food like this before.

It's not complicated theory. It's not profound and innovative approaches to decolonization. Survival just is, despite the immense lack of hopefulness in questions like Azure's: "But when...it's very difficult to heal oneself, when the pattern seems to keep happening. And how do you heal something that's generational? How do you heal something that is a people's healing, especially when you won't be heard as a people, as a sovereign people?" Even with questions that seem unhelpful, Azure presented a solution for healing:

I would wish...for the healing of my people through their pain, because not only physical but there's a great both personal and cultural sadness that comes. And I don't think anyone has any ideas of how to fix it. And we can offer up very simple solutions like a return to the old ways or this, that, and the other. But quite frankly that's not going to happen. We have to integrate while maintaining a cultural identity. And the third one would be for a broader spectrum. It would be for the non-native community for them to have their eyes and their hearts opened, because there's still a lot of racism that's out there.

What Azure is saying reflects continued concerns with entire communities poorly coping and the harm that may cause. She also provides hope for communities coping well.

The chronic pain journey itself may proceed through folds in time and space for the participants. It may repeat itself. But they survive despite everything and sometimes even thrive. Jason argued, "I honestly believe the ones that are going to survive are the ones in tune with Mother Earth and know how to live off of her. Because it seems like things are going kind of bad unfortunately." Shanta described her journey,

Your whole atmosphere, your whole star system, everything. You'll always be a part of that. You'll never be separated from that, no matter where your body is or what your body is like. Those thoughts will always be there. They'll be passed on. When you're gone, those thoughts you had when you were alive will keep perpetuating through the future generations, keep moving in a circle. It's constant. It never stops.

5.5 Conclusion

In this chapter—Surviving: Prayer First, Then Pills—I elaborated on the numerous and diverse healing practices that participants call upon to manage their pain. Remarkably, these healing practices are more likely prayer and ceremony than narcotics. I discussed micro and macro self-care practices that assist participants through both good and bad days with pain. Finally, I presented various sources of strength that participants foster to endure their pain, including ancestral strength, ceremonial strength, individual strength,

and social strength. Ultimately participants seek to survive and thrive as native people in pain.

Conclusion: An Integrated Critical Theory of Chronic Pain

*“All pain is real enough to those who have it; all stand equally in
need of compassion.”*

– A. Miller in *Ingenious Pain*

In this chapter, I consider theoretical, methodological, and practice-based implications of this research. The broader implications are significant, because they help to strengthen the position of those suffering from pain. The person suffering from pain is the expert on their experience and how to best cope. Therefore these implications, like the results of this research, emerge directly from the data. If through this research, I motivate more sociologists and more physicians to engage in healing through their theory, method, and practice, then I have made a deep and lasting point. I want to encourage witnessing to chronic pain with humility. In its essence, each implication is about storytelling—theory that tells more profound, critical, and world-changing stories; methods that uncover more complete and powerful stories; and clinical practice that allows enough time for attending to stories. All of this storytelling needs to occur for healing to occur. As a conclusion, I also present an integrated critical theory of chronic pain that emerges from this study. This theory amalgamates the themes from this study in the broad areas of: characterizing the chronic pain itself, understanding the wide and deep impacts of chronic pain, and nurturing living well with or despite chronic pain. I model this integrated critical theory as a reaction at equilibrium between surviving and thriving—an intersecting living process trending toward balance. I end with study limitations and suggestions for future research.

6.1 For Theory

Participants wanted their chronic pain to be understood within the context of their identity as American Indians who, as such, gather strength for coping from ancestors, community, tribe, and ceremonies. They frequently wished, when asked about three wishes that would make them well, for a better, more peaceful, less environmentally unstable world. Aligning with existing conversation in Indigenous critical theory, the better world participants wish for is a decolonized world. In existing conversations about decolonization, attention paid to those in chronic pain enables much more profound healing. Million, 2013 asserts, “I think that while *healing* has become a ubiquitous word, there is less examination of the terms of this ‘healing’ from a wound characterized as colonization (p12).” Decolonization is the healing Dian Million speaks about with a goal of decolonized care to be removing “the actual hindrances

that impede groups' striving (Povinelli, 2011 p160)." This research examines a symptom of the wound—chronic pain. Therefore I consider the care practices that participants use to alleviate their pain and that enable them to thrive with their pain as decolonized care practices. Decolonized care practices have implications with other groups that have experienced trauma, personal violence, and ethnic violence. For example the Ndebele in Zimbabwe and the Tutsi and moderate Hutu in Rwanda.

"One's door should be opened from the inside (p26)," asserts Lyons, 2010 as a primary principle of decolonization. "We will begin to realize decolonization in a real way," write Alfred & Corntassel, 2005, "when we begin to achieve the re-strengthening of our people as individuals so that these spaces can be occupied by decolonized people living authentic lives (p605)." This quote represents why discussions of decolonization so often lead to non-strategies, non-interventions, and hopelessness. What is real decolonization? How do you re-strengthen? What spaces need to be occupied? Who are authentic decolonized people? Then there is the hopeful recognition that if decolonization results in misunderstanding, that too can be a generative space. "It is precisely experiences of misunderstanding," argues C. J. Throop, 2010, "that potentiate possibilities for new horizons of mutual understanding to arise, even if fleetingly so (p772)." Misunderstandings require an intentional wrestling with victimization and victim mentality. A wrestling that, once moved through, enables letting go and letting be—a living beyond.

The participants in this research provide inspirational models of living beyond. They laugh through their pain. They allow how their ancestors suffered to potentiate their own suffering and foster their endurance. They find micro and macro ways to be positive, hopeful, prayerful, and uplifted people even though they still hurt. They tell themselves positive stories about who they are as dis-eased persons. They enact a "living model' of health [with] social system, economic systems, political systems, biological systems from Indigenous knowledges (Million, 2013 p161)." Million, 2013 describes further a living model of health and care and healing: "Healing is discursively linked to self-determination but in practice rarely informs the political spaces where those conversations take place. Healing gets deferred to conversations about 'capacity building' and 'human capital' (p19)." Taking a credulous tone, Million, 2013 continues, "If the Indigenous don't heal, they may not be able to self-govern; in any case, they would need to heal to be self-sufficient

(p105).” Psychic pain is that which prevents self-determination or economic and political development. Though the participants in this research describe immense psychic pains and feelings of isolation, they live with pain in a decolonized way through many sources of strength. It is not complicated theory. They are not profound and innovative approaches to decolonization. Survival just is. And thriving just comes with a bit more attention to the little things that make pain liveable.

6.2 For Methodology

You should understand
the way it was
back then,
because it is the same
even now (Silko, 2012 p94).
Leslie Marmon Silko states the timelessness of story.

I practiced a methodology with this research that sought out relationship and relied upon reciprocity. Although I initially coded all interviews, participants were able to revise their interview transcripts upon seeing them in writing. In addition, participants provided the definitions of the themes that govern the organization of this dissertation. If a theme failed to connect with their pain stories, participants could eliminate that theme. My methodology strives for the ideal that Gone, 2007 and Keira describe. Gone, 2007 asserts:

As a custodian of so gracious a gift, my obligation is to continue advocating that practitioners and researchers of good will seriously engage the local norms and assumptions of American Indian communities with regard to personhood, distress, and healing. Together, we must collaboratively re-imagine Native American ‘wellness’ in local cultural terms, along with the community-based partnerships and programs ideally suited to its recovery and circulation (p298).

For this research, I participated in events, especially powwows, within the local community. I got to know many members of the Indiana American Indian community in particular, becoming familiar and comfortable with the

local norms. For the communities with whom I had less engagement, I worked through respected community members.

Keira presented her methodological recommendation about listening when I asked her about three wishes for wellness. She told a story to back up her point.

Wish number three would be that someone would listen. The doctors. I'm suicidal, because I won't take your chemotherapy. Bull. You know what I mean. That the doctors would listen. That the healthcare people would listen. That, here's another example, my patient navigator at the hospital, they are having a big national conference and she comes to me, I was wondering if I could use your journey story to make this poster for patient navigation and if we win, we get to go the nationals with it. Ok. What do you want to do? Oh cultural. She had already talked to people and found out it was going to be a 100% go, because culturally when I got the cancer diagnosis, I did self mutilation. I started the scratching, pulling my hair, right in front of the doctor. The doctor says, 'What's going on to my daughter?' 'Oh my mom has PTSD and she thinks with the cancer, she's going to lose who she is and her hair will fall out and hair means a lot to our people and our strength. And she'll be bald. She's talked about she'll not have any color. She'll look like a walking dead person. And she won't be Indian anymore.' And the doctor had NO understanding whatsoever.

And so this patient navigator, she wanted to use this story of how I had found through difficult. I didn't give up. I sent her a Colorado Native American cancer research place. I had found that place and they had hooked me up with a girl and she walked that journey with me. She was Native American, she lost her hair, she walked that journey with me. Umm so the girl I gave her permission to use that. She wrote it up. She won first place. And uh she didn't tell me I won. And I go to group therapy for cancer survivors. And that's a hard thing in itself. And the therapist there said, 'Oh did you hear, she won first place'. 'No really?' I said. 'Man I haven't seen my brother in seven years. He lives in Orlando. That's where the conference is.' And she said, 'Oh well then you get to see your brother.' He had the cancer journey. And we haven't seen each other since we both walked that journey. Oh I get to see my brother. And the whole group is like 'yeah Teresa' and 'what do you need to go' and 'we'll help you'. And they are all just ladies who have walked that journey. I get an email the next day. Well he had told the navigator that

he told me. ‘Oh umm I’m sorry that I didn’t tell you that I won first place. By the way, oh and I’m glad that you hooked up with Dr. maybe she’ll help you deal with some things. And I hope you hook up with Dr. and he might give you better advice for how to deal with your scleroderma. Oh and by the way, I found out there’s no funding available for associates or patients to go to the conference. But I can help you set up on Facebook a webpage to get donations.’

The questions of what qualifies as quality methodology and quality clinical care are difficult to answer. Is quality linked to price? Is quality linked to statistical power? Is quality linked to CBPR methods? Does quality come with more things done? In some ways I have certainly failed to fully meet the above ideals. I have not maintained a long term relationship. I did not attend any powwows this past powwow season while writing. I had to distribute my time between three communities so less time was spent assisting each community than I wanted. I only visited Tulsa for one weekend. I have, however, prepared a model and summary of the findings to give back to the communities and individual participants for their own use. While the pain stories participants told moved through very difficult stages of their life, we ended in a place of hope and resilience. With their strength, participants continue to live well with pain. With my own strength, I continue to advocate for those with forgotten and ignored pain caused by continuing colonial practices. I bore witness to some powerful stories about chronic pain, and I shared them so others may learn.

6.3 For Clinical Practice

Gone, 2007 reminds, “The culture of the clinic is not the culture of the community (p291).” Nevertheless this research provides implications for improving clinical practice. Cultural and structural competency, alongside patient-centered care, in the existing literature, shape the language regarding how to interact with diverse peoples within the clinical encounter. The American Medical Association defines core competencies regarding cultural interaction. Structural competency, proposed by Jonathon Metzler, director of Vanderbilt’s Center for Medicine, Health, and Society, and Helena Hansen, assistant professor of Anthropology and Psychiatry at NYU, re-orientes cul-

tural competency to broader structural constraints on the medical system-population interaction. Metzl and Hansen quote a Robert Wood Johnson survey in their recent *Social Science and Medicine* article introducing structural competency. In the survey 85% of primary care providers agreed that “unmet social needs are leading directly to worse health for all Americans” and yet primary care providers did not “feel confident in their capacity to meet their patients’ social needs,” which “impedes their ability to provide care.” Metzl & Hansen, 2014 write, “Social, in this biomedical frame, becomes a monolithic or immutable force that functions beyond the reach of medical imagination or expertise (p129).” Sanderson et al., 2012 encourages providers, attempting to be structurally competent, “to ask an indigenous patient about perceived causes and even treatments to build a mutual understanding of the condition and treatment strategies.” Other ways physicians may change their practice would be to avoid stereotypes, acknowledge holistic healing more than physiological cures, and recognize healing as a way of life more effective than the unattainable cure for chronic illnesses, like chronic pain.

Keira, Azure, Willow, and Verbena gave their own recommendations for improved clinical practice. Willow decided not to go to the doctor, because of poor clinical practices. “I guess I don’t go to the doctor, because I’m afraid they will see something there that they think they have to deal with, the doctors, and I’d rather not. For Willow, healthcare providers seeing problems with her instead of in her or on her would increase her trust in accessing care. Verbena also distrusted healthcare providers who failed to find something wrong in her body and therefore insisted her pain was all in her head. “Oh I love it when I meet a doctor who goes, it’s all in your head. I had two doctors tell me that. I looked at them and I said, ‘I’ll take offense at that when you can live in my body for just a day and tell me it’s in your head. But in the meantime, you’re a quack and what you got to say doesn’t mean nothing to me.’” The providers, unable to establish causation in conversation with a patient, are quacks, according to Verbena. The trauma from pain and historical trauma silence, while healing gives voice. There is so much left to learn to bring healing to the deep and profound origins of chronic pain. In addition prevention of the sources of chronic pain at the community level is important.

Azure described her relationship with her rheumatologist extensively. It’s

a relationship she built over years and years and therefore will not jeopardize. “And I will happily drive an hour and half one way to see this other doctor I’ve developed a relationship with even though I’ve had problems with him not taking responsibility for his own diagnosis and have had to, especially if you are low income and not white, you have to fight for good medical care.” In part, she will not jeopardize the relationship, because she gets tired of fighting for her healthcare as a poor person of color. Azure also wants to work on a team with her healthcare provider. Willow and Verbena distrusted their providers, because those providers did not participate with them. In other words they were not on the same team. Azure talked more about the partnership.

Well, when I started it was fix me, like run the tests you need to run, I will cooperate with you in whatever I need to. Now it’s like let’s work together as a team to come up with options that I’m comfortable because like the experience with the neurontin that I mentioned. Oh no no no no no. Ummm. When seeking medical care, I’ve noticed that it’s almost, there’s an attitude within the medical system of I am the Doctor, I am the God. You are the lowly patient, you will do what I say. There is not a lot of an attitude of working together as a team, and I’ve almost had arguments like this is my body, you don’t get it. And I will fight for my bodily integrity if I’m not comfortable with what you’re doing to me.

According to Azure, successful teamwork involves providers understanding that patients understand their bodies better than the provider. Therefore treatment arises not top-down from the provider but in conversation about what works. “Trying to tell people with chronic pain that they have to do something will put you in a stress mindset. It’s less of you have to and more of allowing people to set what works for them.” Ultimately, Azure would most trust providers who integrate spirituality with medical practice. “I understand that it’s going to be very hard to try to integrate a spiritual aspect to healing in an overall treatment program especially something that would be formulaic because spirituality in and of itself is not formulaic.”

Keira argued that providers should practice medicine as a calling.

They would be called into the field, all healthcare providers should be called into the field. I didn’t choose to be a storyteller. My grandma was a storyteller and my daddy was a storyteller. My

daughter's a storyteller. My granddaughter's a storyteller. That's something you're born into, you're called into, and I think that medical people should have to take some kind of a screening or something that shows their true heart.

The best providers do not choose to be physicians, according to Keira; they must *be* physicians. In summation, improvements will come in clinical practice if healthcare providers gather the entire illness narrative and work together with the patient to establish diagnosis and treatment. In addition a personal need to be a healthcare provider and a willingness to integrate medicine with spirituality will make providers more successful with patients like the participants in this research. Therefore the medical system that enables integrated care and team-based care likely will be more effective at addressing chronic pain.

6.4 Integrated Critical Theory of Chronic Pain

I sought with this research to create a database of experiences for urban American Indians living with chronic pain. As with other databases, this one can be mined for answers to targeted research questions. In modeling a theory for the chronic pain, I portray the database in its entirety and leave asking more targeted questions for future research. I do this because it is critical to understand the process before intervening to change outcomes. In this context, then, know the experience of chronic pain before trying to reduce the pain burden of a particular community.

So what is the experience of chronic pain for urban American Indians? The combined experience is a story and as Million, 2014 asserts, "Story has always been practice, strategic, and restorative. Story is indigenous theory (p35)." Bullock, a Native IHS provider, quoted in Sanderson et al., 2012, has said with respect to diabetes—an interesting comparison case for chronic pain—that our model has been too small. The western medical approach to diabetes has not considered the health impact of stress created by spiritual imbalance, loss of language and cultural practices and beliefs, and uncertainty of indigenous identities. Therefore the model for chronic pain I present seeks to be larger than existing models of chronic pain. It is deeply rooted in both the quantitative and qualitative data I collected. The model combines

physical and spiritual worlds, it crosses disciplines. It can keep getting bigger and bigger.

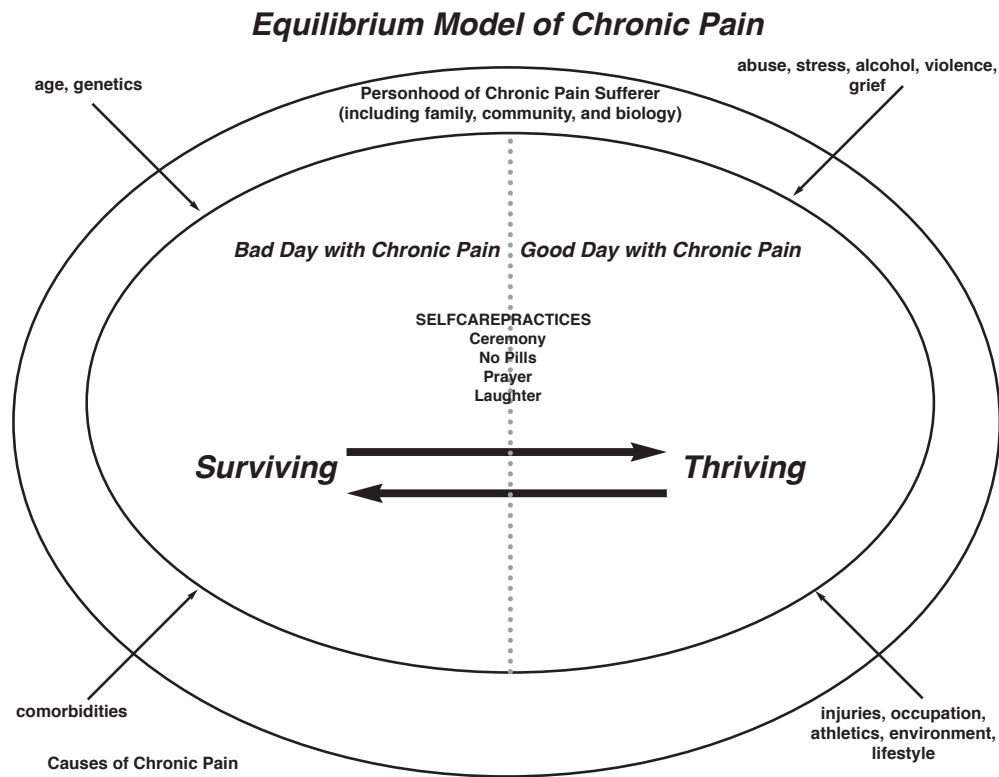


Figure 6.1: Equilibrium Model of Chronic Pain

Figure 6.1 provides the model, which I call an Equilibrium Model of Chronic Pain. The outer circle represents the entire personhood of those who talked with me about their chronic pain. They were American Indian adults living off-reservation embedded in families and pan-Indian communities. They also have a particular biology. Their individual and social personhood is currently struggling with chronic pain—the inner circle in the model. The pain has a personhood itself in relation to the person afflicted with the pain. The pain’s personhood encompasses a lot of the entire personhood. External factors cause the chronic pain. These factors include unchangeable characteristics such as age and genetics; changeable illness burden such as other comorbidities; incidental physical experiences like injuries, occupation, athletics, environment, lifestyle; and psychological and social experiences like abuse, stress, alcohol, violence, and grief. Maynara contended that most pain arises from emotional factors and general imbalance—side effects of abuse.

Cause I really do think the source of most pain, unless it is a physical trauma like an injury, is emotionally related. It's just like in the native, they talk about balance being physically, mentally, spiritually, and emotionally balanced. If you're out of balance, you get screwed up. So most would say if you're emotionally and spiritually out of balance, of course you're going to be physically out of balance.

Despite a diagnosis from a physician or a disease condition known to cause chronic pain, most participants still wonder what, inside the nerves, causes good days and bad days with pain? Participants broke the chronic pain down into physical, emotional, and spiritual. The consensus among participants is that emotional pain is much worse than physical pain and much more difficult to remedy. The inner circle encompasses all of these types of pain.

I have broken the circle in half to reflect an important dichotomy from participants between bad days with pain and good days with pain (Charmaz, 1991). For most participants, the bad days with pain involved taking an analgesic and retreating from the world. The absolute worst pain seemed easier to deal with alone, sleeping, or trying any method of mentally traveling away from the body in pain. Bailey defined good days and bad days. "Ok good days I can do pretty much what I want to do. Bad days, I actually had to take off a day of work about three weeks ago and that rarely happens, because of the pain." Iggy talked about her prayer on good days versus on bad days with the pain. "I think a lot of people that are in chronic pain, if they have any faith at all, like I do, I pray on it. Everyday I pray. Let me have a good day. Blah blah blah. He already knows my thoughts, but I make it a point to do that. I mean when it really gets bad, it's like oh God, what are you doing to me?" For Cassia the moments of most extreme pain radiate into other parts of her being so that she doesn't just hurt physically: "When the pain comes bad is when it starts affecting all your flesh, like you said your spiritual, your emotional, that's when it's bad."

Each morning participants wake up ready for whatever kind of day with pain they might have. Bad days with pain prompt participants to isolate themselves socially and mentally. They put all their energy into fighting negative thoughts. They confront confusion over why they have pain and where it came from. All of these fights leave them feeling isolated, empty, stabbed, and devoured. They do not know where to go next. They have had to change their conceptualization of the future, because they can strive only

to survive that day. Good days with pain allow the participant to become more aware of their body and all the ways it functions despite the pain. They come to perceive and relish in their own strength and the strength of their ancestors. They recognize their identity as a native person as a source of endurance and thus are able to thrive. Azure asserted about this continuum between surviving and thriving: “It’s less of you have to and more of allowing people to set what works for them.” The membrane between bad and good days is permeable. I illustrate that a reaction at equilibrium (or in balance) exists across the membrane. On bad days with pain, the participants succeed in surviving. In what both Alfred & Corntassel, 2005 and Holland, 2012 write, to be inhuman is to be surviving, just surviving. On good days with pain, the participants have the option to thrive. Self-care practices catalyze the movement from surviving to thriving. The goal of bad days with pain is to survive based on immense individual, social, and ancestral strength. The goal of good days with pain is to thrive, which involves immense resilience, gratitude, and forgiveness. Participants resist pharmaceutical interventions, except on the worst days with pain, in contrast to the current opioid abuse epidemic. Sometimes the only way to deal with the droopiness and emptiness, the nagging and frustration is to consider pain “like an old companion” as Verbena asserted.

Million, 2013 discusses one of the goals of my research—to examine a symptom of the wound colonization. “I think that while healing has become a ubiquitous word, there is less examination of the terms of this ‘healing’ from a wound characterized as colonization (p12).” This research begins an examination of decolonized care and hybrid healing practices that remove “the actual hindrances that impede groups’ striving (Povinelli, 2011 p160).”

In summation, pains—physical, emotional, and spiritual—arise from multifactorial causes—biological, familial, occupational, spiritual, cultural—and are experienced in multiple facets of life—identity, psychological, sociological, and cultural—therefore requiring treatment from multiple sources—biomedical, indigenous, and complementary/alternative/integrative. Surviving with chronic pain occurs every day but is particularly profound on the days when the pain hurts the most. Self-care practices may shift the balance from surviving to thriving with chronic pain. Those who thrive most are those who have survived more bad days with pain, more stressful life events, and more grief. Nevertheless each moment for my participants involves de-

termining where on the surviving and thriving equilibrium they will exist in that moment.

6.5 Study Limitations

The small number of participants in this study limits the statistical power of the quantitative analyses. Therefore I used an embedded mixed methods model where the quantitative data provides evidence in support of the qualitative data. In addition, more could be said about findings in both the quantitative and qualitative data if a comparison sample was established. The study population represents a very small subset of American Indians. Indiana and Illinois are rarely seen as Indian Country. The participants from these two states often were not registered with a tribe. Neither state has a reservation and few non-natives in the state realize that native peoples live there. Tulsa, in contrast, is more often considered Indian Country. In addition the failure to do in-depth participatory action research makes the findings slightly less applicable to indigenous communities.

6.6 Future Research

Future research will aim to increase the diversity of the sample as well as the power of statistical analyses. These aims could be met through having a comparison sample. For example, to address if the findings in urban American Indians are unique to that community, I would also collect data from American Indians living on reservations and non-natives living in matched communities. I might ask the following questions regarding care and caregiving in both white settler, immigrant, and indigenous populations. What kinds of care are sought out by each population? How is the care structured and accessed? What are the meanings of care? Who provides the care? Why is the care sought out? To increase statistical power, I would collect a much larger sample. The survey could be made available on the internet and therefore much more widely distributed. In addition future research will bring in other methodologies to create a simultaneously more broad and deep profile of chronic pain in American Indian communities. To collect more

rigorous qualitative data, I would practice a community-based participatory research model. This would involve creating a community advisory board that would assist the researchers in targeting the research questions to particular components of the chronic pain experience deemed most critical. I would also collect biological data from participants in order to determine more about the biological nature of the chronic pain. Biological data would include blood pressure, blood glucose, and cortisol levels at least as well as other cytokine markers of inflammation and stress. Ultimately building a much more complex profile of chronic in American Indians functions to ground recommendations for better treatment practices.

Appendix A

Interview Guide

The interview guide for the qualitative data collection presented in this thesis may be found in a supplemental file named: appendixA_interviewguide.pdf.

Appendix B

Survey Component

The survey collected from chronic pain sufferers for this thesis may be found in a supplemental file named: `appendixB_surveycomponent.pdf`.

Appendix C

Participants' Characteristics

A list of participant assigned number, pseudonyms, and demographic information may be found in a supplemental file named: `appendixC.codenames.participants.pdf`.

Appendix D

Variables

The variables used in the statistical analyses described in this thesis, including any recoding, may be found in a supplemental file named: `appendixD.variables.pdf`.

Appendix E

Pain Profile Correlations

The correlations between components of the pain profile from the McGill Pain Questionnaire and other demographic variables of interest may be found in a supplemental file named: `appendixE_painprofile_correlations.pdf`.

Appendix F

Trauma Profile Correlations

The correlations between components of the trauma profile from the Stressful Life Events Questionnaire, Historical Trauma Questionnaire, and Texas Revised Inventory of Grief and other variables of interest may be in found in a supplemental file named: appendixF_trauma_profile.pdf.

Appendix G

More Information on Participants

More in depth information regarding the story from each of the participants, identified by pseudonym, may be found in a supplemental file named: `appendixG_participants_moreinformation.pdf`.

Appendix H

IRB Approval Letter

The initial IRB approval letter for data collection may be found in a supplemental file named: `AppendixH.IRBapproval.pdf`.

References

- Adler, N. E. (2006). Overview of health disparities. In *Examining the health disparities research plan of the national institutes of health: Unfinished business* (p. 121-173). National Academy Press.
- Alexander, J. C. (2004). *Cultural trauma and collective identity*. University of California Press.
- Alfred, T., & Corntassel, J. (2005). Being indigenous: Resurgences against contemporary colonialism. *Government and Opposition*, 40(4), 597 - 614.
- Andersen, M. L., & Hill Collins, P. (1998). Toward inclusive thinking through the study of race, class, and gender. In M. L. Andersen & P. Hill Collins (Eds.), *Race, class, and gender: an anthology*. Wadsworth Publishing Corporation.
- Arthur, P., Gonzalez, E., Lam, Y., Rice, J., Rodriguez-Garavito, C., & Yashar, D. (2012). *Strengthening indigenous rights through truth commissions: A practitioner's resource* (Tech. Rep.). International Center for Transitional Justice, Truth and Memory Program.
- Barker, J. (2011). *Native acts: Law, recognition, and cultural authenticity*. Duke University Press.
- Baszanger, I. (1992). Deciphering chronic pain. *Sociology of Health and Illness*, 14(2), 181 - 215.
- Baszanger, I. (1998). *Inventing pain medicine: From the laboratory to the clinic*. Rutgers University Press.
- Beck, J. G., & Clapp, J. D. (2011). A different kind of comorbidity: Understanding posttraumatic stress disorder and chronic pain. *Psychological Trauma: Theory, Research, Practice, and Policy*, 3(2), 101.
- Bendelow, G., & Williams, S. J. (1998). *Emotions in social life: Critical themes and contemporary issues*. Psychology Press.
- Bendelow, G. A. (2006). Pain, suffering and risk. *Health, Risk & Society*, 8(1), 59-70.
- Berlant, L. (2006). Cruel optimism. *Differences*, 17(3), 20-36.
- Berlant, L. (2007). Slow death (sovereignty, obesity, lateral agency). *Critical Inquiry*, 4, 754 - 780.
- Bonham, V. L. (2001). Race, ethnicity, and pain treatment: Striving to understand the causes and solutions to the disparities in pain treatment. *Journal of Law, Medicine and Ethics*, 28, 52 - 68. (PMID: 11521272)

- Bourgeault, I. L., Dingwall, R., & DeVries, R. (2010). *The sage handbook of qualitative methods in health research*. SAGE Publications.
- Bourgois, P., & Schonberg, J. (2009). *Righteous dopefiends*. University of California Press.
- Bowleg, L. (2012). The problem with the phrase women and minorities: Intersectionality- an important theoretical framework for public health. *American Journal of Public Health, 102*(7), 1267 - 1273.
- Brault, P.-A., & Naas, M. (2001). To reckon with the dead: Jacques derrida's politics of mourning. In P.-A. Brault & M. Naas (Eds.), *The work of mourning*. University of Chicago Press.
- Brave Heart, M., & DeBruyn, L. (1998). The american indian holocaust: healing historical unresolved grief. *American Indian & Alaska Native Mental Health Research: The Journal of the National Center, 8*(2), 56 - 78. Retrieved from <http://search.ebscohost.com.proxy2.library.illinois.edu/login.aspx?direct=true&db=sih&AN=SN005862&site=ehost-live>
- Braveman, P. (2006). Health disparities and health equity: Concepts and measurement. *Annual Review of Public Health, 27*(1), 167 - 194.
- Brown, P. (1995). Naming and framing: the social construction of diagnosis and illness. *Journal of Health and Social Behavior, 34*-52.
- Brown, P., Zavestoski, S., McCormick, S., Mayer, B., Morello-Frosch, R., & Gasior Altman, R. (2004). Embodied health movements: new approaches to social movements in health. *Sociology of Health & Illness, 26*(1), 50-80.
- Buchbinder, M. (2011). Personhood diagnostics: Personal attributes and clinical explanations of pain. *Medical Anthropology Quarterly, 25*(4), 457-478.
- Buchbinder, M. H. (2010). Children's pain and the ethics of care. *ProQuest Dissertations and Theses*. Retrieved from <http://search.proquest.com/docview/857970250?accountid=14553>
- Butler, J. (2003). Afterword: After loss, what then? In D. L. Eng & D. Kazanjian (Eds.), *Loss: The politics of mourning*. University of California Press.
- Byrd, J. A. (2011). *The transit of empire: Indigenous critiques of colonialism*. University of Minnesota Press.
- Chae, D. H., Nuru-Jeter, A. M., Lincoln, K. D., & Francis, D. D. (2011, 3). Conceptualizing racial disparities in health: Advancement of a socio-psychobiological approach. *Du Bois Review: Social Science Research on Race, 8*, 63-77. doi: 10.1017/S1742058X11000166
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. Rutgers University Press.
- Charmaz, K., & Milligan, M. J. (2006). Grief. In *Handbook of the sociology of emotions* (pp. 516-543). Springer.
- Charmaz, K., & Paterniti, D. A. (1999). Introduction. In *Health, illness and*

- healing: Society, social context, and self* (p. 1-3). Roxbury Publishing Company.
- Clark, R., Anderson, N. B., Clark, V. R., & Williams, D. R. (1999). Racism as a stressor for african americans: A biopsychosocial model. *American Psychologist*, *54*(10), 805 - 16.
- Coakley, S., & Shelemay, K. K. (Eds.). (2007). *Pain and its transformations: The interface of biology and culture*. Harvard University Press.
- Cohen, C. J. (1999). *The boundaries of blackness: Aids and the breakdown of black politics*. University of Chicago Press.
- Conrad, P., & Barker, K. K. (2010). The social construction of illness: Key insights and policy implications. *Journal of Health and Social Behavior*, *51*(1), S67 - S79. (PMID: 20943584)
- Creswell, J. W. (2007). *Qualitative inquiry & research design: choosing among five approaches*. Sage Publications.
- Creswell, J. W. (2009). *Research design: qualitative, quantitative and mixed methods approaches*. Sage Publications.
- Cross, K., Kabel, A., & Lysack, C. (2006). Images of self and spinal cord injury: Exploring drawing as a visual method in disability research. *Visual Studies*, *21*(2), 183–193.
- Das, V. (2015). *Affliction: health, disease, poverty*. Fordham University Press.
- Davidhizar, R., & Giger, J. (2004). A review of the literature on care of clients in pain who are culturally diverse. *International Nursing Review*, *51*(1), 47–55.
- DelVecchio Good, M.-J., James, C., Good, B. J., & Becker, A. E. (2007). The culture of medicine and racial, ethnic, and class disparities in health-care. In *The blackwell companion to social inequalities*. Blackwell Publishing Ltd.
- Desjarlais, R., & Kleinman, A. (1997). Violence and well-being. *Social Science and Medicine*, *45*(8), 1143-1145. doi: doi:10.1016/S0277-9536(97)00021-X
- Duran, E., Firehammer, J., & Gonzalez, J. (2008). Liberation psychology as the path toward healing cultural soul wounds. *Journal of Counseling & Development*, *86*(3), 288–295.
- Dworkin, S. (1994). Somatization, distress and chronic pain. *Quality of Life Research*, *3*(SUPPL. 1), S77-S83.
- Elliott, B. A., Johnson, K. M., Elliott, T. E., & Day, J. J. (1999). Enhancing cancer pain control among american indians (ecpcai): a study of the ojibwe of minnesota. *Journal of Cancer Education*, *14*(1), 28–33.
- Eng, D. L., & Kazanjian, D. (2003). Introduction: Mourning remains. In D. L. Eng & D. Kazanjian (Eds.), *Loss: The politics of mourning*. University of California Press.
- Evans-Campbell, T., Lindhorst, T., Huang, B., & Walters, K. L. (2006). Interpersonal violence in the lives of urban american indian and alaska na-

- tive women: Implications for health, mental health, and help-seeking. *American Journal of Public Health*, 96(8), 1416 - 1422.
- Faschingbauer, T. (1981). The texas inventory of grief—revised. *Houston, TX: Honeycomb Publishing*.
- Fordyce, W. E. (1988). Pain and suffering: a reappraisal. *American Psychologist*, 43, 276 - 283. Retrieved from <http://search.ebscohost.com.proxy2.library.illinois.edu/login.aspx?direct=true&db=eft&AN=508247005&site=ehost-live>
- Frank, A. W. (2004). Asking the right question about pain: Narrative and phronesis. *Literature and Medicine*, 23(2), 209 - 225.
- Freund, P. E. (1999). A sociological perspective on health, illness and the body. In *Health, illness, and the social body: A critical sociology* (p. 2-9). Prentice Hall.
- Glenton, C. (2003). Chronic back pain sufferers—striving for the sick role. *Social Science and Medicine*, 57(11), 2243.
- Gone, J. P. (2007). we never was happy living like a whiteman: mental health disparities and the postcolonial predicament in american indian communities. *American journal of community psychology*, 40(3-4), 290–300.
- Gone, J. P. (2009). A community-based treatment for native american historical trauma: Prospects for evidence-based practice. *Journal of Consulting and Clinical Psychology*, 77(4), 751 - 762. (PMID: 19634967)
- Good, M.-J. D., Brodwin, P. E., Good, B. J., & Kleinman, A. (1992). *Pain as human experience: an anthropological perspective*. University of California Press.
- Goodman, L. A., Corcoran, C., Turner, K., Yuan, N., & Green, B. L. (1998). Assessing traumatic event exposure: General issues and preliminary findings for the stressful life events screening questionnaire. *Journal of Traumatic Stress*, 11(3), 521 - 542. Retrieved from <http://search.ebscohost.com.proxy2.library.illinois.edu/login.aspx?direct=true&db=aph&AN=964258&site=ehost-live>
- Greenhalgh, S. (2001). *Under the medical gaze: Facts and fictions of chronic pain*. University of California Press.
- Hall, J. M. (2011). Narrative methods in a study of trauma recovery. *Qualitative Health Research*, 21(1), 3 - 13. (PMID: 20663939)
- 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.
- Hilbert, R. A. (1984). The acultural dimensions of chronic pain: Flawed reality construction and the problem of meaning. *Social Problems*, 31(4), 365.
- Hogan, L. (2001). *The woman who watches over the world: A native memoir*. WW Norton and Co.
- Hokowhitu, B. (2009). indigenous existentialism and the body. *Cultural*

- Studies Review*, 15(2), 101 - 118.
- Holland, S. P. (2012). *The erotic life of racism*. Duke University Press.
- Jackson, J. (1999). *Camp pain: Talking with chronic pain patients*. University of Pennsylvania Press.
- Jackson, M. (2002). *Pain: The fifth vital sign. the science and culture of why we hurt*. Crown.
- James, S. A., Strogatz, D. S., Wing, S. B., & Ramsey, D. L. (1987). Socio-economic status, john henryism, and hypertension in blacks and whites. *American Journal of Epidemiology*, 126(4), 664–673.
- Jimenez, N., Garrouette, 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. *Journal of Pain*, 12(5), 511-522. (PMID: 21330217)
- Kelley, M. S., Rosenbaum, M., Knight, K., Irwin, J., & Washburn, A. (1996). Violence: a barrier to methadone maintenance treatment for women injection drug users. *International journal of sociology and social policy*, 16(5/6), 156–177.
- Kelley, P., & Clifford, P. (1997). Coping with chronic pain: Assessing narrative approaches. *Social Work*, 42(3), 266–277.
- Kirkham, J. A., Smith, J. A., & Havsteen-Franklin, D. (2015). Painting pain: An interpretative phenomenological analysis of representations of living with chronic pain. *Health Psychology*, 34(4), 398.
- Kirmayer, L. J., Lemelson, R., & Barad, M. (2007). *Understanding trauma: integrating biological, clinical, and cultural perspectives*. Cambridge University Press.
- Kleinman, A., & Geest, S. (2009). ‘care’ in health care: remaking the moral world of medicine. *Medische Antropologie*, 21(1), 159–168.
- Koenig, H. G. (2003). *Chronic pain: Biomedical and spiritual approaches*. The Howarth Pastoral Press.
- Kotarba, J. A. (1983). *Chronic pain: Its social dimensions*. Sage Publications.
- Kramer, B., Harker, J., & Wong, A. (2002). Arthritis beliefs and self-care in an urban american indian population. *Arthritis and Rheumatism*, 47, 588-594.
- Krieger, N. (2012). Methods for the scientific study of discrimination and health: An ecosocial approach. *American Journal of Public Health*, 102(5), 936 - 945.
- Krieger, N., Williams, D. R., & Moss, N. E. (1997). Measuring social class in us public health research: Concepts, methodologies, and guidelines. *Annual Review of Public Health*, 18(1), 341.
- Kugelmann, R. (1999). Complaining about chronic pain. *Social Science and Medicine*, 49(12), 1663.
- Lasch, K. (2000). Culture, pain, and culturally sensitive pain care. *Pain Management Nursing*, 1(3), 16-22. (PMID: 11710145)

- Lyons, S. (2010). *X-marks: Native signatures of assent*. University of Minnesota Press.
- Mehl-Madrona, L. (1997). *Coyote medicine*. Scribner.
- Melzack, R. (1975). The mcgill pain questionnaire: Major properties and scoring methods. *{PAIN}*, 1(3), 277 - 299. Retrieved from <http://www.sciencedirect.com/science/article/pii/0304395975900445> doi: [http://dx.doi.org/10.1016/0304-3959\(75\)90044-5](http://dx.doi.org/10.1016/0304-3959(75)90044-5)
- Metzl, J. M., & Hansen, H. (2014). Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science & Medicine*, 103, 126 - 133. Retrieved from <http://search.ebscohost.com.proxy2.library.illinois.edu/login.aspx?direct=true&db=aph&AN=94309605&site=ehost-live>
- Million, D. (2013). *Therapeutic nations: healing in an age of indigenous human rights*. University of Arizona Press.
- Million, D. (2014). There is a river in me: Theory from life. In A. Simpson & A. Smith (Eds.), *Theorizing native studies*. Duke University Press.
- Mohatt, N. V., Thompson, A. B., Thai, N. D., & Tebes, J. K. (2014). Historical trauma as public narrative: A conceptual review of how history impacts present-day health. *Social Science & Medicine*.
- Monsivais, D., & Engebretson, J. (2011). Cultural cues: review of qualitative evidence of patient-centered care in patients with nonmalignant chronic pain. *Rehabilitation nursing: the official journal of the Association of Rehabilitation Nurses*, 36(4), 166-171.
- Morse, J. M. (2010). How different is qualitative health research from qualitative research? do we have a subdiscipline? *Qualitative Health Research*, 20(11), 1459 - 1464. (PMID: 20693515)
- Mullings, L. (2005). Resistance and resilience: The sojourner syndrome and the social context of reproduction in central harlem. *Transforming Anthropology*, 13(2), 79-91. doi: 10.1525/tran.2005.13.2.79
- Perry, B. L. (2011). Taking the Medical Sciences Seriously: Why and How Medical Sociology Should Incorporate Diverse Disciplinary Perspectives. In Pescosolido, BA and Martin, JK and McLeod, JD and Rogers, A (Ed.), *Handbook of the Sociology of Health, Illness, and Healing: A Blueprint for the 21st Century* (p. 543-562). Springer.
- Pizzo, P., & Clark, N. (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. The National Academies Press. Retrieved from http://www.nap.edu/openbook.php?record_id=13172 (PMID: 22553896)
- Popay, J., Williams, G., Thomas, C., & Gatrell, A. (1998). Theorising inequalities in health: the place of lay knowledge. *Sociology of Health and Illness*, 20(5), 619 - 644.
- Povinelli, E. A. (2011). *Economies of abandonment: Social belonging and endurance in late liberalism*. Duke University Press.

- Rael, J. (2003). *House of shattering light: life as an american indian mystic*. Council Oak Books.
- Rose, D. B. (1999). Indigenous ecologies and an ethics of connection. In N. Low (Ed.), *Global ethics and environment*. Routledge.
- Rose, N., & Novas, C. (2004). *Biological citizenship*. Blackwell Publishing.
- Sanderson, P. R., Little, M., Vasquez, M., Lomadafkie, B., Brings Him Back-Janis, M., Trujillo, O., ... others (2012). A perspective on diabetes from indigenous views.
- Scarry, E. (1985). *The body in pain: the making and unmaking of the world*. Oxford University Press.
- Scheper-Hughes, N. (1992). *Death without weeping: The violence of everyday life in brazil*. University of California Press.
- Scheper-Hughes, N., & Bourgois, P. (2004). *Violence in war and peace: An anthology*. Blackwell.
- Silko, L. M. (2012). *Storyteller*. Penguin Group USA.
- Smith, A. (2014). Native studies at the horizon of death: Theorizing ethnographic entrapment and settler self-reflexivity. In A. Simpson & A. Smith (Eds.), *Theorizing native studies*. Duke University Press.
- Smith, L. T. (2015). Choosing the margins: The role of research in indigenous struggles for social justice. In N. K. Denzin & M. D. Giardina (Eds.), *Qualitative inquiry past, present, and future: A critical reader*. Left Coast Press.
- Smylie, J., Martin, C. M., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2004). Knowledge translation and indigenous knowledge. *International Journal of Circumpolar Health*, 63.
- Strickland, C. J. (2001). Pain management and health policy in a western washington indian tribe. *Wicazo Sa Review*, 16(1), 17.
- Sweet, V. (2006). *Rooted in the earth, rooted in the sky: Hildegard of bingen and premodern medicine*. Routledge.
- Sweet, V. (2012). *God's hotel*. Riverhead Books.
- Throop, C. J. (2010). Latitudes of loss: On the vicissitudes of empathy. *American Ethnologist*, 37(4), 771 - 782.
- Throop, J. C. (2010). *Suffering and sentiment: exploring the vicissitudes of experience and pain in yap*. University of California Press.
- Vizenor, G. (2008). *Survivance: Narratives of native presence*. U of Nebraska Press.
- Wagnild, G., & Young, H. (1987). The resilience scale homepage. *Recuperado em*, 21.
- Walters, K. L., Mohammed, S. A., Evans-Campbell, T., Beltrán, R. E., Chae, D. H., & Duran, B. (2011). Bodies don't just tell stories, they tell histories. *Du Bois Review: Social Science Research on Race*, 8(01), 179-189.
- Walters, K. L., & Simoni, J. M. (2002). Reconceptualizing native women's health: An 'indigenist' stress-coping model. (cover story). *American*

- Journal of Public Health*, 92(4), 520 - 524. (PMID: 11919043)
- Werner, A., Isaksen, L. W., & Malterud, K. (2004). I am not the kind of woman who complains of everything: Illness stories on self and shame in women with chronic pain. *Social Science and Medicine*, 59(5), 1035 - 1045.
- West, A., Williams, E., Suzukovich, E., Strangeman, K., & Novins, D. (2012). A mental health needs assessment of urban american indian youth and families. *American Journal of Community Psychology*, 49(3/4), 441 - 453. (PMID: 21972010)
- Whitbeck, L. B., Adams, G. W., Hoyt, D. R., & Chen, X. (2004). Conceptualizing and measuring historical trauma among american indian people. *American Journal of Community Psychology*, 33(3/4), 119 - 130. Retrieved from <http://search.ebscohost.com.proxy2.library.illinois.edu/login.aspx?direct=true&db=sih&AN=13698726&site=ehost-live>
- Wolfe, P. (2006). Settler colonialism and the elimination of the native. *Journal of Genocide Research*, 8(4), 387 - 409.