Suffering like a Broken Toy: Social, Psychological, and Cultural Impacts for Urban American Indians with Chronic Pain

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Abstract

This paper will explore the difficult conversations and places of tension in the lived experience of chronic pain for urban American Indians from a larger study discerning relationships between chronic pain and colonization. A concurrent transformative mixed methods design with in-depth interviews and a survey was used for the larger study. This paper concerns only the qualitative data. Forty self-identified American Indian adults living in Indiana, Chicago, and Tulsa who reported pain for greater than three months provided their chronic pain illness experiences for this paper. The paper uses three data-derived themes to encompass the broad reaching social, psychological, and cultural suffering inherent in coping with chronic pain: invisibility, psychological peace, and warrior strength. American Indian chronic pain sufferers in this study struggle with the multiplicative invisibility of both their chronic pain and their native identity. The invisibility leads to passing as white in environments hostile to people of color. It also results in family disconnection, loneliness, and isolation. In order to survive socially-mediated assaults, American Indian chronic pain sufferers keep their psyche at peace through stress management, cultural engagement, and non-negativity. They also call upon warrior strength—their understanding that American Indians as peoples have always survived bolsters their individual strength to push through the pain. They seek to function without further debility and to maintain their economic, spiritual, social, and physical wellness. Ultimately the participants in this research tell a profound, critical, and world-changing story that requires attention in overcoming barriers to full thriving with chronic pain.

Keywords

Chronic pain illness experience, urban American Indian, invisibility, psychological peace

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Introduction

A physician treating chronic pain stated, “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” (Jackson, 2002, p.45). In this paper, I use three data-derived themes—invisibility, psychological peace, and warrior strength—to demonstrate how chronic pain impacts social, psychological, and cultural life for American Indians living off-reservation. This paper is part of a larger study on chronic pain illness experience for urban American Indians, focusing especially on the relationships between chronic pain and colonization—a chronic and ongoing history of United States empire. Chronic pain shifts how participants envision themselves and how participants envision themselves also impacts their experiences of chronic pain.

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.” Chronic pain encompasses a variety of pain conditions with various locations and etiologies. To be called chronic, pain persists for more than three months (Beck & Clapp, 2011). 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. Pain sufferers exist in a liminal space without expert knowledge production, without the sanction of society, and without knowable patterns in their pain (Hilbert, 1984). The social, psychological, and cultural problems for chronic pain sufferers result from “the invisibility of pain, narcotic use stigma, [and] sick leave running out” (Glenton, 2003, p. 2249). The pain itself does not threaten social status but “the suspicion that the pain does not really exist” (Glenton, 2003, p.2249) 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.

American Indians

According to the 2010 Census, 71% of American Indians lived in urban areas. Federal legislation in the 1950s and 60s forced many American Indians to relocate to urban areas in an assimilation effort. From 1930 to 1970, 35% of American Indians migrated to cities (Fixico, 2000). American Indians living in urban areas have the neighborhood experiences of other urban minority groups such as poverty, substandard housing, gang violence, racism, and health disparities (UIHC, 2007). Urban American Indians find it difficult to maintain tribal relations and often feel socially, culturally, and spiritually isolated (Wendt, 2012). Cultural loss and increasingly mixed racial heritage cause potent identity and cultural stress among urban American Indians (West, 2012).

As an example of identity conflicts, 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. “It seems that cultural authenticity for Native peoples,” Barker 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” (2011, p.16). 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. Therefore this research sought out American Indian participants living in urban or off-reservation spaces, specifically Indiana, Illinois, and greater Tulsa, OK. The dual invisibility of nativeness and chronic pain afflicts the participants in this research. They struggle daily with Sturm’s questions: “Who is really Indian, how do we know, and who gets to decide?” (2002, p.4). 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 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” (Rose, 1999, p.185), in particular to locate and celebrate the humanity of American Indians with chronic pain.

Chronic Pain in American Indians.

Pain disproportionately burdens racial and ethnic minorities, and healthcare providers disproportionately undertreat racial and ethnic minority pain (Jimenez, 2011). American Indians experience unmet needs related to chronic pain that occurs in part as a symptom of colonization. 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. Previous research has taken a deficit approach in suggesting that the unequal burden of pain in American Indians is due to cultural beliefs, poor provider-patient relationships, and poverty (Lasch, 2000).

In contrast, a critical theory lens suggests that the unequal burden of pain for American Indians is due to a history of injustice that includes forced migration, forced assimilation, and overt physical violence in addition to ongoing encounters with removal, genocide, and cultural devastation—in the context of settler colonialism (Gone, 2009; Walters, 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 to eliminate the native. Thus colonization is pathogenic. Million (2013) writes, “What colonialism actually is in Indigenous terms: a painful dismembering of families and societies” (p.20).

In this paper, I ask about the urban American Indian experience of pain's impact on social, psychological, and cultural life. As the paper title suggests, pain compounded with being an urban American Indian can make participants feel broken. Azure, one participant, offered the following definition for broken: "Feeling broken, either psychologically or physically. Like a broken toy. Not only unable to function, but the feeling of being not whole, not complete, damaged, wrong or incorrect in some essential way." Grounded in the broken toy metaphor, I present three themes that emerged from the data on chronic pain's impact: a dual invisibility of American Indian identity and chronic pain sufferer identity; psychological brokenness from the chronic pain demanding ways to maintain psychological peace for continued functioning with the chronic pain; and engaging culturally to heal wounds that lead to the chronic pain and foster strength demonstrated by ancestors. This paper thus presents ways that pain causes suffering as well as ways that living as a broken toy with pain generates new kinds of identity, peace, and strength.

Methods

Participants, Recruitment, Ethics

Participants were recruited from non-reservation areas in Indiana (n=17), Illinois (especially Chicago) (n=11), and Oklahoma (exclusively Tulsa) (n=12). In Indiana, participants were recruited through flyers distributed at local Powwows where the researcher was volunteering. In Chicago and Tulsa, participants were recruited through key informants and flyers at various cultural centers. Inclusion 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? All participants self-identified as native and were currently in pain that had lasted more than three months. The majority of participants were female (70%) with a mean age of 54, 2-years post-secondary education (14 years), and average self-rated health. Most participants had lived nearly their entire life off-reservation in mid-sized towns. They had been in pain on average 16 years with some having pain just a few months and others having pain their entire life. Participants are characterized in the body of this paper by their age and years with pain. The subset of participants (n=20) involved in this paper was selected through an interpretive phenomenological approach for their shared perspective on the social, psychological, and cultural impacts of chronic pain—the phenomenon under study. Table 1 provides participants' demographics.

Ethics approval was granted by the University of Illinois at Urbana-Champaign Institutional Review Board (IRB Protocol Number: 14664). All participants had an opportunity to ask questions after reviewing consent documents together with the researcher. Participants were reminded that they could pause, clarify, or stop the interview at any moment. Pseudonyms are used to protect participant identity.

In addition participants had the opportunity to review and modify their interview transcript. Participants were compensated for their time and participation. Regarding ethics particular to working with American Indians, recruitment occurred through key informants (i.e. leaders) in the community who also were provided results of the study for use by the community.

Table 1: Participant Characteristics

Number	Pseudonym	Age	Gender	Multiracial	Location	Education	Years w Pain	Self-Rated Health
101	Azure	33	female	yes	small town	18	4	3
103	Cheryl	49	female	no	rural	16	20	5
104	Keira	58	female	yes	urban ghetto	16	58	5
105	Barrett	67	male	yes	large city	19	45	6
106	Kelly	37	female	no	rural	>16	30+	4
107	Cora	36	female	no	large city	16	20+	4.5
113	Iggy	48	female	no	large city	15	20.67	5
114	Maynara	58	female	yes	small town	16	15	4
115	Fern	60	female	no	rural	12	20	3
117	Rosaline	66	female	yes	rural	15	30	7
118	Verbena	52	female	yes	rural	12	25	3
124	Cassia	78	female	no	city	12	50	5
125	Fauna	67	female	no	mid size town	11	10	4
126	Alma	37	female	no	large city	19	1	5
129	Carmen	61	female	yes	large city	12	2	4
134	Strider	25	male	no	city	14	10	7
138	Abby	49	female	no	rural	20	17	6
139	Philip	40	male	no	small town	12	10	2
140	Roscoe	52	male	no	city	12 (GED)	20	4
143	Shanta	55	female	yes	rural	18	3	7

Positionality

As a white well-educated woman, I took numerous steps to foster my relationship with the American Indian communities around Illinois and Indiana. I volunteered at powwows. 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. 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. 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. I wander into interstices, trying to heal.

Data Collection and Analysis

Data collection occurred from June 2014 through February 2015. In the larger study of which this paper is a part, both qualitative and quantitative data were collected concurrently with quantitative data embedded in the framework set forth by the qualitative data. This paper uses exclusively the qualitative data with an interpretative phenomenological analysis of the data regarding the research question: what is the life impact of chronic pain? Rich detail arose from open-ended interviews in which the following questions targeting life impact of chronic pain were asked: Tell me the story of your pain; What does pain mean for your body, your relationships, your work, and your spirituality?; Tell me how being an American Indian might influence how you experience your pain.

Initial coding occurred during transcription of the interviews with codes arising directly from the data. A dialogue between researcher and participants occurred by allowing participants to review and review their interview transcripts. Participants were also asked to provide definitions for codes that had emerged from each transcript, congruent with an interpretative phenomenological approach. Initial codes were organized into themes regarding the meaning and impact of pain in one’s life—the phenomenon under examination. Superordinate themes identified were pain experience, urban American Indian identity, psychological impact, social impact, and cultural engagement. Subordinate themes were: invisibility, self doubt, misrecognition, invalidation, brokenness, strength, secrecy, survival, superwoman, and warrior. In order to describe the meaning and impact of pain, subordinate themes were coalesced around the concept of invisibility, psychological peace, and warrior strength, which in turn demonstrate the superordinate themes of social, psychological, and cultural impact of pain.

Since the anchor is participants’ accounts, the results section is called stories and long sections of participant accounts are preserved; this is also an ethical stance as indigenous voices have often been silenced in social science research. The process followed is 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. (p.96)

Results

The Stories: Invisibility

The broken toy is invisible, abandoned because no one wants to or knows how to play with it. The invisibility of both chronic pain and American Indian identity on the body has lasting social, psychological, and cultural consequences. Verbena reflects, “See my disability makes them think I am faking it; that is stressful because one always feels like they are defending themselves.” Even before her chronic pain diagnosis—a disabling illness without a visible disability—Verbena experienced the need for secrecy and invisibility regarding being American Indian in predominantly white communities. Verbena (52yo, 25yrs pain) frequently encountered other’s ignorance regarding her identity, which her family kept hidden. “‘We killed all the Indians, you can’t be Indian,’ she said. ‘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 (60yo, 20yrs pain) admitted how much of her life she did not and could not live the native life: “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 silence 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 [RLS], 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. (Fern)

As Fern demonstrated, in addition to negotiating an often invisible native identity, resulting in cultural isolation, participants also negotiated an invisible identity as chronic pain sufferers, resulting in social isolation. Azure (33yo, 4yrs pain) recognized that some care about her pain story 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 (40yo, 10yrs pain) 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.

Cause I was in there [hospital] 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.

For Philip, disbelief undergirds much of pain's invisibility.

Shanta, Cora, Strider, and Barrett rarely talked about their pain with other people. Shanta (55yo, 3 yrs pain) 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 (36yo, 20+ yrs pain), 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 (25, 10yrs pain) 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 (67yo, 45yrs pain) 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.

Pain's silence in relationships co-exists with pain's invisibility on bodies. Carmen (61yo, 2yrs pain) and Fauna (67yo, 10yrs pain) recounted the idea that pain itself can be invisible on bodies especially those 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 Cassia did. Cassia (78yo, 50yrs pain) 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 strong image to the world she retreated into isolation.

The invisibility of nativeness and the pain occur as continual assaults. The outside world continues to deny the existence of the participants' nativeness and pain and therefore denies 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 by saying, "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." In conclusion, pain's impact on identity both precedes and follows the pain itself. Just as 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. In this way colonization silences, both through silenced native identity and silenced person with chronic pain identity. Healing, in contrast, gives voice.

Psychological Peace

The broken toy invisible, socially isolated, and lacking a purpose, feels psychologically broken. Greenhalgh (2001) summarizes the psychological experience of chronic pain as "distress is transformed into disease, and the 'diseasing' of social life moves ineluctably forward" (p.3). Psychological peace transpires in the moments when participants do not feel mentally and emotionally attacked by others or their pain. The broken toy can be content with the quiet moments alone on the shelf. Azure defines psychological peace as: "The mental and emotional state of not feeling attacked by others or your own disease. Stress management—that feeling of 'no matter what happens, everything will turn out ok and I can handle/cope with what is happening to me.'"

Azure has been in pain for much of her adult life. The experiential wisdom of many years with illness allows her to face her pain with courage. Yet she notes moments in her pain story where her psyche broke and remained broken until after intensive healing. For Azure (33yo, 4yrs pain) 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. Giving the pain an identity provided her social legitimacy that enabled her to psychologically cope, demonstrating pain's wide-reaching life impact.

Iggy (48yo, 20.67yrs pain) defined how she puts mind over matter to use in her life to feel less broken.

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!

She further 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." Alma (37yo, 1yr pain) 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 (52yo, 25yrs pain) 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.” Though the pain threatens Iggy, Alma, and Verbena with psychological brokenness, cooking and humor foster psychological peace.

Only Roscoe (52yo, 20yrs pain) described how pain actually produced emotional maturity and peace in him. He 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 (25yo, 10yrs pain) also argued that knowing pain meant he could know love, because love and pain are the two most compelling human emotions. For Maynara (58yo, 15yrs pain), 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.

Warrior Strength

Finally the broken toy allows its brokenness to remind itself of those who have been broken but survived. Kelly (37yo, 30+yrs pain) defines warrior strength as: “stand your ground and abide by the law, all the laws, stand up but know when to walk away and follow the law (...spiritual law and law of the land)—too many people lose themselves to society and have their morals and value—if they abide by both laws, they can flourish.” For Kelly, warrior strength was her way of using the pain to re-engage with a cultural heritage and the laws associated with that heritage. Thus despite pain negatively impacting her social and psychological life, the pain positively impacted her cultural life. Kelly relates, “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.

Like Kelly, embracing a warrior identity augmented Maynara's (58yo, 15yrs pain) 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.

Keira, in talking about how she imagined her pain, characterized herself as a superwoman or woman warrior. Referring to the eyes of the woman warrior, 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, 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."

Rosaline (66yo, 30yrs pain) asserted 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 (49yo, 17yrs pain) 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.

Alma (37yo, 1yr pain) 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.

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 (61yo, 2yrs pain), 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.

In order to maintain their ability to perform their sense of self, Native women come together for support. Cheryl (49yo, 20yrs pain) described her culturally-connected 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. Therefore, through warrior strength, participants recall cultural connection, socially connect, and psychologically cope with their chronic pain.

Discussion and Conclusions

In this paper, I discussed the immense and wide-reaching social, psychological, and cultural impact of chronic pain in participants' lives. I began talking about the invisibility of participants' dual identities 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 conceptualize as invisible. The dual invisible identities have a lasting social, psychological and cultural impact for participants that renders them like a broken toy. I then described the ways that pain rendering participants like a broken toy causes psychological impact and demands psychological coping. Finally, I relayed how chronic pain promoted cultural re-engagement, in particular through using warrior strength to enable them to cope with the pain, find a powerful identity, and gather social support.

Haozous (2011) examined perceptions of cancer pain in the Northern Plains and Southwest—distinct native cultures—and found similar results regarding chronic pain's life impact. They noted that participants told stories of pain that “vividly recounted the manner through which pain moved through their bodies” (p.407). 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.

So what is the experience of chronic pain for urban American Indians? The combined experience is a story and as Dian Million (2014) asserts, “Story has always been practice, strategic, and restorative. Story is indigenous theory” (p.35). Communities possess stories with each community member carrying a particular component of the story. For example, veterans carry the stories of their war experiences. Native peoples carry the stories of intergenerational traumas.

The stories are biological, psychological, social, and cultural. The story that the participants in

this research tells prioritizes their identity, their psyche, and their social world as understood through the concepts of invisibility, psychological peace, and warrior strength that emerged from an interpretative phenomenological analysis of chronic pain's life impact.

Participants' native identities were ignored both within their families and within their communities. Their families encouraged them to appear white, and if they appeared white, then they must be white. In addition the participants appeared healthy without visible bodily marks of their chronic pain. To others they must be without pain. Therefore race and chronic pain demand that participants compromise their identity, causing psychological brokenness. The participants push themselves to find psychological peace. Often this psychological peace comes with accepting pain as a permanent consciousness in their lives. As Verbena summarizes, "And that's the whole thing...living with it." Not living in battle with the pain. Not living contrary to all those who perceive the participants as and thus demand they act healthy. The pain is present. Be at peace.

In addition, cultural engagement brings peace and healing. Durie (2004) articulated numerous past research that found less cultural identity associated with poorer health. Overcoming the silencing that the world inflicts on them—a silencing symptomatic of colonization—participants loudly declare their warrior strength. They are profoundly and vocally proud of how their ancestors had survived despite continuous attempts at elimination. They also come to understand themselves as warriors due to the pain. The participants recognize that in their suffering they acquire deeper understandings of who they are as native persons living in a white world. Keira conveys this best in describing how the physical pain overwhelms her during our interview, yet the overwhelming she perceives as a call to prayerfulness and endurance.

Ultimately the story of these participants must be told and retold, translated, and used to convey the complexities and paradoxes of chronic pain. With the greater understanding of chronic pain's life impact conveyed in this research, changes to pain management may occur. Pain management requires making visible the chronic pain sufferer's culture and working with that person's culture to foster healing that recognizes chronic pain as rupturing social, psychological, and cultural worlds. I end with Verbena (52yo, 25yrs pain) comically teaching me the lessons from her grandmother for living with chronic 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.

In the end the profound gift these participants provide in their stories is how well they live like a broken toy.

Limitations

The limitations of the paper lie in the sample population and method of inquiry. The sample population was geographically limited and thus not fully representative of the urban American Indian experience. Illinois and Indiana are states without reservations and therefore states where the majority of the population denies the contemporary existence of native persons. Tulsa, on the other hand, is widely-accepted as located in Indian Country, yet American Indians in this geography are not reservation confined. A more robust follow-up study would recruit urban American Indians with chronic pain from across the continental United States. The method of inquiry, while ethical in using key informants and engaging with the community, was not a community-engaged project. The researcher derived the questions related to chronic pain experience, not the community members. Follow-up studies would begin with asking the urban American Indian communities recruited about their concerns regarding chronic pain in their communities. No data analysis would occur separate from a community advisory board. The outcome would have direct impact on improving the experience of chronic pain.

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